

Share Your Story!

Your Experience of living with LHON

Thank you for agreeing to share your thoughts and experiences. If you would like to offer any additional information please feel free to add it at the end. Please be as brief or detailed as you wish.

If you have a friend or family member who would like to share their experiences we would love to hear from them also. A form for them is at the bottom of this document.

Name

Length of time you have lived with LHON

Describe your life before, or at the time of, diagnosis.

You may wish to include details of work, family life, hobbies, interests, your hopes for the future

Describe your experience of becoming visually impaired

Consider including the following:

A description of how you came to realise your sight was affected, your age at onset, how you felt upon diagnosis or in the early days

How have you adapted to living with sight loss?

This could be practically or emotionally. Consider any support networks you accessed and think about your current opinion of being visually impaired and even if LHON has added anything positive to your life

Describe your life now

Consider work, hobbies, interests, family life etc

What advice would you give someone recently diagnosed with LHON?

Would you like to be kept up to date with occasional news and views from the LHON Society? Y/N

Thank you for responding to our questions. Please return them along with a photo of yourself to James Ferguson at jamesf32@yahoo.com

For Those Close to Someone Living with LHON

Thank you for agreeing to share your thoughts and experiences. We know that when someone acquires LHON it has an impact on the people close to them, as well as the individual. We want the LHON Society's website to be a source of support for those close to someone affected as well as the individual directly affected.

If you would like to offer any additional information please feel free to add it at the end. Please be as brief or detailed as you wish.

Your name

The name of your friend/relation who lives with LHON

Your relationship to the person affected?

Describe how you felt upon hearing the news your friend/relation was affected by LHON.

**Has your relationship changed since they acquired LHON?
If so please describe how.**

Have you accessed any support, either for yourself or your friend/relation that you found beneficial?

If you have provided, or continue to provide, any practical or emotional support please share what has helped either you/them or both of you!

What advice would you give a friend or relation of someone recently diagnosed with LHON?

Would you like to be kept up to date with occasional news and views from the LHON Society? Y/N

For the purposes of consistency we may edit your responses. We will always seek your approval before posting the final draft.

Thank you for responding to our questions. Please return them along with a photo of yourself to James Ferguson at jamesf32@yahoo.com