



LHON & Migraine

Many individuals with an LHON mutation, with or without vision loss, experience migraine.

What is a migraine?

"A migraine is a headache that can cause severe throbbing pain or a pulsing sensation, usually on one side of the head. It's often accompanied by nausea, vomiting, and extreme sensitivity to light and sound. Migraine attacks can last for hours to days, and the pain can be so severe that it interferes with your daily activities."¹

What does the research say?

While a connection between carrying an LHON mutation and experiencing migraine and its associated symptoms has not been fully proven, a very high percentage of those with an LHON mutation — affected and unaffected — experience migraine. LHON is a mitochondrial disease, and some research indicates there is a connection between mitochondrial disease and migraine.^{2,3} More research is needed to explore the relationship between mitochondrial disease and migraine and, more specifically, LHON and migraine.

What types of care are available?

Your existing medical care providers may be a helpful resource to discuss your symptoms and potential treatments. Additional specialists to consider include:

- Mitochondrial Disease Specialists
Medical care specialists who provide coordinated, multidisciplinary care for patients with mitochondrial disease have experience that may be helpful.
→ **Find one near you by searching the Mitochondrial Care Network:**
www.mitonetwork.org
- Headache or Migraine Specialists
There are doctors who specialize in treating various types of headaches, including and sometimes exclusively migraine.
→ **Find one near you by searching the American Migraine Foundation's "Find a Doctor" tool:**
www.americanmigrainefoundation.org/find-a-doctor

When discussing migraine with your medical care providers, it can be helpful to remind them that LHON is a mitochondrial disease. Especially if you have not experienced vision loss but do or are likely to carry a LHON mutation, it may help to connect the dots with symptoms you are experiencing. Becoming educated on both LHON and mitochondrial disease can be an important step in ensuring that you receive the best medical care.

"You have a legitimate, inherited, neurological disease,"

says Dr. Matthew Robbins in his presentation "Migraine Long Haulers: Lasting Effects" at the 2022 Migraine World Summit.

What treatments are available?

There are several prescription drug, non-prescription drug, and non-drug options that are available to prevent and/or treat migraine. In recent years, new treatments have emerged that use different pathways in the body to prevent or treat migraine. Some research suggests a potential benefit of taking Riboflavin (Vitamin B2) for its preventive effects.⁴ Ask about all available treatments when meeting with your medical care providers. **Learn about new treatments here:** www.americanmigrainefoundation.org/resource-library/new-migraine-treatments

Additional Resources

- American Migraine Foundation: www.americanmigrainefoundation.org
- Migraine World Summit: www.migraineworldsummit.com
- Mitochondrial Care Network: www.mitonetwork.org
- Ten-step approach to the diagnosis and management of migraine (Eigenbrodt et al, *Nat Rev Neurol*, 2021): <https://www.nature.com/articles/s41582-021-00509-5/figures/1>
- LHON & Migraine video: <https://www.youtube.com/watch?v=m5loGlf8z9k>

¹Migraine. Mayo Clinic. Updated July 2, 2021. Accessed December 20, 2021. <https://www.mayoclinic.org/diseases-conditions/migraine-headache/symptoms-causes/syc-20360201>

²Kraya T, Deschauer M, Joshi PR, Zierz S, Gaul C. Prevalence of Headache in Patients with Mitochondrial Disease: A Cross-Sectional Study. *Headache*. 2018; 58(1):45-52. doi:10.1111/head.13219

³Vollono C, Primiano G, Della Marca G, Losurdo A, Servidei S. Migraine in mitochondrial disorders: Prevalence and characteristics. *Cephalalgia*. 2018; 38(6):1093-1106. doi:10.1177/0333102417723568

⁴Yamanaka et al., Experimental and Clinical Evidence of the Effectiveness of Riboflavin on Migraines. *Nutrients*. 2021; 13(8):2612. doi:10.3390/nu13082612