



Eye monitoring for patients taking hydroxychloroquine or chloroquine

This leaflet contains important information for people taking hydroxychloroquine or chloroquine



What are these medications used for?

Hydroxychloroquine and chloroquine are used to treat various conditions including rheumatoid arthritis, systemic lupus erythematosus (SLE), some skin conditions (especially photosensitive ones) and other conditions that involve inflammation.

Your doctor has prescribed hydroxychloroquine or chloroquine to help manage your condition. Hydroxychloroquine and chloroquine are safe and effective drugs but, like all medicines, they can cause side effects.

This leaflet is to tell you about the benefits and risks of taking hydroxychloroquine and chloroquine and of the importance of regular eye tests and monitoring.

The West Yorkshire Health and Care Partnership would like to thank the [Macular Society](#) for their support in the production of this patient information leaflet.

Hydroxychloroquine and Chloroquine retinopathy

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

Severe retinopathy, especially in the central area of the retina called the 'macula', causes significant, irreversible sight loss. It is for this reason that the NHS now offers regular eye health checks for patients taking hydroxychloroquine or chloroquine to monitor them for signs of retinopathy.

Monitoring for hydroxychloroquine and chloroquine retinopathy

The aim of monitoring is not to prevent retinopathy but to detect the earliest signs of it before a patient notices any symptoms. Depending on your chosen treatment, dosage and time period on treatment it is expected you will be invited to take part in the monitoring programme.

Where will the monitoring take place?

If your clinician determines you are at low risk of developing retinal damage, you will receive an eye assessment appointment for yearly monitoring at your local hospital eye department **after 5 years of starting hydroxychloroquine**. Monitoring your eyes helps to detect very early signs of damage to the retina.

If you have **been prescribed chloroquine**, you are at an increased risk of developing hydroxychloroquine retinopathy and will be referred to the hospital eye care department for monitoring within 12 months of commencing treatment, then annually thereafter.

Patients in the following **three categories are at an increased risk of developing hydroxychloroquine retinopathy**. If you are one of these patients, you will be offered **monitoring within 12 months of starting hydroxychloroquine** and will continue to be monitored annually thereafter.

1. Patients on higher dose of hydroxychloroquine.
2. Patients taking tamoxifen for breast cancer.
3. Those with poor kidney function.

At your monitoring appointment, a number of photographs and scans will be taken of your retina to assess your eye health and your suitability for monitoring.

Please note that not all patients can use the equipment needed for monitoring, possibly due to advanced dementia or Parkinson's disease. If you cannot be monitored for whatever reason, the doctor who prescribed hydroxychloroquine or chloroquine for you should assess the risk and decide with you whether or not it is still appropriate for you to continue with treatment without monitoring.

The routine monitoring tests

There are several tests used to monitor your eyes for signs of retinopathy involving different types of imaging of the retina.

These tests are all non-invasive which means that nothing touches or enters the eye so there is no pain and no risk that the eye will be damaged in any way.

You may however require dilating 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 so it's a good idea to have a pair of sunglasses with you, especially if it's bright outside.

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

The first test you receive will require you to be seated in front of a large, camera-like machine with a chin rest.

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



You could be offered a scan that detects abnormal levels of a pigment called lipofuscin in the retina, which may be an early sign of retinopathy. This test is called **fundus autofluorescence (FAF) imaging**. An alternative colour photograph could be taken of the surface of your retina, called a **fundus photograph**.

You may have several photographs and scans done on each machine to obtain good images of a large part of your retina.

All the scans and photographs will be assessed by an ophthalmologist (hospital eye doctor) who will decide whether an additional test called a visual field assessment is required.

Once all the required tests are completed a report will be sent to you and to your GP and / or the hospital doctor who prescribed hydroxychloroquine or chloroquine.

No signs of retinopathy

If all the OCT and FFA or photography tests show a normal retina then there are no signs of retinopathy.

The images of your retina will be kept on file until your next test when the new images will be compared to the original ones to check for any changes.

After the first five years of treatment, you will continue to be monitored every year until you stop taking hydroxychloroquine or chloroquine.

Possible retinopathy

If there is an abnormality found in any of the tests, this means there could be signs of hydroxychloroquine retinopathy. You will then be asked to undertake a **visual field test**.

