

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. This leaflet is available on audio CD.

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

Hallucinations can occur because of sight loss, particularly through macular degeneration. The hallucinations are not a sign of mental illness.

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.

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 years. For most people 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, 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. 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 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 antiepileptic or anti-dementia drugs.

When are visual hallucinations not 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
www.macularsociety.org/references

If you are experiencing visual hallucinations due to sight loss which are causing distress, our professional telephone counselling can help.

Call the helpline for information.

0300 3030 111

**Monday to Friday
9am – 5pm**

**help@
macularsociety.org
www.macularsociety.
org**

How we help

We are the national charity for anyone affected by central vision loss.

We provide free information and support to improve lives today.

We fund research so that one day we can overcome macular disease.

All our services are free to those with macular conditions, their family and friends.

As well as the helpline, our services include:

Counselling – confidential telephone support from a professional counsellor.

Support groups – we have over 300 local groups around the UK.

Telephone befrienders – particularly helpful for those who find it hard to get out and about.

Gadget Guides – tips on using gadgets and technology to help people adapt to living with sight loss.

Skills for Seeing – training to help people make best use of remaining sight.

We produce a range of leaflets covering many aspects of macular disease available in large print, audio CD or to read or listen online, including:

- Driving
- Lighting
- Low Vision Aids
- Nutrition and Eye Health
- Protecting Your Eyes
- Registering as Sight Impaired
- Smoking and Sight Loss
- Using Technology

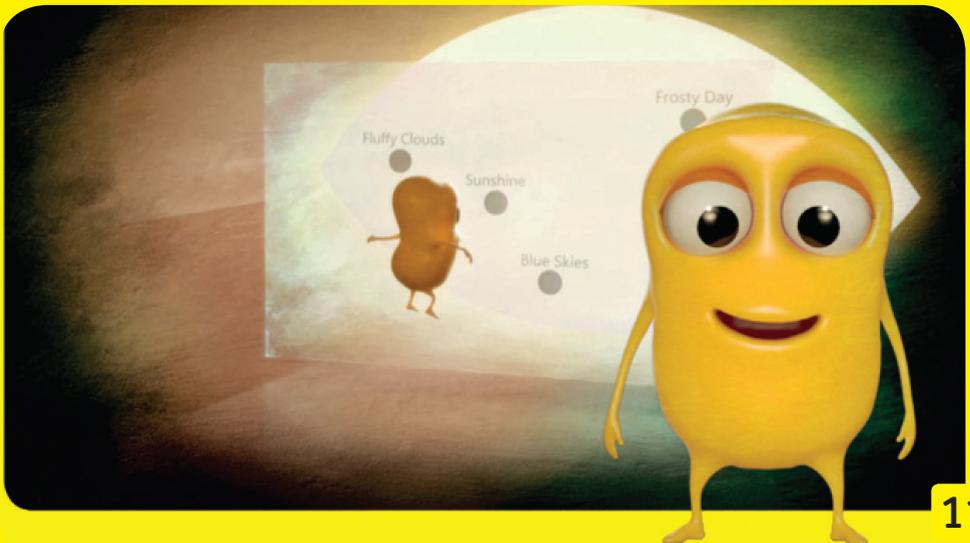
For your copy call our helpline or go to www.macularsociety.org/resources

Explaining AMD to family and friends

Explaining AMD isn't easy, from a medical point of view or an emotional one. For anyone affected by macular disease this can be frustrating and upsetting, as they'll need to be understood and will need support from their family and friends.

We'd like as many people as possible to understand AMD and to raise awareness of the support the Macular Society is able to offer. To help with all the above, we've made a short video, featuring a character we've created called Mac.

This film can be seen at
www.macularsociety.org/mac



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Macular Society

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