



Esme's Umbrella

FOR EVERYONE WORKING FOR THE GREATER AWARENESS OF

Charles Bonnet Syndrome

Founder - Judith Potts

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Visual Hallucinations after sight loss - known as Charles Bonnet Syndrome (CBS)

For Help and Support

www.charlesbonnetsyndrome.uk

judith@charlesbonnetsyndrome.uk

UK - Helpline 0303 123 9999

(calls are answered for Esme's Umbrella by the RNIB. Callers can be referred to Esme's Umbrella).

USA – Dr Gary Cusick garycusick@icloud.com 502 439 0398

Important – CBS is not a mental health condition



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Over 1 million people in the UK live with CBS

Understanding Charles Bonnet Syndrome (CBS)

What is Charles Bonnet Syndrome?

CBS is a condition which can develop when someone of any age – children too - has lost a variable amount of sight. This loss can be from one of the many eye diseases, stroke, cancer, accident, diabetes, multiple sclerosis or another condition which damages the optic nerve. It causes vivid, silent visual hallucinations which range from disturbing to terrifying – but it is not a mental health condition.

Why does it happen?

When you have full sight, there are messages which run all the time from the retina in the eye to the visual cortex in the brain. The eye acts like a camera and the brain interprets what is being seen. As sight diminishes, these messages slow down or stop entirely, but the brain – left with nothing to interpret - fires up and creates its own images. What is seen depends on which part of the brain is firing at that moment.

It is estimated that there are, at least, 1 million people in the UK living with CBS and it is very important to remember that CBS is not a mental health condition, but due entirely to sight loss.



Sight loss and CBS

Sight loss itself can cause anxiety, fear and loneliness, but when CBS is added, the isolation – even from family members – can exacerbate the downward turn in quality of life. Living in a world of uninvited images – even if they are pleasant – impacts on everyday life.

During the lock-down caused by COVID 19, people living with CBS reported a higher number of hallucinations and saw images which were much more frightening - thus proving that isolation and stress exacerbate the condition.

Coping with Charles Bonnet Syndrome

Esme's Friends' support groups

These are support groups hosted by local low vision charities or the RNIB.

Confiding in someone about the hallucinations and how they make you feel will help. Your local low vision charity may be running an **Esme's Friends** telephone/online/face-to-face or hybrid support group. These allow people who live with CBS – and their families or caregivers – to exchange experiences and share coping strategies. Most importantly, members find that they are not alone and are able to talk to others who understand CBS, in a safe environment and where they are believed.



Esme's Umbrella can refer you to one of these groups – either locally or through the RNIB.

Contact Esme's Umbrella (www.charlesbonnetsyndrome.uk) for a list of groups or the **RNIB on 0303 123 9999**.

Pop-up Esme's Friends' days are planned.

Living with Charles Bonnet Syndrome

Not everyone with Charles Bonnet Syndrome needs treatment for the hallucinations. Once you know that the hallucinations can be a normal consequence of visual loss and that there are things you can do yourself that might help stop the hallucinations when they occur or reduce their impact, for most people this will be all that is required. However, before using self-help techniques, it is important to confirm you have Charles Bonnet Syndrome and rule out other factors that might be contributing to the symptoms.

There is no test for Charles Bonnet Syndrome so your doctor needs to think about whether other possibilities apply to you. The current recommendations are that your doctor thinks about physical health conditions that can cause hallucinations (for example infections), whether your eye condition can be improved (for example cataract surgery or macular disease treatment if you have these conditions) and for those over 60 years old, early memory problems. This may involve referral to a specialist service to advise.



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Your doctor also needs to think about medications you are taking for other reasons that may be making the hallucinations worse and whether they can be changed or reduced in dose.

Important note - only stop taking medication when you have discussed this with your doctor.

The main medications we know that might make CBS worse are listed below.

Medication type	Examples
Urinary incontinence medication	Oxybutynin
Anti-cholinergic eye drops	Atropine eye drops
Tricyclic antidepressants	Amitriptyline
Proton pump gastric ulcer medication	Lansoprazole Omeprazole
Synthetic opiates	Tramadol

Coping Strategies and complementary therapies

Important note - please contact your GP before using any complementary therapies.

These Coping Strategies have been suggested by people who live with CBS. They work for them but may not work for everyone.





