

# Charles Bonnet Syndrome: so much more than just a side effect of sight loss

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Charles Bonnet was a Swiss lawyer, naturalist and philosopher. In 1760, he documented the experiences of his grandfather, Charles Lulin, who had cataracts in both eyes and very little sight. Lulin began to see images of ‘men, women, birds, carriages, buildings, scaffold patterns and physically impossible circumstances’ despite the fact that he was ‘full of health, of ingenuousness, judgement and memory. All these visions appear to him in perfect clarity and affect him as strongly as if the objects themselves were present’ (translation from Bonnet’s papers by Dr Dominic ffytche).

This description encapsulates Charles Bonnet Syndrome (CBS). The vivid, silent, visual hallucinations can develop in anyone of any age who has lost over 60% of vision. As sight diminishes, the messages from the retina to the visual cortex slow or stop, but the brain does not. It fires up and creates its own images, which range from disturbing to terrifying. CBS is not a mental health condition but, far too often, is mis-diagnosed as such. People who report their hallucinations find themselves ushered down the psychiatric pathway and given ineffectual medication – thus wasting precious NHS (National Health Service) resources and causing more distress.

My mother, Esme, had probably lived with CBS for months before she told me about her ‘visions’ of faceless people sitting on her sofa, the Edwardian street-child and the grotesque, gargoyle-like creature – not to mention the times the whole room morphed into an alien place. Despite her ability with the daily cryptic crossword, the word ‘dementia’ hung in the air. This was finally dispelled when I read a short piece in a newspaper about a hallucinatory condition caused by sight loss and confirmed by Dr Dominic ffytche at King’s College, London. He is the sole, globally acknowledged expert in CBS and has just been announced as the world’s number one for all types of visual hallucinations.

Dr ffytche explained that there was no proven medication suitable for Esme, nor any CBS consultants. Devising coping strategies – sweeping the gargoyle off the table, reaching out to the girl or tapping the seated people on their shoulders – was the only support I could give her. The constant hallucinations destroyed any quality of life she had left and reduced her to despair, depression and isolation.

Until Dr Dominic ffytche began his groundbreaking research in the 1990s – which continues today – the door on CBS had been firmly shut. Through his work, Dr ffytche has debunked the myths that had grown up around the condition. We know now that children are as likely to develop CBS as are adults, that the condition can remain with the person for life and that the images are not always pleasant.

Esme’s ophthalmologist refused to discuss CBS and neither her GP nor her optometrist had heard of the condition. It was obvious that an awareness campaign was needed. In November 2015 – supported by The Help and Information Service – I launched Esme’s Umbrella at the House of Commons, with Dr ffytche as my medical adviser.

Since then, I have highlighted the CBS community in the United Kingdom – so much so that, last year, the overwhelming number of calls to my Helpline forced me to relinquish it to the Eye Health Team at the Royal National Institute of Blind People (RBN). Esme’s Umbrella is still only me! Information about Esme’s Umbrella is provided in Table 1.

Not being able to differentiate between what is real and what is not means that people with multiple hallucinations can become house-bound. Suicidal thoughts arise when the nature of what is seen is intolerable and the challenge of eating and drinking, with perceived worms and slugs

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**Table 1.** Esme’s Umbrella: Key information.

Website	www.charlesbonnetsyndrome.uk
Email address	esmesumbrella@gmail.com
Helpline	020 7391 3299 (answered by the Eye Health Team at the RNIB)
Fundraising	<a href="https://www.justgiving.com/fundraising/EsmesUmbrella">https://www.justgiving.com/fundraising/EsmesUmbrella</a>

writhing on food or in drink, often leads to tragic consequences. Falls can happen when avoiding a hallucinated brick wall, pit bull terrier or leaping flames. Purely through lack of knowledge, the GP or hospital doctor may then misdiagnose.

Research is imperative and, thanks to three eye research charities in the UK (Fight for Sight, Thomas Pocklington Trust and National Eye Research Centre), Esme’s Umbrella has a researcher at Newcastle University, who is comparing the brains of people with sight loss and CBS against those with sight loss who do not develop the condition – there are some. If we can identify the difference in the brains, we hope to find a non-medication, non-invasive treatment which is being researched at the same university, funded by the Macular Society. The United Kingdom is currently the only country funding CBS research.

The hallucination seen by Dr Amit Patel is particularly disturbing. He sees a girl, wearing long white robes, with blood and mud pouring from her face. Intriguingly, his guide dog, Kika, has begun to alert him before the hallucination begins. The Medical Detection Dogs’ charity has agreed to conduct a piece of research for Esme’s Umbrella, to see what is being detected by Kika. If we can feed that information into the research in Newcastle, who knows what we might discover . . .

Dr ffytche estimates that there are 1 million people in the United Kingdom with CBS. If I can find the funding, I hope we can also find the answer to how many children live with the condition. Prevalence data are essential, as are specialist CBS nurses to support family members too, because the condition puts huge stress on relationships.

Fearing that the hallucinations heralded a mental health issue prevented people from confiding in their ophthalmologists or optometrists. Consequently, it was assumed by these health-care professionals that CBS was an easily tolerated and rare condition, not needing to be mentioned. They understand now that forewarned is forearmed. If a giant rat skips across the floor, a second world war soldier appears or a Lilliputian family dance by, knowing it is probably CBS gives a little comfort.

This step forward has been reflected by the World Health Organisation, who I have persuaded to include CBS in International Classification of Diseases (ICD) 11. Now it is the turn of the NHS to spearhead a campaign of research, with a proper pathway of diagnosis, treatment and support. We really need to clone Dr ffytche!

I am encouraging Esme Room Support Groups, Esme’s ‘Buddies’ and Esme’s ‘Counsellors’, so that no one is left to cope alone with what has been described as ‘the theatre of the mind’.