

Our logo is a digital image of a blue eye with a yellow iris and a blue center. The blue eye is surrounded by a pattern of what looks like yellow flower petals.

Have you or someone you've known seen something or someone that is not there?

Are you or someone you know experiencing frightening images or objects and not telling anyone?

Has a disease, accident, or injury compromised your vision or the vision of someone you know?

If you can answer yes to any of the questions above, you or someone you know may have Charles Bonnet Syndrome!

What is Charles Bonnet Syndrome?

Charles Bonnet Syndrome (also known as CBS) is a physiological condition that affects individuals who have lost a significant percentage of their visual acuity to eye disease, accident, injury, or illness, causing them to have silent visual hallucinations. These hallucinations are not auditory or tactile and can vary from simple (shapes, patterns, colors or shadows) to complex (people, animals or text) and sometimes even nightmarish. These individuals are NOT mentally ill, mad, or crazy, and they can be helped.

We are a US- based 501(c)(3) nonprofit on a mission to provide awareness, education, support, and information about Charles Bonnet Syndrome (CBS) to those living with CBS, the medical community, research organizations/foundations, and the general population.

Who can be affected by Charles Bonnet Syndrome?

- Any person of any age who has experienced significant vision loss. CBS is indiscriminate of age, race, gender, ethnicity, sexual orientation, or socioeconomic status
- Any person of any age who has lost their vision due to an eye disease, accident, injury, illness, or diseases such as MS, Diabetes, stroke, cancer, and autoimmune conditions that can cause vision loss. It can also affect people born with low vision.

If CBS affects so many people, why does it go unrecognized?

 In adults, CBS is often misdiagnosed as Dementia, Schizophrenia, Lewy Body Dementia, and Severe Bipolar Disorder.

- In children, CBS is often misdiagnosed as a dissociative disorder, Schizophrenia, Severe Bipolar Disorder, Schizoaffective Disorder, and/or major depressive disorder.
- People with CBS often live in fear of reporting their symptoms to family, friends, and caregivers due to the possibility of being given a mental health diagnosis
- CBS does not have a designated billing code for doctors to be reimbursed for correctly diagnosing and treating CBS

If I know someone with Charles Bonnet Syndrome, how can I help them?

- If someone tells you they are experiencing CBS symptoms, BELIEVE them!
- Do NOT refer to them as mad, crazy, or mentally ill

- Get them to their doctor or ophthalmologist as quickly as possible and express your concerns.
 Inform the doctor that the World Health
 Organization granted CBS an ICD-11 code in
 2019, making CBS a physiological condition in its own right. (Keep in mind, this code is not a billable code in the US for diagnosing or treating CBS)
- Request an information packet and Letter to Doctors from Mary Carmel's Light website at marycarmelslight.com to give to all your health care providers
- Get involved with our support group
- Give them our helpline number 704.389.0160
- Get informed about CBS and learn the difference between the facts of CBS and the disinformation often found online

What are the risk factors for people living with Charles Bonnet Syndrome?

- Misdiagnosis (a diagnosis other than CBS)
- Improper medication administration
- An uninformed medical community
- Global misunderstanding of CBS
- Lack of resources and research
- Finding misinformation on many online outlets
- Falling
- Self-isolation
- Self-harm
- Abuse/Neglect/Bullying
- Forced Isolation
- Admission to a psychiatric hospital/ward
- Erroneous incarceration
- Placement in an assisted living facility/nursing home
- Diminished quality of life
- Homelessness
- Suicide/Suicide Ideology

Where can I find information or help for Charles Bonnet Syndrome?

- For information and resources, go to marycarmelslight.com
- You can call Mary Carmel's Light helpline for information and/or support at 704.389.0160 and speak with one of our volunteers
- Email us at marycaremelslight@gmail.com
- Contact Dr. Gary Cusick, the leading CBS specialist in the United States at 502.439.0398

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.