

Checklist for family members of patients with vision loss

LHON can be a life changing event for you and your loved one. However, most of the affected people readjust to their new level of visual functioning within a few years after the first symptoms of LHON appear. Here's a checklist to help you get started.

- Fill out our 'symptom tracker' to record the progressing symptoms of LHON
- Be aware of the potential triggers and risk factors you need to avoid
- Identify a local neuro-ophthalmologist or ophthalmologist who understands LHON
- Complete a baseline vision exam with an LHON specialist
- Try and get an LHON diagnosis confirmation as soon as possible
- If you don't have genetic test results, develop a plan for how you can get it done, if needed
- Maintain an electronic file for all the visual and genetic tests that have been undertaken
- Obtain and store a copy of a maternal relative's test results
- Identify a genetic counsellor to discuss LHON issues within your family
- Approach a mental health therapist to cope with their diagnosis
- Identify the changes you will need to make around the home so that the person with LHON can move around without difficulty
- Contact your local organisations or schools for the visually impaired and find out how they can offer guidance and support