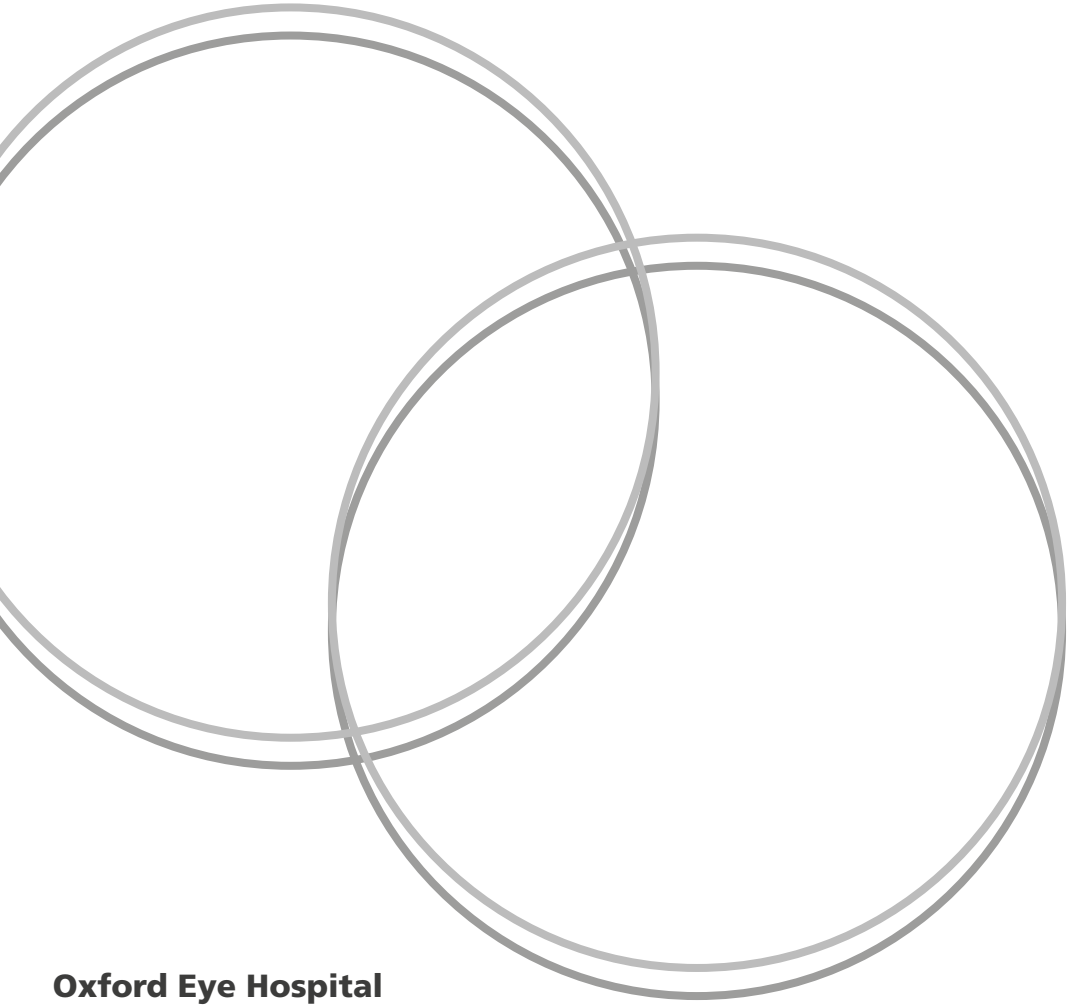
NHS
Oxford University Hospitals
NHS Foundation Trust

Treatment of Age Related Macular Degeneration

Information for patients



Oxford Eye Hospital

AMD Coordinator

When contacting the AMD Coordinator by email or telephone please quote your hospital (MRN) number and full name.

Email: **amd.coordinator@oxnet.nhs.uk**

Telephone: **01865 234 567**

Working hours: **Monday to Friday, 8.00am to 4.00pm**

This booklet has been produced to give you information about age related macular degeneration and its treatment. It contains a record of your injections and Oxford Eye Hospital appointments.

Information about the Oxford Eye Hospital

The Eye Hospital is based in the West Wing of the John Radcliffe Hospital in Headington, Oxford. We also have a centre at the Horton Hospital in Banbury and hold a number of out-patient clinics at Abingdon, Bicester, Shipston-on-Stour, Wantage and Witney.

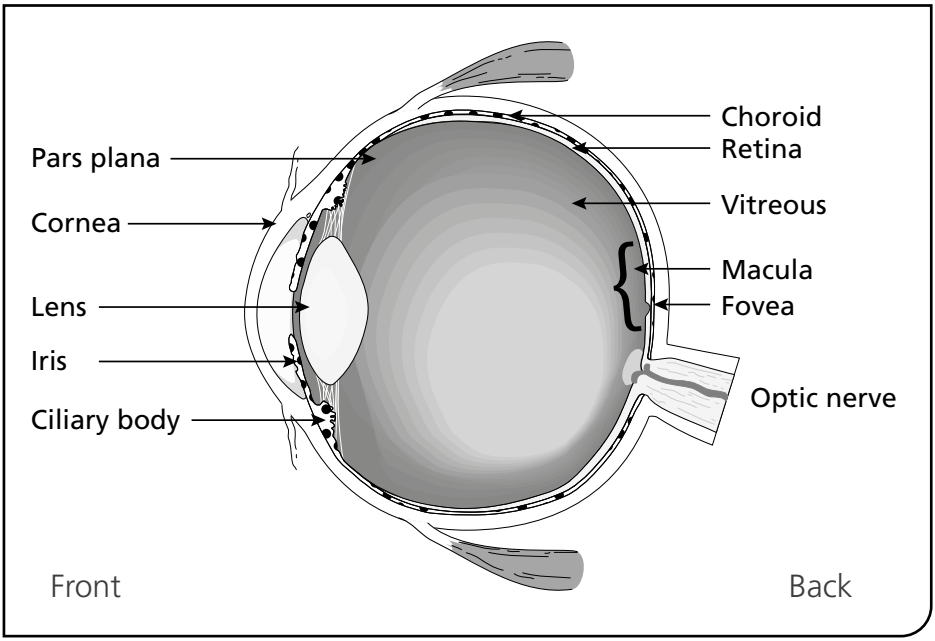
For further information please visit:
www.ouh.nhs.uk/eye-hospital

