

MACULAR SOCIETY QUESTIONNAIRE

We are surveying our members to find out more about how one particular, common side-effect of sight loss can affect people. The condition is called Charles Bonnet Syndrome and it causes a person to experience visual hallucinations so they see things which are not there. These might appear as patterns, faces (sometimes distorted), people, plants, trees, animals or other objects. The Syndrome is not a mental illness; it is a normal response of the brain to the loss of visual stimulation to the areas which normally process what we see. If you do not have Charles Bonnet Syndrome we are still interested in what you know about it and have indicated which questions we would like you to answer.

Please answer Question 1 to Question 7 even if you do not have Charles Bonnet Syndrome

1. How old are you?

- 18 – 35 years
- 36 – 50 years
- 51 – 65 years
- Over 65 years

2. Are you male or female?

- Male
- Female

3. Do you have macular disease?

- Yes
- No
- Don't know

4. How long have you had macular disease? (Duration in months / years)

5. What type do you have?

- Wet
- Dry
- Wet & Dry
- A juvenile form (name)
- Don't know
- Other

6. Does it affect both eyes?

- Both
- Left only
- Right only

- Different types in each eye

7. Do you have Charles Bonnet Syndrome?

- Yes
- No

If you do not have Charles Bonnet Syndrome please go to Question 24 and continue the questionnaire.

8. What of images did you / do you see? (tick all that apply)

- Patterns
- Faces
- Figures
- Animals
- Objects

9. When did the Charles Bonnet Syndrome start? (month / year)

10. When was your last hallucination? (month / year)

11. Do you consider your hallucinations to have stopped?

- Yes
- No

12. How long did / does each hallucination last on average? (tick shortest duration that best describes your typical hallucinations)

- Seconds
- Minutes
- Hours
- Continuous

13. At worst, how frequently did / do the typical episodes described in Q12 occur? (tick the frequency that best describes the hallucinations at their worst)

- Something was occurring all the time
- I had a hallucination almost every hour
- I had a hallucination almost every day
- I had an hallucination most weeks
- I had a hallucination most months

14. What best describes your reaction to Charles Bonnet Syndrome when it first occurred? (tick all that apply)

- Amused
- Curious
- Intrigued
- Startled

- Frightened
- Terrified
- Indifferent
- Other

15. What is your reaction to Charles Bonnet Syndrome now? (tick all that apply)

- Amused
- Curious
- Intrigued
- Startled
- Frightened
- Terrified
- Indifferent
- Other

16. What did you think might be the cause when you first experienced Charles Bonnet Syndrome? (tick all that apply)

- I had been told it might occur
- Thought it must be to do with sight loss
- Thought I might have illness such as Alzheimer's disease
- Thought I might have a mental illness.
- Did not know what to think
- Other

17. Did / does Charles Bonnet Syndrome interfere with the following abilities? (tick all that apply)

- Moving about
- Watching television
- Cooking
- Sleeping
- Has no effect
- Other

18. Charles Bonnet Syndrome had / has the following effect on my life? (tick the one that best applies)

- A very negative effect
- Fairly negative
- No real effect
- A fairly pleasant effect
- A very pleasant effect

19. Who have you told about your hallucinations? (tick all that apply)

- Medical professionals
- Spouse
- Other family
- Friends

- Other people with macular disease
- No one
- Other

20. What reasons have prevented you from telling people? (tick all that apply)

- Embarrassed by symptoms
- Feared others would think I was developing a serious illness e.g. Alzheimer's or mental problem
- I don't have anyone close to tell
- I don't discuss my health with other people
- I was not concerned about it
- Other

21. Did you already know about Charles Bonnet syndrome when you first experienced the hallucinations?

- Yes
- No

22. If you have consulted a medical professional, what did they say it was? (tick one that best applies)

- They gave a clear account of Charles Bonnet Syndrome
- They were unsure or did not know
- They gave a different diagnosis of:

23. What difference did finding out about Charles Bonnet Syndrome make to your feelings about the hallucinations? (tick all that apply)

- Reassured
- Relieved
- Confused
- Angry that I hadn't been told about it earlier
- It made no difference
- Other

24. Had you heard of Charles Bonnet Syndrome before this questionnaire?

- Yes
- No

25. How did you find out about it? (tick all that apply)

- Ophthalmologist
- Eye clinic nurse
- Optometrist
- GP
- Social worker
- Rehabilitation officer

- Sensory awareness team
- Friend or family
- Macular disease society
- Internet research (by self/family/friend)
- Radio, television, newspaper or magazine article
- Other