

Hydroxychloroquine (Plaquenil® or Quinoric®) - Importance of Eye Screening

This leaflet is for patients that have been prescribed Hydroxychloroquine (Plaquenil®) and have been referred to the Ophthalmology department, for eye screening.

What is Hydroxychloroquine?

Hydroxychloroquine is a medication used to treat several conditions, including (active) rheumatoid arthritis, juvenile idiopathic arthritis, discoid and systemic and cutaneous lupus erythematosus, solar urticarial.

Your doctor has prescribed hydroxychloroquine to help manage your condition. This medication is safe and effective, but it can cause side effects.

What is Hydroxychloroquine retinopathy?

Patients that have been prescribed hydroxychloroquine for more than five years (especially in high doses) are at risk of damage to the back of the retina. This is known as retinal toxicity or retinopathy.

Severe retinopathy, especially the macula (the central area), can cause significant, irreversible sight loss. For this reason, patients are referred to Ophthalmology department for regular eye health checks to screen for signs of retinopathy.

What is the aim of screening for hydroxychloroquine retinopathy?

The aim of screening is not to prevent retinopathy but to become aware of the earliest definitive signs of it before the patient notices any symptoms. Patients usually need to be taking hydroxychloroquine for at least five years before any changes are noted.

Patients usually receive an eye appointment ideally within 6 months of starting treatment of hydroxychloroquine.

What will happen at the Ophthalmology appointment?

At the Ophthalmology outpatients appointment the following will happen:

- Visual Acuity Check (Checking your distance vision, please bring your TV or/and driving glasses with you)
- 10-2 Humphrey Visual Fields test (using a white stimulus), testing one eye at a time, clicking a button when you see a light appear in the machine.
- Intraocular Pressure Check
- Dilating drops applied (Please **do not drive** to this appointment as the dilating drops will blur your vision and affect your driving) Dilating the pupils allow more light into the eye to give a better view of the retina (Back of the eye)
- OCT Scan (Ocular Coherence Tomography) Baseline scan of the macula (both eyes)
- Fundus Photography (Baseline photographs of the back of the eyes) including colour photographs and Auto fluorescence Imaging (a different type of filter, that detects

abnormal levels of a substance called lipofuscin in the retina, which can be an early sign of disease).

- Ophthalmologist (Eye Doctor) who will assess all of the information from the tests and will give you feedback in clinic, who will then send a report to the patient and to the professional who has prescribed hydroxychloroquine.

All the tests are non-invasive (they do not cause pain)

How often will I need to be screened for hydroxychloroquine retinopathy?

If the patient's eyes are healthy, it is likely that the patient will be screened again after five years. The new images will be likened to the original scans/photographs. If there is still no sign of disease then the patient will be screened again, every year.

An annual visit is usually needed to the Ophthalmology outpatients department, especially if the patient is:

- On a very high dose of hydroxychloroquine.
- Taking tamoxifen for breast cancer
- With poor kidney function
- Taking a similar drug, chloroquine.

If the patient stops taking hydroxychloroquine, then screening for any hydroxychloroquine retinopathy will cease.

What happens next?

If there are **no signs** of hydroxychloroquine retinopathy, then after five years will be screened every year until you stop taking hydroxychloroquine.

If there is a **possibility** of hydroxychloroquine retinopathy, due to an abnormality found in any one test, the patient may need to repeat any of the tests again. In cases of possible retinopathy, the patient will need to continue taking hydroxychloroquine. This is due to there being no definitive evidence of retinopathy, and that the patient will continue benefitting from taking hydroxychloroquine.

If there is a **definite** hydroxychloroquine retinopathy, due to two of the tests showing signs of abnormalities, and both are consistent with hydroxychloroquine toxicity. The degree of retinopathy will be described as 'mild', 'moderate', or 'severe'.

If the degree of retinopathy is mild, and the patient is responding well to hydroxychloroquine, the prescribing physician may decide to continue with the medication, possibly at a lower dose.

If the retinopathy is moderate to severe, it is inappropriate for the ophthalmologists to stop the hydroxychloroquine treatment, and the patient will be referred to the prescribing physician for discussion about switching medication to a suitable alternative or will continue to monitor the patient condition.

Progression of Retinopathy

In most cases it is expected that stopping hydroxychloroquine treatment will stop the retinopathy worsening.

If the condition does progress, over time the patient may experience a significant loss of vision over time. This can be disturbing to the person and should be offered support and information

to help cope with the impact of sight loss. If the vision does deteriorate, the ophthalmologist can refer the patient to the Low Visual Aids Clinic/Service for further assessment and advice, including the use of equipment and devices especially designed to help people with a visual impairment.

What should I do if I have a problem?

If you develop any significant change in your vision and/or need urgent advice about your eye(s), please telephone (in the information please provide your hospital 'X' number (if known), Name, Date of Birth and a contact telephone number) :

Conquest Hospital Eye Clinic - Tel: (01424) 755255 Ext: 8971 - during 9.00am and 5.00pm.
Eastbourne DGH Eye Clinic - Tel: (01323) 417400 Ext: 4118 - during 9.00am to 5.00pm.

For Out of Hours contact you may leave an answerphone message on the telephone numbers above, and a member of staff will contact you the next working day. Otherwise if you feel you need to be seen urgently, please attend your local Accident and Emergency Department.

Consent

Although you consent for this treatment, you may at any time after that withdraw such consent. Please discuss this with your medical team.

Sources of information

Macular Society.2018. Eye screening for patients taking hydroxychloroquine (Plaquenil®).
The Royal College of Ophthalmologists. 2018. Clinical Guidelines. Hydroxychloroquine Retinopathy: Recommendations on Screening. The above information can be accessed via the internet.

Important information

The information in this leaflet is for guidance purposes only and is not provided to replace professional clinical advice from a qualified practitioner.

Your comments

We are always interested to hear your views about our leaflets. If you have any comments, please contact the Patient Experience Team – Tel: (01323) 417400 Ext: 5860 or by email at: esh-tr.patientexperience@nhs.net

Hand hygiene

The Trust is committed to maintaining a clean, safe environment. Hand hygiene is very important in controlling infection. Alcohol gel is widely available at the patient bedside for staff use and at the entrance of each clinical area for visitors to clean their hands before and after entering.

Other formats

If you require any of the Trust leaflets in alternative formats, such as large print or alternative languages, please contact the Equality and Human Rights Department.

Tel: 01424 755255 Email: esh-tr.AccessibleInformation@nhs.net

After reading this information are there any questions you would like to ask? Please list below and ask your nurse or doctor.

Reference

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The following clinicians have been consulted and agreed this patient information:

Mr Pantelis Ioannidis (Consultant Ophthalmologist, Clinical Governance Lead)

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The directorate group that have agreed this patient information leaflet:

Ophthalmology

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