

# Think sight loss, think Charles Bonnet syndrome

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Charles Bonnet syndrome (CBS) was first described in 1760 by the Swiss philosopher Charles Bonnet, whose father was troubled by visual hallucinations after losing his sight. CBS is characterised by visual hallucinations in those with sight loss from any cause, but no contributing psychiatric component or cognitive impairment. It can occur at any age, but it typically affects older people, reflecting the mean age at which common underlying conditions, such as age-related macular degeneration, diabetic retinopathy and glaucoma, cause loss of vision. Patients have insight into the nature of the hallucinations, which range from simple geometric shapes/patterns to complex visualisations of people, objects or landscapes. Also known as visual release hallucinations, CBS is theorised to be a result of de-afferentation of the visual cortex, and studies have revealed cortical hyperexcitability.<sup>1</sup>

The reported prevalence ranges from 0.4% to 30% in those with sight loss,<sup>2</sup> although it is considered to be underreported due to patients' fears of being categorised as mentally ill and a relative lack of awareness among the medical profession.<sup>3</sup> There are no recognised successful treatments for CBS, although anticonvulsants and antipsychotics have been trialled.<sup>4</sup> Patients' experience of their hallucinations varies widely, from indifference to enjoyment or fear. Around one-third report negative sequelae, including stress linked to uncertainty over the origin and meaning of the hallucinations, particularly if patients have not been informed of the sight loss complication.<sup>5</sup>

## Raising awareness

In November 2018, Moorfields Eye Hospital NHS Foundation Trust held its first CBS patient day for affected individuals, their carers and key stakeholders, including rehabilitation officers for the visually impaired and the major UK sight loss charities, attracting more than 80 participants. Experts and patients shared their medical knowledge and personal experiences of CBS, with a workshop on techniques to cope with visual hallucinations (Box 1). To evaluate the workshop, seven attendees with CBS completed the National Eye Institute Visual Functioning Questionnaire–25 (NEI VFQ-25) to measure the impact of visual disability and symptoms on generic health domains and repeated the questionnaire 2 months later to establish the effect on quality of life once coping mechanisms were introduced [this study was approved by the National Research Ethics Committee (12/LO/0141) and was conducted in adherence to the tenets of the Declaration of Helsinki; informed written consent was obtained from all participants]. The mean overall composite score was 39.86 at baseline; this increased to 43.20, up by 8.38% ( $p=0.407$ ) 2 months later (a higher score indicated better functioning). Specific domains such as ocular pain yielded a 38.71% ( $p<0.05$ ) increase in score from 55.36 to 76.79, and mental health increased by 23.40% ( $p=0.229$ ) from 41.96 to 51.79 (Figure 1).

Education can help patients feel more in control of CBS, in terms of coping and managing it. The

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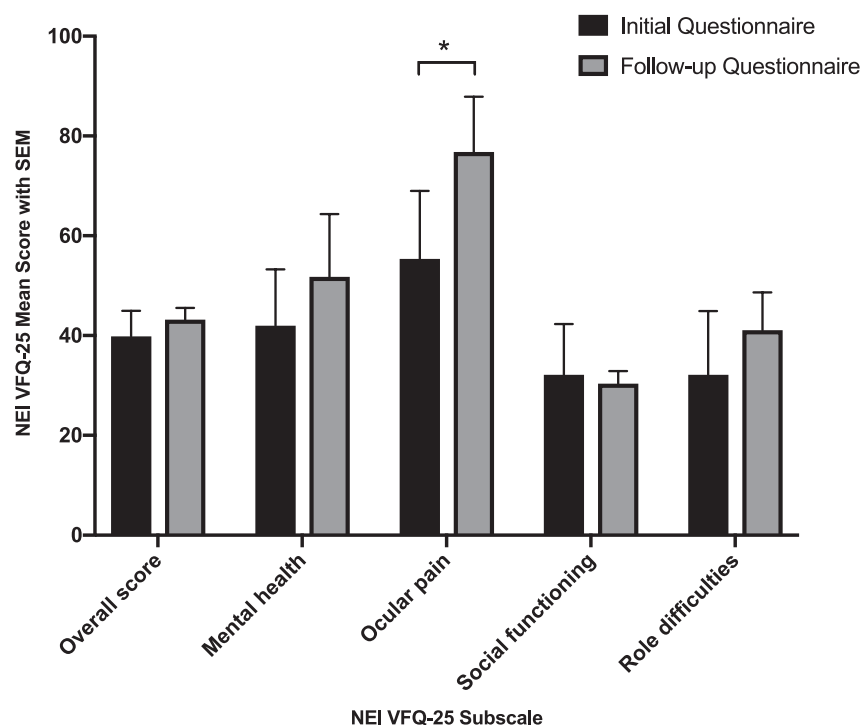
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### Box 1. Techniques for minimising or eliminating visual hallucinations secondary to Charles Bonnet syndrome.

- When the hallucinations start, look from right to left once every 15s without moving your head
- Try to touch the hallucination
- Stare straight at the hallucination
- Turn your head to alternative sides, then move the head towards each shoulder in turn
- Walk around the room or to another room
- Shine a torch from below your chin in front of (not into) your eyes
- Change the light level in your room or the activity you are doing



**Figure 1.** Graph comparing the mean scores ( $\pm$ SEM) of different domains of the VFQ-25 before and 2 months after the patient day,  $*p < 0.05$ .

NEI VFQ-25, National Eye Institute Visual Functioning Questionnaire-25; SEM, standard error of measurement.

National Institute for Health Research (NIHR) SHAPED (Study of HAllucinations in Parkinson's disease, Eye disease, and Dementia) programme is underway to inform the UK National Health Service (NHS) practice and policy in relation to visual hallucinations and produce sets of guidelines for clinicians, patients and carers. Too often, those with sight loss are unaware that they may experience visual hallucinations. Informing patients and following up with coping strategies can have a positive impact on patients' quality of life.

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