



The ROYAL COLLEGE of
OPHTHALMOLOGISTS

Clinical Guidelines

Hydroxychloroquine and Chloroquine Retinopathy: Recommendations on Monitoring

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Lay Summary

Hydroxychloroquine is a medicine that is effective in treating various long-term inflammatory disorders of the joints and skin. In general, hydroxychloroquine is a safe and cost-effective medication, particularly when compared to newer anti-inflammatory medicines which can have more significant adverse effects on the body. However, some patients taking hydroxychloroquine, or a similar medication called chloroquine, can suffer permanent loss of vision due to the harmful long-term effect of hydroxychloroquine on the retina. The retina is the light sensitive layer at the back of the eye which allows light to be sensed and relayed to the brain so that an image is perceived or “seen” by an individual. This condition where hydroxychloroquine can affect the retina and vision when taken for a long period of time is called “hydroxychloroquine retinopathy”.

Hydroxychloroquine retinopathy becomes more likely the longer any individual is taking the medication. The disorder is rarely seen within the first five years of treatment, but becomes more common with a longer duration of use. Between 20 and 50% of people taking hydroxychloroquine for more than 20 years may have some signs of hydroxychloroquine retinopathy. Overall, 7.5% of individuals taking hydroxychloroquine for more than five years may have some signs of retinal damage detected on specialised tests.

If advanced, hydroxychloroquine retinopathy can cause symptoms of loss of peripheral vision, and then in later stages, central vision can become affected too. If hydroxychloroquine retinopathy is advanced, it can result in permanent loss of sight in both eyes that can impact quality of life and activities such as driving and reading. It is unlikely that all the visual field will be lost, even in advanced hydroxychloroquine retinopathy. However, once hydroxychloroquine retinopathy results in noticeable loss of vision, the damage to the retina is permanent and often continues to get worse even if the medication is stopped.

It is possible to detect early signs of hydroxychloroquine retinopathy using specialised techniques that can look at layers of the retina with photographs of the eye, and by visual field testing. Visual field testing is tested by an individual pressing a button when they see a light on a specialised type of eye test. These tests, when taken together, can detect early signs of hydroxychloroquine retinopathy before the condition is noticed by an individual (before it causes symptoms) and therefore are able to detect the condition at a much earlier stage.

Looking for a particular condition in a person thought to be at risk, in order to detect it early and minimize the risk of harm is a process called “monitoring”. In the United Kingdom, monitoring for hydroxychloroquine retinopathy is now recommended on the National Health Service for all individuals taking either hydroxychloroquine or chloroquine, who are expected to remain on the medication for more than five years. The aim of monitoring for hydroxychloroquine retinopathy is to detect the earliest definite signs of the condition to allow those individuals

to seek alternative medications in consultation with their doctor. This will reduce the amount of sight that is lost at the time of detection (diagnosis), and reduce the risk of the sight getting any worse (by stopping the medication).

Monitoring for hydroxychloroquine retinopathy involves having “baseline tests” at the eye service where the monitoring will take place. This will mean having a photograph taken of the retina (after the instillation of dilating eye drops) within a year of starting hydroxychloroquine medication. The reason for these baseline tests is to determine whether an individual can undergo monitoring, and whether any conditions of the retina or the eye already exist which may make monitoring difficult or impossible. Thereafter, most patients will be monitored after five years of taking the medication, and will be monitored annually thereafter, with a combination of retinal photographs and visual field tests. Those patients considered at higher risk of developing hydroxychloroquine retinopathy (such as those who also take Tamoxifen, those who take chloroquine, those who have impaired kidney function, and those who are taking a high daily dose of hydroxychloroquine) will be seen annually after they start taking the medication. Should the standard monitoring tests prove inconclusive, it may be necessary to repeat some tests, or rarely, have a patient undergo more specialist tests at a different eye centre where such tests are available.

The result of monitoring (whether any given individual has any signs of retinopathy on the tests or not) will be communicated to that individual, the General Practitioner and the prescribing physician (such as the rheumatologist or dermatologist) if relevant. If an individual is diagnosed with having hydroxychloroquine retinopathy, they will have an appointment in the hospital eye service so that the results of the tests can be discussed further, any questions can be answered and any additional support can be provided to that individual. It is also expected that before stopping hydroxychloroquine, a consultation will be arranged with the prescribing doctor so that an alternative medication can be identified if the decision to stop hydroxychloroquine has been recommended by the monitoring process.

More information on hydroxychloroquine and monitoring for hydroxychloroquine retinopathy is available from:

The Macular Society: www.macularsociety.org/

British Association of Dermatologists: www.bad.org.uk/for-the-public/patient-information-leaflets