Visual hallucinations

Some people with sight loss experience visual hallucinations. Many worry unnecessarily about the cause of these.

This leaflet is available on audio CD.

You don’t have to face macular disease alone. For the best information and support call us on 0300 3030 111.
Hallucinations can occur as a result of sight loss.

Up to half of all people with macular degeneration are thought to experience visual hallucinations at some time.

They are more likely to occur if both eyes are affected by sight loss. The hallucinations often start after a decline in vision.

When hallucinations happen as a result of sight loss, they are known as Charles Bonnet syndrome, after an 18th century Swiss scientist and philosopher who first described the condition. Charles Bonnet hallucinations are not a sign of mental illness.

**What is a visual hallucination?**

A visual hallucination is the same experience as really seeing something, but the ‘something’ is not actually there.

Visual hallucinations appear to exist in the real world rather than in the mind’s eye. They come and go unannounced and can last for just a few seconds or as long as a day or more.
The syndrome itself can last from days to many years. For most people the hallucinations improve with time.

**What do these hallucinations look like?**

Charles Bonnet hallucinations can be simple unformed flashes of light, colours or shapes. However, many people see more elaborate forms such as geometrical grids and lattices.

Some people report seeing landscaped gardens or vistas, animals, people, or processions of miniature costumed figures wearing hats, or even disembodied faces with staring eyes.

The hallucinations are often seen in more vivid detail than real life. Some people enjoy their hallucinations. However, they are more often an unwanted distraction and can be frightening.

When they cause rooms or buildings to seem altered, it can be disorientating.

**Can you stop the hallucinations?**

The Macular Society has sponsored research by Dr Dominic ffytche of
the Institute of Psychiatry in London into non-drug treatments for visual hallucinations.

Dr ffytche recommends using eye movements to lessen the impact and length of hallucinations.

Eye movements activate visual parts of the brain in people with macular disease – even if they have little remaining vision.

These movements may stop certain types of hallucinations, particularly the grids, checkerboards, lattices and colours.

These exercises may help hallucinations disappear:

• Imagine two points about a metre (3ft) apart on a wall in front of you. Stand about a metre and a half away and look from one point to the other once every second or faster for 15–30 seconds, followed by a break of a few seconds. Keep your head still and hold your eyes open during these movements.

• If your hallucinations continue, try repeating this exercise. If the hallucinations are still
there after four or five attempts, the technique is unlikely to work. You may however want to try again on another occasion or for a different type of hallucination.

• Shut your eyes or look away from the image.
• Switch on the room lights.
• Simply get up and do something else.

This can cause the hallucinations to disappear; however, they often continue.

The Macular Society has sponsored a project to investigate whether using a non-invasive mild electric current can stop visual hallucinations. The technique is called ‘transcranial direct current simulation’ (tDCS). If successful it will offer an alternative to medication.

Why do the hallucinations happen?

When visual signals leave the eye they go to the back of the brain (the occipital lobe) to the primary visual receiving area, called V1.

From V1 the signals are relayed to a series
Visual hallucinations

of map-like areas, each specialised in a different aspect of seeing. There is an area specialised for movement, an area for colour, several for faces, one for landscapes and many others.

Scanning studies have revealed what happens in the brains of people while they hallucinate. These studies help explain some of the features of Charles Bonnet hallucinations.

With our eyes open, the visual brain expects to receive and process a flood of complex electrical signals. In people with eye disease or a break in the visual pathways, what was once a flood becomes a trickle. This leaves the visual areas of the brain with little to do.

The idle visual brain cells, waiting for an appropriate trigger, begin to fire spontaneously. If this happens in the colour area, people experience hallucinations of colour; if in the object area, they see objects and so on.

After a while, the visual brain gets used to the lower level of information from the eye and the spontaneous firing lessens or stops.
This explains why, for many people, the hallucinations gradually reduce over time.

**What do we still need to know?**

More research into Charles Bonnet syndrome is needed. For example, we do not know why only some people with sight loss have hallucinations. We do not know how to stop the spontaneous firing without affecting other brain activities.

One thing that is certain is that hallucinations do not mean the person is mentally ill.

However bizarre, frightening or funny their content, Charles Bonnet hallucinations are no more than a normal brain’s response to reduced visual input. While they may be an inconvenience, they are not a cause for concern.

If you find your hallucinations upsetting, talk to your doctor or ophthalmologist about the problem.

Take this leaflet with you as some health professionals outside the eye specialty may not know about Charles Bonnet syndrome.
Treatment, if any, might depend on establishing whether there are any other causes apart from eye disease.

Some people can be helped with drugs used to treat other conditions such as anti-epileptic or anti-dementia drugs.

These characteristics might suggest that hallucinations are not the result of Charles Bonnet syndrome:

- voices and visions
- absence of patterns and simple phenomena
- elaborate explanation
- escalating responses to hallucinations
- confusion / memory concerns
- accompanying person more aware of problem than patient.

With thanks to Dr Dominic ffytche, Institute of Psychiatry, London.

For research references visit macularsociety.org/references
Beating Macular Disease

Macular disease is the biggest cause of sight loss in the UK, with around 300 people diagnosed every day.

The Macular Society is the only charity determined to beat the fear and isolation of macular disease with world-class research, and the best advice and support.

To support people affected by macular disease now, the Macular Society provides a range of support, information and services:

The Advice and Information Service (0300 3030 111). Available Monday to Friday, 9am to 5pm. Alternatively, you can email help@macularsociety.org

Our website at macularsociety.org provides a wide range of information and resources for people affected by macular disease.

Our network of over 400 Macular Society Support Groups across the UK. Each one offers practical and emotional support for people with macular disease, from those living with it today.
Our free, confidential **Counselling Service**, which offers support over the phone from one of our trained counsellors. You can also call our Advice and Information Service for more information and to be referred for counselling.

Our **Telephone Befriending Service**, which pairs you up for regular telephone calls with another person with macular disease who knows what it is like to live with the condition. Calls can be about anything, and provide friendly support.

Our **Treatment Buddies Service** will connect you with someone else who has received treatment for macular disease to talk you through the process and any worries you may have.

**Skills for Seeing training**, which can help you with techniques to make the most of your vision.
Here are some hallucinations people have described to us...

- Edwardian gentlemen on bicycles
- Traffic lights that look like fireworks
- Floating gargoyle heads
- Honeycomb patterns on the wall
Working with you to Beat Macular Disease:

• We provide the best advice and information on living with macular disease.

• Macular Society Support Groups can help you to beat the isolation of macular disease, by connecting you with other local people who know what you’re going through – offering support and companionship.

• Our research programme is focused on finding new treatments and a cure to Beat Macular Disease forever.

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