

Eye monitoring for patients taking hydroxychloroquine (Plaquenil[®])

This leaflet contains important information for people taking hydroxychloroquine.

This leaflet is available on audio CD.

**You don't have to face macular disease alone.
For the best information and support call us on
0300 3030 111.**

This leaflet has been produced in
association with



The ROYAL COLLEGE *of*
OPHTHALMOLOGISTS

The College is unable to offer direct advice to patients. If you're concerned about the health of your eyes, you should seek medical advice from your GP or ophthalmologist.

Hydroxychloroquine is a medication used to treat several conditions including rheumatoid arthritis, systemic lupus erythematosus, some skin conditions (especially photosensitive ones) and others that involve inflammation.

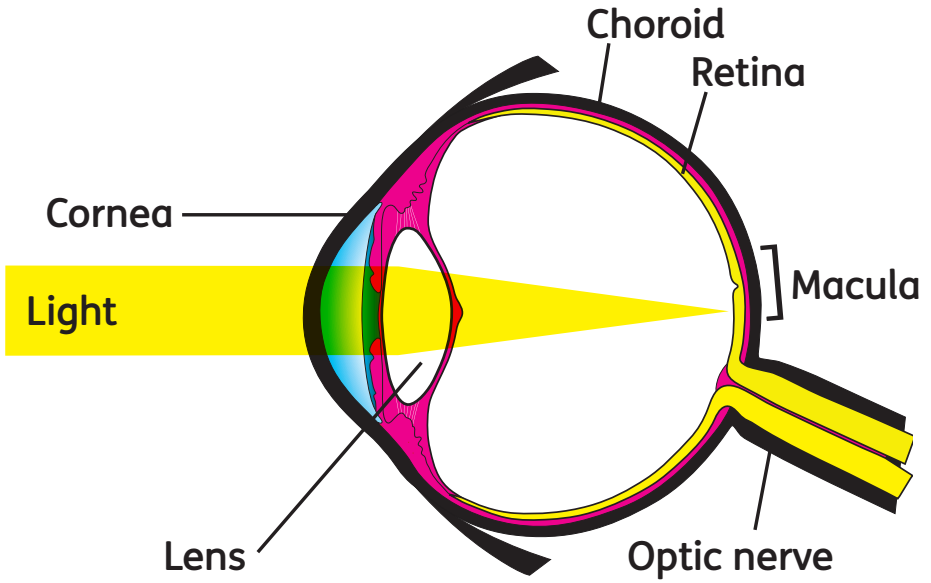
It was previously used in the treatment and prevention of malaria. However, it is no longer effective for this as the malaria parasite has developed resistance to hydroxychloroquine and chloroquine.

Your doctor has prescribed hydroxychloroquine (also called Plaquenil®) to help manage your condition. It is a very safe and effective drug but, like all medicines, it can cause side effects.

Hydroxychloroquine retinopathy

It is known that some people who take hydroxychloroquine for more than five years and/or in high doses are at increased risk of damage to their retina, the light sensitive layer of cells at the back of the eye. This is known as retinal toxicity or retinopathy.

Cross-section of the eye



Severe retinopathy, especially in the central area called the macula, causes significant, irreversible sight loss.

For this reason patients taking hydroxychloroquine who qualify for regular eye health checks on the NHS will be offered them. Some patients may have to pay for this service privately.

Monitoring for hydroxychloroquine retinopathy

The aim of monitoring is not to prevent retinopathy but to detect the earliest definitive signs of the condition, before a patient notices any symptoms.

The risk of getting hydroxychloroquine retinopathy is negligible unless you have been taking the drug for at least five years, so you will only be invited into the annual screening programme after this time unless there are exceptional circumstances.

All appointments, assessments and/or screening will take place in your local eye hospital or opticians.

The monitoring tests

Annual monitoring assessment

Once you have been taking hydroxychloroquine for five years you may be invited for annual monitoring tests on the NHS. However some patients may not be entitled to this on the NHS. You might be invited before five years of treatment if you are taking a high dose, your kidneys are not working properly, or you are also taking tamoxifen. If you are taking chloroquine rather than hydroxychloroquine, you will be invited to enter the annual monitoring programme after one year of treatment, because the risk of retinopathy is much higher with chloroquine.

During the annual monitoring assessment you will have two types of retinal photographs or scans.

One scan provides a cross-sectional image of the various layers of your retina. This is called an Optical Coherence Tomography (OCT) scan. The second type of scan is called a fundus autofluorescence scan which produces an image of the retina that can detect abnormal levels of a

substance called lipofuscin in the retina; this may be an early sign of disease. This scan uses a brighter light that may be slightly uncomfortable for you.

During these tests you will be seated in front of a large, camera-like machine with a chin rest. You may have several photographs and scans taken to ensure that good images are obtained of your retina.

Before the tests you may be given eye drops that temporarily widen (dilate) your pupils. This is to allow more light into the eye to give a better view of your retina. The drops will make your vision blurry for a few hours or longer in some people. You may also be more sensitive to light.

Most individuals will not need any further tests. Typically, the retinal scans are inspected after you have left the clinic. A letter will be sent to you, and the GP or prescriber of hydroxychloroquine/ chloroquine to let you know the outcome of the monitoring assessment.

Rarely, some individuals may be asked to perform a test called a visual field test.

