

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

Support throughout central vision loss

This leaflet contains important information about eye health checks for people taking hydroxychloroquine.

**No one need face macular degeneration alone.
For information and support call 0300 3030 111.**

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.

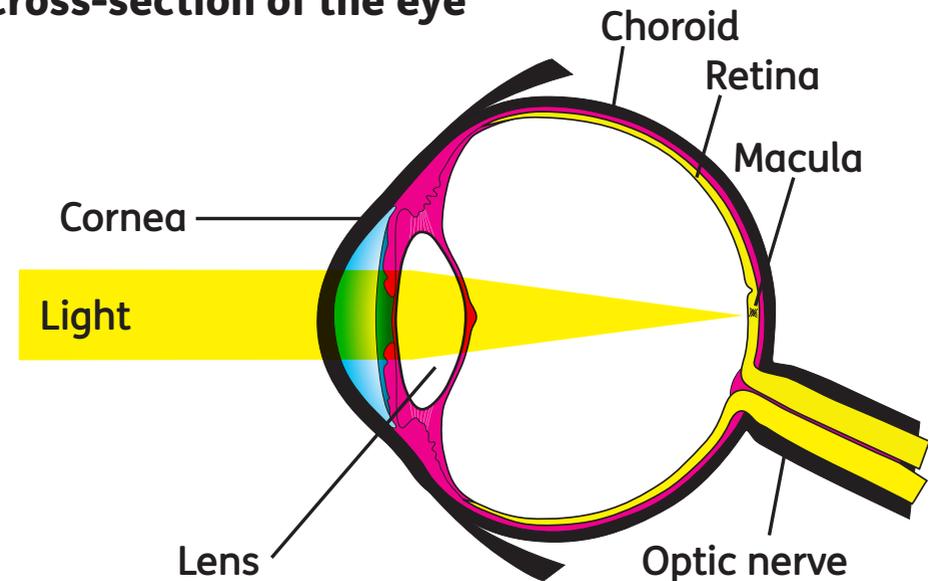
It was previously used in the treatment and prevention of malaria although it is no longer effective in this use as the malaria parasite has developed resistance to hydroxychloroquine and chloroquine.

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



Overall, around seven patients out of every 100 taking hydroxychloroquine for more than five years may develop retinopathy that can be detected with specialised tests.

The risk is much higher in patients who have been taking the drug for 20 years or more. In these patients between 20 and 50 out of 100 will develop retinopathy.

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

For this reason the NHS now offers patients taking hydroxychloroquine regular eye health checks to screen them for signs of retinopathy.

Screening for hydroxychloroquine retinopathy

The aim of screening is not to prevent retinopathy but to detect the earliest definitive signs of it before a patient notices any symptoms. It is expected that you will need to take hydroxychloroquine for at least five years. Because of this you will be invited to take part in the screening programme.

Where will the screening take place?

You will receive an eye assessment appointment at your local hospital eye department within 12 months of when you started taking hydroxychloroquine.

At this appointment, a number of photographs and scans will be taken of your retina to assess your eye health and your suitability for screening. (Not all patients can use the equipment needed for screening, such as people with advanced dementia or Parkinson's disease).

If your eyes are healthy, it is likely you will be screened again after five years. The new images will be compared to the original scans. If again there is no sign of disease you will then be screened every year.

Monitoring your eyes in this way helps to detect very early signs of damage to the retina.

Some patients will be offered annual screening from the start. These are people

- on a very high dose of hydroxychloroquine
- taking Tamoxifen for breast cancer
- with poor kidney function
- taking a similar drug, chloroquine

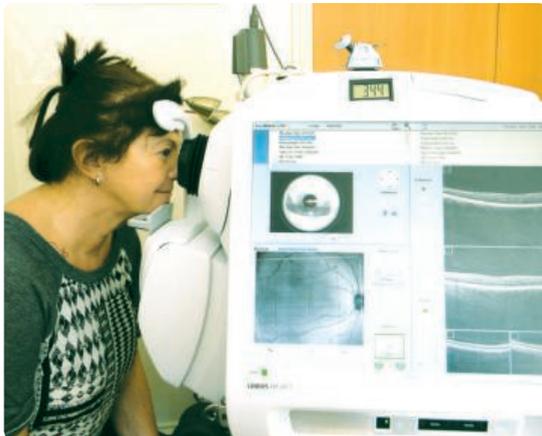
The screening tests

There are several tests used to screen your eyes for signs of retinopathy. They all involve different types of imaging of the retina and are non-invasive (they do not cause pain and do not risk damaging the eye in any way).

