- blinking
- closing and opening you eyes
- switching a light and off
- looking at, or walking away from the hallucination
- talking to, or shouting at the hallucination
- talking to others about your experiences
- widening your social circle and activities
- improving your physical condition.

A small number of people, who find this condition seriously disturbing, may benefit from medical treatment. If you are having problems with yours, talking to your GP may be a good way to find some help.

7. CAN CBS BE CURED?

In many cases of CBS the condition disappears with time; often over a period of several weeks or months. Only a few people find the visual hallucinations persist. In some people with macular and corneal degeneration and CBS, visual hallucinations have disappeared as blindness progressed.

Early recognition and reassurance will alleviate any distress or suffering experienced by most people, helping them come to terms with it.

8. WHAT IF I WOULD LIKE FURTHER INFORMATION?

If you would like to know more about Charles Bonnet Syndrome or have any questions or concerns, please contact:

British and Irish Orthoptic Society

62 Wilson Street London EC2A 2BU

Tel: 01353 665541

Website: www.orthoptics.org.uk Email: bios@orthoptics.org.uk

Royal National Institute for the Blind (RNIB)

105 Judd Street London WC1H 9NE

Tel: 0845 766 9999 020 7388 2525

Website: www.rnib.org.uk

Charles Bonnet Syndrome



British and Irish Orthoptic Society



1. WHAT IS CHARLES BONNET SYNDROME (CBS)?

Charles Bonnet Syndrome (CBS) is a term used to describe the condition in which psychologically normal people with a severe visual impairment experience visual hallucinations.

2. WHAT CAUSES CBS?

We do not know what causes this condition. At present little is known about how the brain stores visual information and how we use this information to create the pictures we see. There is some research that shows when we see, the information from the eyes stops the brain from creating its own pictures. When people lose their sight or part of their sight, the brain is not receiving as many images and sometimes new fantasy pictures or old images stored in our brains are released and experienced as though they were seen. These hallucinations tend to happen when there is not much going on, when people are sitting quietly alone or when they are lying in bed at night.

This condition has been described as being similar to phantom limb. People who have had a limb amputated may still feel their fingers or toes or experience itching of an arm or leg that is no longer there.

3. WHO GETS CBS?

Studies have shown that 10-40% of people with visual impairment can suffer from CBS. CBS affects a variety of people including people who suffer from:

- age related macular degeneration
- retinal disorders with loss of vision
- visual field defects following stroke or neurosurgery.

The condition is one that is more commonly seen in the elderly population but can also occur in younger adults and children.

4. HOW MIGHT CBS AFFECT ME?

The visual hallucinations experienced in CBS may be relatively simple e.g. patterns or lines which can form in to more complicated patterns such as brickwork, netting, mosaic or tiles. Some people experience more complex hallucinations such as people, animals and places. Sometimes whole scenes will appear, like landscapes or groups of people, some of which are life size or others reduced or enlarged in size.

These episodes occur without warning and may last for a few minutes or for several hours. They can be black and white or in colour, they can be stationary or involve movement and they can seem real e.g. horses in a field or

unreal e.g. dragons. Generally the pictures are pleasant although the effects can be frightening.

5. DOES HAVING VISUAL HALLUCINATIONS MEAN I AM MENTALLY ILL?

NO, it is important to realise that CBS is NOT part of a psychiatric disorder and people affected by this condition know what they see is not real. It is natural that people will worry that the hallucinations are caused by mental illness. They may also be concerned that other people will think similarly. As a result people experiencing CBS may be reluctant or ashamed to talk about it. CBS is no more than a side effect of vision loss.

6. IS THERE ANY TREATMENT?

Reassurance about the condition and the benign course of visual hallucinations is essential. The majority of people are not troubled by these visual hallucinations, probably because they know they are not real and they can be amusing or entertaining.

There is no specific treatment for CBS however there are various tactics which can help you cope with these episodes. These include:

change your activity i.e. if sitting, stand up and move around