In this test, one eye is tested at a time while the other is temporarily covered with a patch. You will be seated in front of a machine called a perimeter and asked to look through a viewfinder at a fixed spot inside the machine.

A computer randomly flashes points of light and when you see a light, you press a button. It is important to keep looking straight ahead – don't move your eyes to look for the light, wait until it appears in your side vision. It is normal for some of the lights to be difficult to see and a delay in seeing a light does not necessarily mean your field of vision is damaged. If you need to rest during the test, just tell the operator and they will pause until you are ready to carry on.

Very rarely, it may be necessary to undergo a test called multifocal electroretinography. This is a test which measures the responses of the macula area to an array of flashing hexagonal lights using electrodes placed around the eye.

This test may be used in very specific circumstances to help to determine if an individual has definite retinopathy when at least one other test is suggestive of retinopathy but two others appear normal.

No signs of retinopathy

If the tests do not show signs of retinopathy, you will be invited back for re-screening in one year. The results of your tests will be kept for comparison with future results.

Possible retinopathy

If there is an abnormality found on one of the retinal scans, you may be invited back for a visual field test and possibly to have some of the retinal scans repeated.

Even if one test result is consistently abnormal, you may be advised that treatment can be continued as a definite diagnosis of retinopathy will not have been made.

You should be reassured that the monitoring of your eyes for hydroxychloroquine retinopathy is designed to pick up the very earliest evidence of retinopathy, before it has a significant impact on your vision.

Definite retinopathy

If two of the tests are found to show abnormalities, and both are consistent with hydroxychloroquine toxicity, it means there are definite signs of retinopathy. The degree of retinopathy will be described as ‘mild’, ‘moderate’ or ‘severe’.

If the degree of retinopathy is mild and you are having a good response to the hydroxychloroquine, you and your doctor may decide to continue with it, perhaps at a lower dose.

If there is a suitable alternative, you and your doctor may decide to switch medications. If you are diagnosed with retinopathy, you will no longer be monitored in this way. However, your GP and/or the hospital doctor prescribing

hydroxychloroquine will continue to monitor your condition.

It is very important that you attend all your monitoring appointments. If you cannot attend on a given day, contact the eye screening department or opticians to make an alternative appointment as soon as possible.

What to do if you are worried about your vision

If, at any time, you notice a change in your vision you should make an appointment to see an optometrist at your local optician as soon as possible. Make sure you tell the optometrist that you are taking hydroxychloroquine.

If you are already on the monitoring programme for hydroxychloroquine retinopathy, and your last monitoring tests were normal, it is very unlikely that your symptoms are due to hydroxychloroquine retinopathy. The next monitoring visit does not need to happen sooner than planned. However, the optometrist will

check your eyes for other conditions, such as cataract formation, which might need further review or treatment.

If you have not been monitored for hydroxychloroquine retinopathy, it is important you ask your GP or specialist to refer you for monitoring.

Progression of retinopathy

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

If the condition does progress, a person may experience significant loss of vision over time. This can be traumatic and you should be offered support and information to help you deal with the impact of sight loss.

If your vision does deteriorate, you can ask to be referred to your hospital, social services or local sight loss organisation's 'low vision' service.

These services offer an assessment of your vision and advice on how to cope with it including the use of equipment and devices designed especially to help people with a visual impairment.

Driving

If you have any retinopathy affecting both eyes you must, by law, inform the DVLA – even if it is not affecting your vision. If you do not do so your driving licence and insurance are invalid and you can be fined up to £1,000. You may also be prosecuted if you have an accident. The DVLA will ask for a medical report on your vision. If your vision is still good enough to drive you may be given a limited time driving licence which you need to renew at the end of the specified time, for example every year or every three years.

If your sight is not good enough to drive, your licence will be revoked.

For more information on driving, call the Macular Society Advice and Information Service on **0300 3030 111** or go to **[macularsociety.org/driving](https://www.macularsociety.org/driving)**

DVLA:

gov.uk/driving-medical-conditions/telling-dvla-about-a-medical-condition-or-disability

DVA in Northern Ireland:

nidirect.gov.uk/information-and-services/driver-licensing/medical-conditions-and-driving

Beating Macular Disease

Macular disease is the biggest cause of sight loss in the UK, with around 300 people diagnosed every day.

The Macular Society is the only charity determined to beat the fear and isolation of macular disease with world-class research, and the best advice and support.

Our research programme is focused on finding new treatments and a cure to Beat Macular Disease forever. To support people affected by macular disease now, the Macular Society provides a range of support, information and services:

The **Advice and Information Service (0300 3030 111)** is available Monday to Friday, 9am to 5pm. Alternatively, you can email help@macularsociety.org

Our **website** provides a wide range of information and resources for people affected by macular disease. You can also find out more about the services we offer. Visit it at macularsociety.org

Our network of over 400 **Macular Society Support Groups** stretches across the UK. Each one offers practical and emotional support for people with macular disease, from those living with it today.

We provide a free, confidential **Counselling Service** over the phone. Call the Advice and Information Service for more information.

Working with you to Beat Macular Disease:

- We provide the best advice and information on living with macular disease.
- Macular Society Support Groups can help you to beat the isolation of macular disease, by connecting you with other local people who know what you're going through – offering support and companionship.
- Our research programme is focused on finding new treatments and a cure to Beat Macular Disease forever.

Macular Society

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