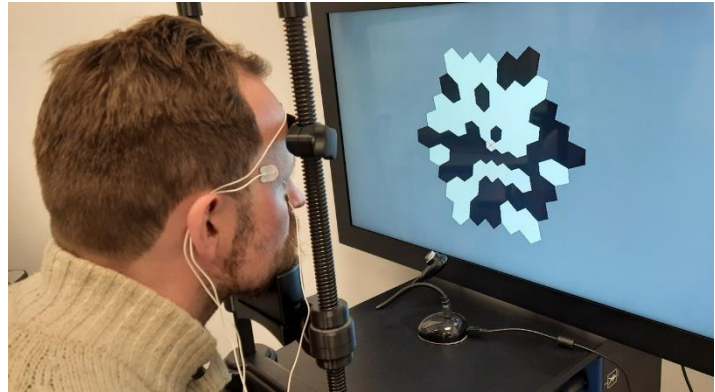
In this test, one eye is tested while the other is temporarily covered with a patch. You will be seated in front of a machine called a perimeter and asked to look through a viewfinder at a fixed spot inside the machine.



A computer randomly flashes spots of light around the machine and when you see a light, you press a button. 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. Prior to the test the technician will go through the instructions with you.

If the abnormality doesn't appear on the visual field testing, you may be asked to take an additional **multifocal electroretinography (ERG) test**.

During an ERG, the doctor will ask you to lie down or sit in a comfortable position. They'll usually dilate your eyes with eye drops in preparation for the test.



The doctor will attach electrodes to your skin to detect faint electrical signals made by the retina. You will then watch a flashing light. Your doctor will conduct the test in normal light and in a darkened room. The electrode enables the doctor to measure your retina's electrical response to light.

The information from the electrodes transfers to a monitor. The monitor displays and records the information.

You will be told if any further tests are necessary and when you should be monitored again.

In cases of possible retinopathy, you will be advised to continue taking hydroxychloroquine or chloroquine. This is because definite evidence of retinopathy hasn't been identified so you should therefore continue to benefit from taking the drug.

You should be reassured that the monitoring 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 a specialist would recommend discussing stopping hydroxychloroquine or chloroquine and considering an alternative medication or treatment.

Definite retinopathy

If both retinal scans and visual field test results show abnormalities, and both are consistent with damage to the retina, 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 or chloroquine, 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 or chloroquine will continue to monitor your condition in partnership.

It is very important that you attend all your monitoring appointments.

If you cannot attend on a given day, contact the eye department to make an alternative appointment as soon as possible.

What to do if you are worried about your vision

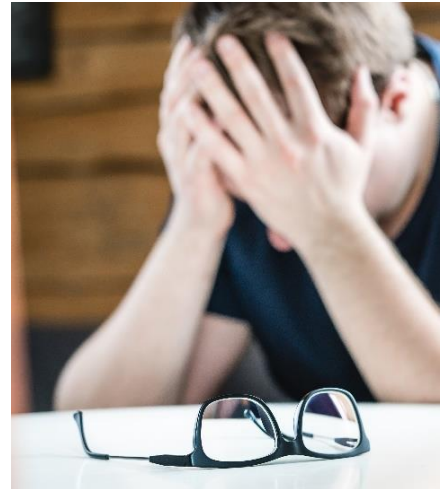
If you notice a change in your vision at any time you should make an appointment to see an optometrist at your local opticians as soon as possible.

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

If you are already on the monitoring programme for hydroxychloroquine retinopathy, and your last eye health 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, 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 to the eye clinic for monitoring.



Progression of retinopathy

In most cases it is expected that stopping the hydroxychloroquine or chloroquine treatment will stop the retinopathy from getting worse.

If the condition does get worse, you may experience significant loss of vision over time. This can be very traumatic so you should be offered support and information to help you deal with the impact of sight loss. You will be referred to your hospital, social services, or your local '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, tell the DVLA, even if it's not affecting your vision. If you fail to do this, your driving licence and insurance will become invalid, and you could 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 driving licence will be withdrawn.

Helpful information

The Macular Society provides **free** information and support for people diagnosed with macular disease, their families and their carers. The charity has more than 260 support groups in Airedale, Bradford, Calderdale, Huddersfield, Leeds and Wakefield as well as a helpline, counselling and advocacy service.

For more information call the Macular Society Helpline on: **0300 3030 111**
(Monday to Friday 9am to 5pm) or email: info@macularsociety.org

Or you can visit the charity's website at:
www.macularsociety.org

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