

The Blind Leading The Blind

When doctors couldn't diagnose 90-year-old Sheffielder Bessie Goddard's strange hallucinations, she went and found out for herself – and she now runs a support group for sufferers of the little-known Charles Bonnet Syndrome

Imagine walking to the shops and suddenly seeing a fence blocking the pavement, flowers on your ceiling, a strange woman standing next to your bed, or other, more terrifying things. These are all visions that have been experienced by sufferers of Charles Bonnet Syndrome (CBS). Never heard of it? Don't worry, not many people have – and that includes GPs, opticians and top eye specialists.

It was around 10 years ago that Bessie Goddard, who is now 90 years old and lives in Sheffield, began to have strange, unexplained hallucinations. 'I was registered partially blind at the time, and I would see things like flowers on the walls and ceiling; sometimes I'd even see people climbing up the walls,' she recalls. As her eyesight deteriorated, the visions began to increase. Outside, she saw barriers across the road, and once she missed several buses because she was standing at the back of a bus stop that was full of people – only the bus stop was actually empty.

Bessie ignored the visions for almost two years, until she began going to the Sheffield Royal Institute for the Blind (SRIB). There, she got talking to some people who suffered with similar visions and learnt that what she had was called Charles Bonnet Syndrome, named after an 18th century French naturalist and philosophical writer, who documented his psychologically sound but nearly blind grandfather's vivid hallucinations.

Bessie began attending a support group for CBS sufferers at the SRIB, where people would mainly discuss their visions which, Bessie discovered, were highly individual. 'Some people have them inside, others outside, whilst others have them at specific times and specific places,' she explains. 'One woman sees a "lovely little girl", whilst one of the men sees a woman in a crinoline dress at the side of the bed. But we are lucky – other people see some really terrible things.'

What Bessie found most saddening was that many of the people in the group were suffering alone, scared they were going mad. 'For them, the group was the only time they discussed their visions, but what they needed was more support,' she says. The problem is that so little is known about CBS. 'Neither my GP nor the people at the low vision centre had heard of it. And when I

asked the eye specialist at the Royal Hallamshire Hospital about CBS, he said "What's that?"'

Determined to find out more, Bessie got in touch with Dr Dominic Ffytche, an expert on CBS, who told her that the condition affects some elderly people with macular degeneration, and that it might be caused by the brain compensating for this loss of vision. He also encouraged Bessie to become more involved in the support group, and it wasn't long before she was running it. That was five years ago and it is still going strong. 'We like to keep it light-hearted – you have to have sense of humour or else you're in trouble,' says Bessie. 'We also have a gentleman who writes wonderful poems about his visions, and his reaction to them.'

The support group also helps to provide understanding of the condition to the families of sufferers, many of whom find it difficult to deal with. 'I'm very lucky, my family understands, so when I see a brick wall in the road, or a large group of cyclists, they make a joke of it,' says Bessie. 'Unfortunately, other people don't react like that, they won't accept it, which can make things difficult.'

For a while, Bessie's support group was the only one in the UK – there are at least two more now. As such, over the years she has been contacted by a number of people struggling to cope with a loved one's condition. One of those was Judith Potts, whose mother Esme had CBS. Judith is the founder of Esme's Umbrella, a campaign group working towards greater awareness of CBS.

Whilst Esme's Umbrella is working hard to persuade eye specialists to warn their patients that CBS might develop, there is a long way to go in their campaign. As for Bessie, she has no plans to stop running her group any time soon, and even has plans for her own awareness-raising campaign. And with her energy and determination, hopefully her vision will become a reality.

Sheffield Royal Society for the Blind
0114 272 2757
www.srsb.org.uk

Esme's Umbrella
Helpline number: 0345 051 3925
www.charlesbonnetsyndrome.co.uk

CHARITY CALENDAR

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ON THE BALL

Get your gladrags to the dry cleaners for this year's Construction Ball, a sumptuous three-course dinner plus live music from The Silvertones, in support of Bluebell Wood Children's Hospice. **21 October, Sheffield City Hall**
Tickets: £850 for a table of 10
www.bluebellwood.org

RIDING HIGH

Support the great work of the Yorkshire Air Ambulance at the Shibden Dale Riding Club's 50th Anniversary Ball, which includes a three-course meal and entertainment throughout the evening. **21 October, The Moorlands Inn, Ogden**
Tickets: £35 per head / £325 for a table of 10
www.yorkshireairambulance.org.uk

PRETTY IN PINK

Enjoy a three-course meal, plus entertainment, tombola, raffle and mini auction at the Pink Lunch, in aid of Cancer Support Yorkshire. Don't forget to wear something pink! **29 October, The Midland Hotel, Bradford**
Tickets: £35
www.cancersupportyorkshire.org.uk