



The Royal College of Ophthalmologists

PRESS RELEASE



The
Macular
Disease
Society

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Patients at risk of losing their sight need to be told they could develop visual hallucinations

The Royal College of Ophthalmologists and The Macular Disease Society are jointly calling for all eye doctors to warn patients with macular degeneration they may develop visual hallucinations – Charles Bonnet Syndrome.

Patients with sight-destroying conditions such as macular degeneration should be advised, at the time they are diagnosed with a sight diminishing condition, that they have at least a 20% chance of developing visual hallucinations. These can often be disturbing and can lead patients to believe they are suffering from psychosis or dementia, say doctors and patient groups.

It is thought that up to 60% of patients, with severe vision loss, develop Charles Bonnet Syndrome, which is caused by a lack of visual stimuli and does not indicate any kind of mental dysfunction. Normally sighted people could develop Charles Bonnet Syndrome if they were blindfolded for long enough.

It is thought that Charles Bonnet Syndrome occurs when visual images are no longer channelled into the brain, which goes on to replace real images with its own stored images.

The chairman of the scientific committee of the Royal College of Ophthalmologists, Mr Winfried Amoaku, says: “A significant number of medical professionals and the general public have inadequate

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knowledge about visual hallucinations caused by eye problems such as macular degeneration.”

“The hallucinations often involve seeing people’s faces, landscapes, people or objects which aren’t there, as well as patterns, grids and brickwork. These can be very frightening.”

“Working with The Macular Disease Society, and psychiatrist Dr Dominic ffytche from the Institute of Psychiatry, we are aiming to raise awareness of Charles Bonnet Syndrome. We want to ensure that patients are aware of the link between visual hallucinations and their sight loss. In our experience forewarning and knowledge of the possibility of hallucinations helps patients cope when they occur and allows them to realize that this indicates only that there is a functional problem with their sight, and not a problem with their mind.”

“Each ophthalmologist will use their own judgement and knowledge of the patient, to judge how best to break the news about the possibility that patients may develop visual hallucinations.”

Mr Tom Bremridge, chief executive of The Macular Disease Society, says: “The campaign was inspired by one of our members, a patient in Scotland, who was misdiagnosed after she went to A&E complaining of her visual hallucinations. This lady, who is in her 80s, was referred to a psychiatrist by the A&E doctor and spent six months wrongly assuming she was suffering from dementia.”

The Macular Disease Society has been interviewing members in detail about their experiences of Charles Bonnet Syndrome. Of 35 patients who approached the Society to discuss their experiences, none was informed by their doctor or optician of the possibility they might develop Charles Bonnet Syndrome, before they experienced visual hallucinations. Very few of these patients were told by their doctor or optician about the Syndrome after developing symptoms



and all 35 said they would have been relieved to know what was causing the visual hallucinations.

Mr Bremridge said: “Clearly we are aiming to educate health professionals as well as the public that having visual hallucinations without warning can compound the stress of sight loss especially if people are scared to mention it to friends and family for fear of being thought to be imagining things.”

Dr Dominic ffytche, a senior lecturer at the Institute of Psychiatrists who is an expert in Charles Bonnet Syndrome, says: “There is no evidence that being forewarned would cause unnecessary anxiety, people prefer to be told.”

“At least 10% of people with Age Related Macular Degeneration (AMD) get Charles Bonnet Syndrome. The small number of studies conducted in eye clinics show around a 10-20% prevalence of Charles Bonnet Syndrome. One study looked at patients with severe visual loss [caused by a range of different eye conditions] and this figure was closer to 50-60%.”

“We think around 100,000 patients have Charles Bonnet Syndrome as a side effect of their Macular Disease.”

The Macular Disease Society runs a telephone helpline, which is available to all macular patients and their families. Please telephone 0845 241 2041. Lines are open 9-5, Monday to Friday.

Note to editors

1. For full details of the causes of Charles Bonnet Syndrome please see <http://www.acnr.co.uk/pdfs/volume4issue2/v4i2reviewart3.pdf>

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