

Visual hallucinations

Support throughout central vision loss

Some people with sight loss experience visual hallucinations. Many worry unnecessarily that there is something wrong with their mind.

**No one need face macular degeneration alone.
For information and support call 0300 3030 111.**

In this leaflet we look at why people with sight loss sometimes experience visual hallucinations and at possible ways to cope with them.

Given the right circumstances, we can all see things that are not actually there. For some of us, the visions, more correctly termed hallucinations, come naturally while falling asleep or when waking up – a sort of waking dream.

Hallucinations can also occur because of sight loss, particularly through macular

degeneration. It is important to understand that the hallucinations are a natural experience and not a sign of any mental illness. 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.

Up to half of all people with macular degeneration are thought to experience Charles Bonnet hallucinations at

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

What is a visual hallucination?

We can all conjure up pictures in our mind's eye, for example, a picture of a tomato. We can rotate the imaginary tomato, examine its redness and the smooth texture of its skin. However, the image is vague, entirely under our control and

we understand it is part of our imagination. This sort of internal picture, correctly termed a visual image, is not a hallucination.

A visual hallucination is the same experience as really seeing something, the only difference being that 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 years but, for most patients, the hallucinations do eventually disappear.

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 disembodied faces with staring eyes,

landscaped gardens or vistas, animals, people, or processions of miniature costumed figures wearing hats.

Ironically, the hallucinations are often seen in more vivid detail than real life.

Some people enjoy their hallucinations but more often they are an unwanted distraction and can be rather frightening.

When they cause rooms or buildings to seem altered, it can be disorientating when trying to get around.

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.

Try these exercises to help make the 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. 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.

Other things to try:

- Shutting your eyes or looking away.
- Switching on the room lights.

- Sometimes simply getting up and doing something else can cause hallucinations to disappear, however they often continue unaffected.

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 of map-like areas, each

specialised for 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 patients 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 firing happens in the colour area, patients 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 stimulation 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 activities of the brain.

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

However bizarre, frightening or comical 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 cause for concern.

If you find your hallucinations very 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 antiepileptic or antipsychotic drugs

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

Helpline

Our expert helpline team can provide you with information, or refer you to our free telephone counselling service.

**Call 0300 3030 111
Mon-Fri 9-5.**

email help@macularsociety.org

Macular Society services

Helpline: Our helpline team is there for anyone affected by macular conditions. Call 0300 3030 111 Mon-Fri 9-5 or email help@macularsociety.org

The helpline can give advice and information about all aspects of macular disease including diagnosis, treatment and living with central vision loss.

Befriending: Having a macular condition can leave you feeling isolated especially

if it's hard to get out and about. Your dedicated befriender will call regularly for a friendly, social chat about anything you like including, but not always, macular disease.

Counselling: It's natural to feel upset or angry when you're told you have a macular condition especially if you have lost central vision. Sometimes it is compared to a bereavement.

Many people find it helps to talk, in confidence, to a professional counsellor.

We have a free telephone counselling service for anyone who would like to use it. Our counsellors are fully qualified and regulated by BACP.

Treatment buddy: About to have injections for your macular disease? Find out what to expect. Our helpline can put you in touch with people who've already had the treatment for an informal, friendly chat.

No one has to face macular disease alone. Find out more about all our services, including our local groups on 0300 3030 111.

Want to talk online?
Join one of our forums.
www.macularsociety.org/forum
or
www.macularsociety.healthunlocked.com/join

If you've found this leaflet useful please consider making a donation to support our work.

**Macular Society**

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