Charles Bonnet Syndrome

Charles Bonnet Syndrome (or CBS for short) is a term used to describe the situation where mentally healthy people with significant vision loss have vivid, complex, recurrent visual hallucinations.

People experiencing CBS start to see things which they know are not real. These are sometimes called ‘hallucinations’ or ‘phantom images’. It is possible to experience a wide variety of these images. Images of complex coloured patterns and images of people are most common, followed by images of animals, plants or trees and inanimate objects. The hallucinations also often fit into the person’s surroundings. They can also be quite bizarre, such as dragons or fairies, or have unusually vivid colours. People generally realise that the hallucinations are not real. The hallucinations are also only visual and do not occur in any other senses such as hearing, smell or taste.

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 which 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 their problems for fear of being considered as having a mental health problem.

Who is affected by Charles Bonnet Syndrome?

Charles Bonnet Syndrome typically affects people with significant vision loss 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 hallucinations may come and go and will often stop altogether within a year to eighteen months. In some people, hallucinations 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 or hallucinations at some stage.

What causes Charles Bonnet Syndrome?

The simplest explanation for CBS is that when vision is lost the brain is not receiving as many pictures, and new fantasy pictures or old pictures stored in the brain are released and experienced as though they were real. These experiences seem to occur more commonly when there is little happening such as when sitting alone in a quiet, familiar place or when lying in bed at night or sitting in the dark.
**What concerns may arise with Charles Bonnet Syndrome?**

Seeing things which aren’t there can be concerning for some people, even though the images themselves are usually non-threatening. Some worry that Charles Bonnet Syndrome hallucinations are a sign of mental health problems and therefore don’t share their concerns with a relative, carer or doctor. CBS is caused by failing eyesight and not a mental health problem. Having CBS does not mean that you are more likely to develop any other health conditions.

**What kind of images do people see?**

There seem to be two main kinds of images people see:

Firstly, there are hallucinations of repetitive patterns and lines, which can be quite detailed like brickwork, netting, fences, mosaic or tiles.

Secondly, there are more complicated pictures of people or places. Whole scenes may appear such as landscapes or groups of people which can be life-size, or reduced or enlarged in size. These images can appear quite randomly for a few minutes or several hours. Additionally, the images may be recurrent with similar patterns, scenes or people appearing.

The images can be either black and white or colour, and they may involve movement or they may be stationary and can appear real or unreal.

**What are the effects of the hallucinations?**

Generally the hallucinations will not impact everyday life and activities. For some people, the complicated pictures can make it difficult to get around. For example, streets and rooms may have their shape changed or brickwork and fencing appear directly in front of the person 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 particular 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 deal with the hallucinations with indifference, but they can still be worrying for some.
Is there a cure for Charles Bonnet Syndrome?

There is no treatment of proven effectiveness for CBS. The frequency of hallucinations can vary greatly for each individual. Some people experience hallucinations 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 eighteen months but this will not happen for everyone.

For those experiencing CBS, understanding the syndrome, knowing it is not a mental health issue, and coming to terms with their hallucinations appears to be the best treatment.

There are a few activities that may help to make the hallucinations stop. Interrupting vision for a short time by closing the eyes or blinking or moving the eyes from left to right or up and down may help. Sometimes changing the environment also works, e.g. if in the dark, switching on the light and vice versa, or sitting down then changing to standing up.

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 hallucinations, a number of medications can sometimes be helpful, however, none are effective for everyone and this should be discussed with an ophthalmologist.

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 hallucinations.

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 which may have been difficult to initiate or explain.

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.

Contact Macular Disease Foundation Australia if you require further information or support on CBS or low vision.
Macular Disease Foundation Australia has developed a comprehensive range of publications on macular degeneration, diabetic eye disease and other macular diseases. Information and advice on living well with vision loss is also available. Call the Foundation for a free information kit or to register to receive newsletters and invitations to attend education sessions and events.

Macular Disease Foundation Australia
Suite 902, 447 Kent St
Sydney NSW 2000
Phone: 1800 111 709
Email: info@mdfoundation.com.au
Web: www.mdfoundation.com.au

Disclaimer: Information contained in this fact sheet is considered by the Macular Disease Foundation Australia to be accurate at the time of publication. While every care has been taken in its preparation, medical advice should be sought from a doctor. The Macular Disease Foundation Australia cannot be liable for any error or omission in this publication or for damages arising from its supply, performance or use, and makes no warranty of any kind, either expressed or implied in relation to this publication.