At the first, or 'baseline' screening appointment you will have two tests:

The first is a colour photograph taken of the surface of your retina, called a **fundus photograph**.

The second is a scan that provides a cross-sectional image of the various layers of your retina. This is called an **Optical Coherence Tomography (OCT) scan**.



You may also be offered a scan that detects abnormal levels of a substance called lipofuscin in the retina, which may be an early sign of disease. This test is called **fundus autofluorescence (FAF) imaging**.

In all 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 done on each machine to obtain good images of a large part of your retina.

Before the tests you will 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.

You should not drive for several hours after having your eyes dilated and you will probably need someone with you at the appointment.

If there is any sign of disease you will be offered another 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.

All the tests will be assessed by an ophthalmologist (hospital eye doctor) after you have left the clinic. A report will be sent to you, your GP and/or the

hospital doctor who prescribed hydroxychloroquine.

No signs of retinopathy

If all the tests show a normal retina then there are no signs of retinopathy. The images of your retina will be kept on file and you will be invited back 12 months later for a repeat of the tests. The new images will be compared to the original ones to check for any changes. You will continue to be screened every year until you stop taking hydroxychloroquine.

Possible retinopathy

If there is an abnormality found in any one test it means there is a possibility of there being signs of hydroxychloroquine retinopathy. If the abnormal test is the visual field test, you may be asked to repeat it to make sure of the results.

You will be told if any other tests are necessary and when you should be screened again.

In cases of possible retinopathy, you will be recommended to continue taking

hydroxychloroquine. This is because definitive evidence of retinopathy hasn't been identified and you should therefore continue to benefit from taking the drug.

You should be reassured that the screening of your eyes for hydroxychloroquine retinopathy is very likely to pick up the earliest evidence of definite retinopathy. It is only at this point that specialists would recommend having a discussion about stopping hydroxychloroquine and considering an alternative medication or treatment.

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

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.

Even if the retinopathy is more advanced, you and your doctor may still decide to continue with treatment. This decision will depend on what is likely to be the result of stopping hydroxychloroquine on the condition for which you are taking it.

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 screened in this way. However, your GP and/or the hospital doctor prescribing hydroxychloroquine will continue to monitor your condition.

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 shop as soon as possible.

Make sure you tell the optometrist that you are taking hydroxychloroquine.

If you are already on the screening programme for hydroxychloroquine retinopathy, and your last screening tests were normal, it is very unlikely that your symptoms are due to hydroxychloroquine retinopathy. The next screening 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 screened for hydroxychloroquine retinopathy, it is important you ask your GP or specialist to refer you to the eye clinic for screening.

Progression of retinopathy

Unfortunately, in some people with more advanced retinopathy, stopping hydroxychloroquine treatment does not prevent the disease from getting worse. At the moment there is no treatment for hydroxychloroquine toxicity.

If the disease does progress a person may experience significant loss of vision over time. This can be traumatic and emotional and you 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.

There are many other organisations able to help with information and support.

The Royal College of Ophthalmologists
www.....

Macular Society
www.macularsociety.org/hydroxychloroquine
Helpline 0300 3030 111 (Mon – Fri, 9-5)

RNIB www.rnib.org.uk 0303 123 9999

Lupus UK www.lupusuk.org.uk

Hibbs Lupus Trust www.hibbslupustrust.org

Arthritis Care www.arthritiscare.org.uk

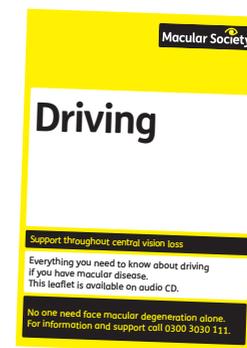
British Skin Foundation
www.britishskinfoundation.org.uk

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 helpline on **0300 3030 111** or go to **www.macularsociety.org/resources**



DVLA

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

DVA in Northern Ireland:

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

Six months free membership

If you would like to receive regular updates about living with macular conditions, treatments and medical research to find a cure then membership is for you.

Join for free today by calling 01264 350 551 or go to www.macularsociety.org/6months

**Macular Society**

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