CBS hallucinations tend to occur more often when people are in a state of quiet wakefulness – about to fall asleep, just waking up, sitting in a chair or being driven in a car. Establish whether or not the visual hallucinations occur when you are in a particular place or situation as this may help develop strategies to avoid having them.


Coping strategies which some people find helpful

We know that the hallucinations are often worse during a quiet time, so keeping the brain active may help to keep the hallucinations at bay.


Everyone's experience of CBS 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.

 At night, try wearing a thick eye mask

 Sing or whistle

 Clap your hands or click your fingers

 Blink your eyes slowly once or twice

 Concentrate on your breathing. Take a slow breath in, hold it and count 2, then breathe out slowly. Repeat.

Professor ffytche's specific eye movement exercise

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.

Medical Treatment for Charles Bonnet Syndrome

Please remember that no medication nor coping strategy works for everyone. Each person's experience of Charles Bonnet Syndrome is different.

When Charles Bonnet Syndrome becomes a problem

For most people the approaches above are all that is needed but for some, Charles Bonnet Syndrome becomes so distressing and unpleasant that other treatments need to be given. Currently, there is no Charles Bonnet Syndrome-specific medication but, if the visual hallucinations are intolerable, there are several types of medication that can be tried. They are all designed for other medical conditions but have been shown in clinical case reports or small clinical trials to be effective in CBS even if you do not have the condition the medication is usually used for. The main types of medication used for Charles Bonnet Syndrome are listed here -

The following medications are based on evidence from clinical trials or published case reports.



Medication type	Examples
Anti-convulsant	Gabapentin
Cholinesterase inhibitor	Donepezil
SSRI	Citalopram
Anti-psychotic (not for older patients)	Risperidone
Chinese traditional medicine	Yi-Gan-San

A study at Newcastle University shows that the occurrence of CBS hallucinations can be significantly reduced by the use of a non-invasive electrical brain stimulation technique that makes the visual parts of the brain less excitable although this is not yet available for routine clinical use.

Anecdotal evidence

People with Charles Bonnet Syndrome have let us know the following medications or complementary therapies helped their symptoms. We do not know all the details about their medical circumstances so are unable to judge whether these medications might be appropriate for everyone. Evidence for the use of these medications is less compelling than medications with published case reports or clinical trials to support their use.



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Medication / Complementary therapy
Prochlorperazine
Omega 3
CBD oil
Ginger
Mindfulness Meditation
Breathing exercises
Relaxation exercises
Yoga
Counselling
Group Therapy

GPs and other healthcare professionals may not be aware of CBS and would welcome the information on this website. Complementary therapies and counselling

Professional counselling is proving successful for some people and Esme's Umbrella can refer you to its VI counsellors, one of whom also lives with CBS.

Mindfulness therapy is being explored at some of the Esme's Friends' support Groups:

www.nhs.uk/conditions/stress-anxiety-depression/mindfulness/ as is aromatherapy massage.



Using real ginger in food and drink – ginger ale/tea/biscuits etc - has been found to be helpful to some people. However, it is imperative to check with the doctor as ginger may interact adversely with certain medications.

Similarly, omega 3 supplements may be of help.

Recent reports suggest CBD oil and capsules – the ones that are legal in the UK – may be of some help too.

Sometimes, establishing where the hallucinations occur more often – maybe in a particular room or part of the garden – helps.

Falling over, whilst avoiding an image, is a real danger. Check the area around you before moving.

Research and the World Health Organisation

There is CBS research happening in the UK, with funding sourced by Esme's Umbrella, at the Universities of Oxford, Cardiff, Manchester and Newcastle, Moorfields and Great Ormond Street Hospitals and by the Medical Detection Dogs. The Ministry of Defence (Office for Veterans' Affairs) has awarded Bravo Victor a substantial grant to research CBS. The UK is leading the world in this research.



After working with Professor Andrew Dick in the UK and Dr August Colenbrander in the USA, Judith Potts persuaded The World Health Organisation to give CBS a code in its taxonomy of diseases and conditions – ICD 11. This means CBS is now considered a condition in its own right and not just a side effect of sight loss. The code is 9D56 but word ‘temporary’ is still in the description because it was not possible to have this removed. It is not an accurate description of CBS and we hope the WHO will remove it for the next publication.

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