



Mary Carmel's Light

*...empowering people living with
Charles Bonnet Syndrome*

MaryCarmelsLight.com

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In 2019, Charles Bonnet Syndrome (CBS) received a code from the World Health Organization ICD-11. CBS is now considered a medical condition in its own right. **Presently, reimbursable billing codes for the medical community are H53.16.8 (Other psychophysical visual disturbances) and R44.1 (Visual Hallucinations). While these codes help the medical community for billing purposes, they do a disservice to the CBS community. These codes are vast and can lead to unnecessary medication administration as well as improper treatment plans. Mary Carmel's Light is searching for a doctor aligned with the American Medical Association to apply for a CPT code that would read "Charles Bonnet Syndrome" verbatim.**

IMPORTANT INFORMATION: CBS is **NOT** a mental health condition. It's estimated that millions of people in the US live with Charles Bonnet Syndrome.

We are not doctors or medical professionals. We are a 501(c)(3) organization that provides awareness, education, and information about Charles Bonnet Syndrome (CBS). We do not offer medical advice, diagnosis, or treatment of CBS.

WHAT IS CHARLES BONNET SYNDROME?

The vivid, silent **visual** hallucinations, which some people experience after losing a percentage of their vision or going blind after being sighted, is a condition called Charles Bonnet Syndrome (CBS). CBS does not discriminate; it can affect anyone at any age. It knows no gender, age, race, ethnicity, lifestyle, or socioeconomic status. It also presents with no warning. The person affected has no time to prepare for this life-altering condition, no time to be informed, no time to understand what may be happening to them, and presently, no medical services or resources to assist them. As well, family members and caregivers are thrust into a caregiving role with no guidance on how to help their loved one or the patient in their care.

When you have full sight, some messages run constantly from the retina to the visual cortex in the brain. As sight diminishes, these messages slow down or stop entirely, but – for some reason not yet understood –

the brain does not slow down; it fires up and creates images. What is seen depends on which part of the brain is firing.

It is estimated that millions of people in the US are living with CBS, and it is essential to remember that CBS is NOT a mental health condition; it is entirely due to sight loss. This loss can result from any one of the myriad eye diseases: stroke, cancer of the eye, accidents or injuries to the eyes, diabetes, multiple sclerosis, or any condition that can damage the optic nerve. In adults, CBS is often misdiagnosed as schizophrenia, dementia, Lewy body dementia, or severe bipolar disorder. In children, CBS is often misdiagnosed as a dissociative disorder, schizophrenia, autism, severe bipolar disorder, schizoaffective disorder, and/or major depressive disorder.

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

Confiding in someone about the hallucinations and how they make one feel can certainly help. Mary Carmel's Light offers a helpline. We provide an outlet for individuals who live with CBS, their families, and caregivers. Our support groups allow individuals to share their experiences and coping strategies. Most importantly, we provide a safe, confident, and non-judgmental space for people to express themselves. Individuals with CBS can speak openly and freely about their experiences.

Mary Carmel's Light can help individuals with CBS, along with their families and caregivers. We can assist you in finding suitable doctors who can hopefully provide a proper diagnosis and connect you with Dr. Cusick, who can help you understand CBS and support you through what you may be experiencing. Additionally, we do our best to connect

individuals living with CBS to services that offer coping strategies, counseling, grief counseling, and support groups.

Hallucinations can often be more intense during quiet moments when the sun begins to set and when individuals feel lonely or isolated. Certain types of therapy, such as music therapy, audio tapes, pet therapy, light therapy, and rapid eye movement, have successfully redirected individuals with CBS.

During the lockdown caused by Covid 19, people living with CBS reported more frequent episodes of hallucinations and saw more frightening images, proving that isolation and stress may exacerbate CBS. Fever from infections such as UTIs and hyponatremia (low sodium concentration in the blood) may also worsen CBS.

Establishing where the hallucinations occur more often, in a particular part of the home or landscape, helps. It can be extremely distressing to have your life constantly disrupted by CBS hallucinations, but there are measures that can be taken to attempt to dispel the hallucination when it occurs. However, everyone is different, and some strategies work better than others. If the hallucination does disappear at that moment, it may return later.

RISK FACTORS ASSOCIATED WITH CBS

FALLING: Individuals coping with CBS may be at substantial risk of falls. As the hallucinatory images seem very real, the individual may try to follow, avoid, run from, or attack them, which could result in a fall.

Individuals misdiagnosed with something other than CBS (usually Schizophrenia, Dementia, or severe bipolar disorder) may be given psychotropic medication that can create and/or increase the fall risk.

ABUSE/NEGLECT: CBS is a challenging diagnosis, not only for the individual coping with the condition but also for family members and/or caregivers providing support and care for the individual with CBS. Caregivers and family members can often lose patience with individuals who are convinced their hallucinations are real. We must remember that to the individual with CBS, they seem real. With proper support, the individual with CBS will learn that these images are not real, but are simply a product of their brain firing images in their mind that appear in front of them.

Often, familiar relationships that may already be tense or abusive can easily cross the line and become emotionally, mentally, and physically abusive. Individuals with CBS must feel safe to report this to other family members and/or authorities without fear of retribution.

ISOLATION: Because CBS is often misdiagnosed as Schizophrenia or Dementia, people will often not report their symptoms – even to their spouse - for fear of being labeled “mentally ill”. Individuals with CBS will often suffer in silence, closing themselves off from friends and family, increasing the risk of falling into a deep depression. Isolation can intensify the severity and longevity of the hallucinogenic episodes.

