



RANZCO

The Royal Australian
and New Zealand
College of Ophthalmologists

Charles Bonnet Syndrome

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1. Purpose and Scope

Charles Bonnet syndrome (CBS) is an under-recognised condition affecting people who have lost vision as a result of various eye conditions such as Age-Related Macular Degeneration (AMD), glaucoma, and diabetic retinopathy.

The purpose of this statement is to improve awareness of CBS amongst ophthalmologists, patients and their carers. One third of medical professionals are either uncertain or unaware of CBS.¹

2. Causes and Characteristics

CBS was first described in 1760 by Charles Bonnet (1720-1792), an eminent naturalist and philosopher who described the visual hallucination suffered by his grandfather. It was named in 1937 by George de Moasier who, like Charles Bonnet, was a native of Geneva, Switzerland.

CBS is characterized by vivid, elaborate and recurrent visual hallucinations in psychologically normal people.² It most often occurs in older, visually impaired persons. AMD has been reported as a leading cause. The prevalence of Charles Bonnet Syndrome varies and ranges from 0.4% to 30% depending on the study.³ The wide variability in prevalence is due to several reasons. There is no universally accepted definition of CBS, the diagnosis of CBS is made across different disciplines and many people are hesitant to report that they experience visual hallucinations.³ The incidence of CBS is higher in subjects with worse visual acuity.⁴ Worse vision is associated with increased risk of experiencing visual hallucinations. Complex hallucinations tend to occur in people with lower acuity, more extensive field loss and poor social contact. Some authors have suggested there may be increased risk of CBS symptoms in those with declining cognitive function³. However, this remains controversial and other studies have suggested this is not the case and that a requirement for diagnosis of CBS is normal neuropsychological function.

CBS may occur due to a significant ocular disorder such as AMD, or cortical causes such as damage of the sensory nerve fibres in the cerebral cortex, the outer layer of the cerebrum in the brain. A simple explanation is that the visual hallucinations experienced by some people with vision loss are like the phantom limb sensations that may occur after amputation – the brain is active and is filling in vision gaps caused by the underlying disorder.

CBS hallucinations can range from simple shapes and dots of colours to detailed pictures of people, animals, landscapes or buildings. The images usually last for a few minutes, but in some cases, a few hours. CBS only affects vision and none of the other senses, i.e. hearing, smelling, touch and taste. CBS hallucinations occur in a clear state of consciousness when the patient is alert and awake. People may experience CBS for

months before the hallucinations becomes much less frequent, however it is highly variable and persists in 75% of patient for 5 years or more.¹

CBS not only occurs in patients with AMD but also in other diseases that affect the visual system. In cases of hemianopia (blindness in half the visual field) following brain surgery the hallucinations tend to resolve over a period of weeks. Patients with pituitary tumours became aware that the hallucinations were replaced by sparkling lights when the tumour was removed.

3. For Ophthalmologists

To alleviate the anxiety which may be associated with CBS, ophthalmologists, particularly those working in vision rehabilitation, should be aware of and openly discuss the possibility of CBS with people who have lost vision as a result of conditions such as AMD, glaucoma, and diabetic retinopathy.

CBS can be very distressing for patients and they may not be forthcoming with their eye health professionals for fear of being misinterpreted as having a mental illness, in particular dementia, at a time when they are also dealing with their loss of vision. To alleviate the impact and anxiety, eye health professionals should be aware of this syndrome and provide support and counselling as necessary. Other neurological symptoms should prompt referral for consideration of other diagnoses.

It is important that patients are informed that experiencing visual hallucinations after vision loss is common and not a sign of dementia or mental illness. Simply knowing this is of great comfort and improves their quality of life. It is beneficial to inform patients that although visual hallucinations usually resolve spontaneously, they may persist for years.

They can be advised to determine if their hallucinations can be diminished or eliminated completely by making some changes to their environmental conditions or activities. Low vision rehabilitation, blinking, improved lighting conditions, concentrating on something else, encouraging interpersonal contact and talking to the hallucinations are anecdotal techniques to eliminate visual hallucinations.³

4. For Patients and Carers

- Experiencing visual hallucinations after vision loss is common and not a sign of dementia or mental illness
- There is no cure for CBS but you may find it helps to talk about your hallucinations with your GP, an eye health professional, family, friends or carers
- Frequency and duration of CBS hallucinations decrease over time

- CBS hallucinations affect only vision, and not hearing, smell, taste or touch
- CBS hallucinations may disappear by shutting the eyes or changing the environmental conditions or performing different activities. For example, if the hallucinations occur in the dark, then try switching on the light. Some people also find that eye movements help.
- Patients should be encouraged to join support groups to meet other individuals suffering from ocular pathologies who may be experiencing similar phenomenon.

5. References

1. Cox TM, Ffytche DH (2014). Negative outcome Charles Bonnet syndrome. *Br J Ophthalmol*. 98:1236-9.
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3. Pang L (2016). Hallucinations Experienced by Visually Impaired: Charles Bonnet Syndrome. *Optometry and Vision Science*. 93 (12): 1466-1478.
4. Khan JC, Shahid H, Thurlby DA, Yates JRW, Moore AT(2008). Charles Bonnet Syndrome in age-related macular degeneration: the nature and frequency of images in subjects with end-stage disease. *Ophthalmic Epidemiol*.15:202-8.