



SHARE YOUR STORY

If you are affected by LHON, we would love to hear from you. The following questions provide an optional structure for you to share your story with us, but please feel free to tell your story how you like.

Once completed, you can either upload your story [here](#) via the LHON Society website or email your completed form to us at info@lhonsociety.org. If you have any issues, please don't hesitate to get in touch.

Full name:

Date of birth:

Location:

Which of the following best describes you?

I am...

- A. Living with LHON
- B. A carrier of an LHON mutation
- C. A family member, carer or friend of someone affected by LHON
- D. Another perspective (please specify in the box below):

How would you describe yourself in three words?

In a few words, what are your key passions in life?

Email:

Phone number:

YOUR STORY

The following questions provide an optional structure for your story, but please feel free to tell your story how you like.

Could you tell us a bit about your life right now – do you work/study/volunteer; are in a relationship/have family; have key things you do for fun etc?

How have you been affected by LHON?

WRITING NOTES:

- If you are living with LHON, you could share where you were in your life when you first started to develop LHON, how you reacted to the first signs and how and when you were diagnosed (month, year) and what the impact was.
- If you are a carrier, you could share when you first learnt that you carry a LHON mutation (month, year) and how it affected you.
- If you are a family member, carer or friend of someone with LHON, feel free to share your experience and the impact LHON has had on you or anything else you wish to share.

In brief, how would you describe LHON to others?

How have you learnt to adjust to LHON/a LHON mutation, or helped someone live with LHON /a LHON mutation? What support have you received and/or given and what has made the greatest difference to you and/or them?

What advice would you give someone who's in a similar situation to you, whether recently diagnosed with LHON, experiencing early symptoms, a carrier or wanting to support someone affected?

Any final comments or reflections?

If you'd like us to post a photo of you with your story, please attach one along with this form. Image file should be no bigger than 3MB. Aim for a portrait layout.

CONSENT

Please Confirm That You Consent For Your Story To Be Posted On Our Website And/Or Promoted Via Our Social Media Channels: *

N.B. Your submission will be reviewed by us and converted into our case study template. We will also do a proof and editorial check. Once ready to go online, we will share it with you to confirm you are happy with the final piece before it is posted.

YES, I AM HAPPY FOR MY STORY TO BE SHARED