

CHARLES BONNET SYNDROME



Macular
Disease
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Charles Bonnet Syndrome (CBS) describes the situation where mentally healthy people with significant vision loss have vivid, recurrent visions known as phantom images. You might experience a wide variety of these images, particularly coloured patterns, people, animals, plants, trees and other inanimate objects.

These phantom images are sometimes incorrectly labelled hallucinations, which refers to sensory experiences that the recipient believes to be real. On the other hand, people experiencing CBS are aware that the things they see are not real.

The phantom images also often fit into your surroundings. They can also be quite bizarre, such as dragons or fairies, or have unusually vivid colours. People generally realise that the visions are not real. CBS does not affect any other senses such as hearing, smell or taste – only vision.

A Swiss philosopher named Charles Bonnet first described this condition in 1760 when he noticed that his grandfather, who was almost blind, saw patterns, figures, birds and buildings that were not there. Although the condition was described over 250 years ago, it is still largely unknown by many health professionals. This is partly because of a lack of knowledge about the syndrome and partly because people experiencing it don't talk about it because they're concerned others might think they have a problem with their mental health.

Who is affected by Charles Bonnet Syndrome?

Your eye works very much like CBS typically affects people with significant vision loss as a result of various eye conditions including age-related macular degeneration, glaucoma and diabetic retinopathy, and usually only people who have lost their sight later in life. It can however affect people of any age, usually appearing after a period of worsening sight. People with relatively minor vision loss can sometimes be affected but this is rare.

The phantom images may come and go and will often stop altogether within a year to 18 months. But for most people, visions may continue for many years and be a source of frustration. Research has shown that up to 30% of people with significant vision loss can experience phantom images at some stage, however this number may be underestimated because of the reasons mentioned above.



What causes Charles Bonnet Syndrome?

The most widely accepted explanation for CBS is that when vision is lost, the brain is not receiving as much input from the eyes. The part of the brain responsible for vision will create phantom images, which may be experienced as though they were real. These experiences seem to occur more commonly when there is little happening, such as when you're sitting alone in a quiet, familiar place or when you're lying in bed at night or sitting in the dark. They occur when you are awake and alert.

What kind of images do people see?

There seem to be two main kinds of images you might see. Firstly, there are visions of repetitive patterns and lines, which can be quite detailed, like brickwork, netting, fences, mosaics or tiles. The images can be black-and-white or in colour, moving or stationary, and appear real or unreal.

Secondly, there are more complicated pictures of people or places. These tend to occur in those with poorer vision, and poor social contact. Whole scenes may appear, such as landscapes or groups of people. They can be bigger, smaller or the same size as real life. These images can appear quite randomly for a few minutes or several hours. The images may also be recurrent with similar patterns, scenes or people appearing.

What are the effects of the phantom images?

Generally the phantom images will not impact your everyday life and activities. For some people, the complicated pictures can make it difficult to get around. For example, streets and rooms may change shape or brickwork and fencing might appear directly in front of you, making it difficult to judge exactly where you are and whether you can walk straight ahead. Good knowledge of the surroundings can help overcome this problem.

The complicated pictures can sometimes be challenging. Although the visions themselves may not be of anything frightening, it can be disturbing to start seeing strangers in the home or garden. Some people have overcome this by getting to know the figures in their visions. One man stated that when he wakes up in the morning, he says to the figures he is seeing: "Welcome to my new day". This allows some control over the way he feels about phantom images of unknown people. With an understanding of the cause of CBS, most people will not be concerned about the visions, but they can still be worrying for some.

Is there a cure for Charles Bonnet Syndrome?

There is no proven treatment for CBS. The frequency of phantom images can vary greatly between you and other people living with the condition. Some people experience visions from anywhere from a few days up to many years, and they can last only a few seconds or continue for most of the day. Generally these experiences will disappear after about a year or 18 months but this will not happen for everyone.

If you're experiencing CBS, the best way of managing the condition is to understand the syndrome, know it is not a mental health issue, and come to terms with your visions.

There are a few activities that may help to stop the phantom images. Interrupting vision for a short time by closing your eyes, blinking or moving your eyes from left to right or up and down may help. Sometimes changing the environment also works. If you're in the dark, switch on the light, or if you're sitting down, stand up.

Maximising your remaining vision may also reduce the likelihood of the phantom images. Undergoing a low vision assessment is helpful to see if your remaining vision can be optimised, and to find strategies that can assist with daily activities.

For most people, the best treatment is just knowing CBS is a result of their vision loss and not other health problems. For those with serious, disturbing visions, a number of medications can sometimes be helpful. However, none are effective for everyone and this should be discussed with an ophthalmologist.

Caring for someone with Charles Bonnet Syndrome

If you're caring for someone with CBS, reassure them the condition is not a mental illness or dementia. It may be helpful to encourage them to speak with health care professionals or join a support group to meet people who may be having a similar experience.

Carers can help someone living with the condition by being supportive, non-judgmental, and empathetic. Take an interest in their visions to help them feel comfortable about opening up, and encourage them to try and touch their phantom images to reassure

them the visions aren't real. Let them know that CBS is a common side effect of vision loss, and comfort them that they don't have a mental condition to reduce the stigma around this condition.

What next?

Discuss your CBS with your ophthalmologist. Also, talking about your feelings with your GP, a low vision specialist, counsellor or psychologist can help provide ways of coping with the phantom images.

Since many healthcare workers are not familiar with CBS, use this fact sheet as a way of introducing your experiences. This can enable you to begin the conversation that may have been difficult to initiate or explain.

More information about the condition is also available from the Charles Bonnet Syndrome Foundation. Visit charlesbonnetsyndrome.org or call **1300 121 123**.

Managing vision loss

When managing vision loss, a key priority is maintaining quality of life and independence. Contacting a low vision organisation can be helpful as they can work with you to assess your individual needs and determine which aids and technologies can help. There are many excellent solutions to help you live well with low vision.





Need more information?

Learn more about macular disease at www.mdfoundation.com.au.

How's your macula? Take the quiz at www.CheckMyMacula.com.au.

You can also access our free, personalised support services and order information kits and Amsler grids by calling our National Helpline on **1800 111 709**.

M DFA has a free newsletter and you can sign up to receive invitations to education sessions and events in your area.

Macular Disease Foundation Australia is committed to reducing the incidence and impact of macular disease, by providing up-to-date information, advice and support.



National Helpline

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May 2021