Charles Bonnet Syndrome

Approved by: Board  
Approval date: 24 September 2014  
Next review: 24 September 2017
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.

2. Causes and Characteristics

CBS was first described in 1769 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\(^1\). It most often occurs in older, visually impaired persons. AMD has been reported as a leading cause. One study reported the prevalence in an elderly, low-vision population to be 17.5\(^2\). However some authors point out that specific diagnostic criteria have not yet been established, so prevalence can be difficult to quantify.

Research has identified that CBS is common in people with poor vision. In a 2008 study 24\(^%\) of the 50 patients in a low vision clinic had symptoms of CBS and half of them were experiencing daily hallucinations\(^3\). In a prospective study in the Netherlands the prevalence in patients with AMD with low vision was 11\(^%\) and it was associated with acuity of 0.3 in the best eye\(^4\). Complex hallucinations tend to occur in people with lower acuity, more extensive field loss and low quality social contacts.

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. People may experience CBS for up to 18 months before the hallucinations becomes much less frequent, however it is highly variable and may never subside.

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. 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. In certain cases the incidence of CBS may be reduced by low vision rehabilitation.

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.
- CBS hallucinations affect only vision, and not hearing, smell, taste or touch.
- In some cases CBS hallucinations will 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.
5. References


6. Record of Amendments

<table>
<thead>
<tr>
<th>Page</th>
<th>Details of amendment</th>
<th>Date approved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entire document</td>
<td>Created</td>
<td>24 September 2014</td>
</tr>
</tbody>
</table>