SELF-HARM: In the worst-case scenarios, an individual with CBS may feel hopeless and may harm themselves by gouging out their eyes, cutting, or committing suicide.

SO, WHAT CAN WE DO? HOW DO WE HELP INDIVIDUALS LIVING WITH CBS TO DO SO WITH DIGNITY AND GRACE?

- If you know someone with low vision or vision loss, provide a safe environment for them to talk about the experience of their vision loss journey. If they are experiencing hallucinations, take them to a doctor for treatment. **BELIEVE THEM!**
- **DO NOT** call them “crazy” or tell them, “They are losing their minds.” Reassure them that you will do all you can to help them.

- Provide the doctors treating the individual with information about Charles Bonnet Syndrome
- The CBS client should seek out a medical professional to help rule out any other mental illnesses or conditions
- If your family member or friend is diagnosed with CBS, learn about the condition so you can understand what your loved one is experiencing.
- Seek a support group for the individual with CBS, yourself, family members, and caregivers.
- Find a counselor who provides Cognitive Behavioral Therapy (CBT) and have the individual begin therapy as soon as possible to help the person with CBS deal with the anxiety, grief, and sudden change of life due to vision loss.
- Recommend that the individual with CBS seek grief counseling. Losing your vision is traumatic – life is forever altered.
- Music therapy has been known to help bring individuals out of episodes by redirecting thoughts and memories.
- Audio books have been found to bring individuals out of episodes and to redirect thoughts.
- It has been discovered (and is currently being researched in the UK) that domestic and service animals can detect when someone with CBS has an episode and will alert the person and redirect the individual.
- EDUCATE and bring AWARENESS to everyone you possibly can. Knowledge is power, and as a community, we need to support and empower people living with CBS.

STRATEGIES/COPING SUGGESTIONS TO STOP HALLUCINATIONS OR LESSEN THE SEVERITY OF IMAGES

- Reach out towards the hallucination, try to touch it, or sweep your hand to brush the image away.
- Shine a flashlight upwards from below your chin, in front of your eyes (DO NOT DIRECT THE LIGHT INTO YOUR EYES)

- If sitting, try standing up and walking around the room. If standing, try sitting.
- Walk into another room or another part of your present environment.
- Turn your head slowly to one side and then to the other. Dip your head to each shoulder in turn.
- Stare straight at the hallucination.
- Change whatever you are doing at that moment – turn off/turn on the television, radio, or music.
- Change the light level in the room. Make the room as bright as possible.
- Music therapy: turn on your favorite songs
- Talk with someone, a friend, family member, or caregiver. If alone, call someone.
- Sing or whistle.
- At night, wear a thick eye mask
- Clap your hands or snap your fingers
- Blink your eyes slowly once or twice
- Try this specific eye-movement exercise created by Professor Dominic ffytche (Medical advisor to Esme’s Umbrella and sole, globally acknowledged expert in CBS based in the UK):
 “When the hallucination begins, look from left to right about once every 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 if the exercise has no improvement or benefit.”
- Concentrate on your breathing. Breathe in and out slowly to calm your pulse rate and/or anxiety. Count as you breathe in and out.
- Using organic ginger in food and drink – ginger ale/tea/cookies, etc. – has been found to be helpful to some people. However, it is imperative to check with your doctor as ginger may interact adversely with certain medications. Similarly, Omega 3 supplements may be of help. Recent reports suggest that CBD oil

and capsules – the ones that are legal in the US – may also be helpful.

- Do your best to remind yourself that these hallucinations are not actual; they cannot harm you or those you love.
- Form your hand into a “finger gun” and shoot at the images
- Use a spray bottle with a nontoxic liquid and spray at the images (use caution as the liquid could land on the floor and become a hazard and fall risk)
- If the hallucinations are intolerable, don't hesitate to get in touch with your doctor. Not all doctors are aware of CBS – take this information with you.
- Join a support group. Call Mary Carmel's Light Helpline in the US at 704.389.0160 and ask for `Eva Potts.
- Reach out to the US CBS Education/Information Specialist, Dr. Gary Cusick, at 502.439.0398.
- Whatever you do, don't suffer in silence. Reach out so we can help align you with support and services.

At present, the only countries properly recognizing, researching, advocating for, and treating Charles Bonnet Syndrome are the United Kingdom (Esme's Umbrella) and Australia (Charles Bonnet Syndrome Foundation). The US must get involved, as treatment for CBS is critical for these individuals.

As we age, our eyesight diminishes. Not everyone will experience vision loss; however, most of the US population will experience a decline in visual acuity with age. The baby boomer population alone will dramatically increase the number of individuals with CBS. We must educate ourselves, our communities, and our medical professionals about Charles Bonnet Syndrome. We must start recognizing children suffering from CBS to avoid lifelong misdiagnosis that can lead to unfortunate outcomes and possibly cause other mental health issues. CBS must be normalized as a possible outcome of losing one's vision.

The immediate response is to reassure people living with CBS that they are not crazy or losing their minds – that they are not mentally ill. The cure cannot begin without understanding the cause. The vision loss journey is a substantial challenge in its own right; adding CBS to the passage creates anxiety, steals energy, and creates an unfavorable environment for healing.

Join us in our fight to bring Charles Bonnet Syndrome to light in the US, allowing those living with CBS to do so with dignity, grace, and inclusion while preserving or improving their quality of life. “Inclusion should not be an illusion for people living with CBS or any other disability,” EMP.