Contents

What is the retina and macula?

The retina is a delicate layer that lines the back of the eye. It contains cells that detect light. The macula is the part of the retina responsible for your central vision (sight straight in front of you). The rest of the retina is responsible for your peripheral vision (sight at the edge of your vision). If you think of the eye like a camera that receives pictures, then the retina is like the film or chip in the camera in the camera where those pictures are recorded.

Cross section of the eye



What is age related macular degeneration?

Age related macular degeneration (AMD) is an eye condition which causes damage to the central part of the retina (the macula), at the back of the eye, resulting in loss of central vision. Peripheral vision is usually not affected. AMD usually occurs in people over 60 years of age, but may develop earlier than this.

The initial symptom of AMD is blurred or distorted central vision, which usually progresses to a blank or dark patch. This can make driving, reading, and detailed work difficult or not possible at all.

AMD can affect both eyes. One eye may be affected before the other, which can lead to a delayed diagnosis, as the 'good' eye compensates for the affected eye, so you may not notice the problem.

There are different types of AMD can be identified by an Ophthalmologist or Optometrist:

- Early AMD which is not usually associated with any symptoms.
- Wet (exudative or neovascular).
- Dry (geographic atrophy, 'patch of cells which are no longer working').

Dry AMD (otherwise known as geographic atrophy)

This is where the retinal cells in the macular region have died away too early. This causes patches to be missing in your vision. This is not caused by blood vessels, and is different from wet AMD. Dry AMD usually develops very slowly, often over years.

Dry AMD cannot be treated with the same medication as wet AMD. There is promising research into possible therapies for this form of AMD, but there is no treatment yet available.

Wet AMD

Initial symptoms of wet AMD may be blurred or distorted vision, which without treatment can progress to a dark or blank patch affecting the centre of the vision.

Wet AMD is characterised by the development of new blood vessels beneath the retina. Bleeding from these vessels causes central visual loss and scarring. This process can progress rapidly within a few months, but the timescale varies between individuals and can sometimes be even faster.

In order to find out which type of AMD you have (wet or dry), and whether your type of AMD would be likely to respond to treatment, your eyes may need further assessment. You may need to come for special imaging investigations, such as angiography (a dye test to look at the back of your eye); an optical coherence tomography (OCT) scan of your retina; and review by a retinal specialist, who will discuss with you the pros and cons of the treatments.

How is wet AMD treated?

Anti-angiogenesis agents (vascular endothelial growth factor (VEGF) inhibitors) are used for the treatment of wet AMD. They work by blocking VEGF, which plays a major role in the development of the new blood vessels beneath the retina. They are given as an injection into the eye. Anaesthetic drops are used to numb the eye before the procedure, so you do not feel any pain. Antiseptic drops are also used which are very important in reducing the risk of infection. Most people tolerate the procedure very well, with minimal discomfort.

VEGF inhibitors are more commonly known as anti-VEGFs. They have been introduced relatively recently and have revolutionised the treatment of wet AMD, with up to 90% of people (90 in every 100) experiencing stabilisation of blood vessel growth.

Anti-VEGF treatments are only suitable for people with wet AMD if there is not too much pre-existing scarring.

The usual regime when using anti-VEGFs is to start with a course of 3 injections spaced a month apart. Most people need a number of injections over a few years. This will depend on which drug is used and your response to the treatment.

Lucentis (ranibizumab) injections

Lucentis is a licensed drug used for the treatment of wet AMD. Studies have shown very encouraging results, and approximately 90% of people experience stabilisation of their AMD at 2 years. However, the number of injections needed is still not fully known for each individual.

Eylea (aflibercept) injections

This is a similar licensed drug to Lucentis. Studies have shown that it is equally as effective as Lucentis in treating wet AMD. Eylea has the potential to enable extended intervals between injections in some individuals. The first three injections are given a month apart and then the interval between intravitreal injections will be increased depending on a positive response to treatment. Treatment usually continues for at least 2 years and in some cases longer than this.

The timing of your injections will be decided on the basis of your response to treatment and will be extended to as long as possible between injections while maintaining control of the condition.

Faricimab (vabysmo)

This is another anti-VEGF agent but this medication also acts on a different pathway involved in new blood vessel growth (angiopoetin 2). We also use this medication for the treatment of patients diagnosed with wet AMD. For newly diagnosed patients, this is given as a course of 4 injections spaced a month apart. You will have scans of your eye taken or be seen on clinic on the day of the last injection, and based on this we will determine how often subsequent injections are required. The interval between the injections is determined by how active the changes are at the back of your eye.

Ongavia (ranibizumab)

There are now several companies that make ranibizumab, and these highly similar copies of the original medicine are called biosimilars. These medicines are regulated in the UK, by the Medicines and Healthcare products Regulatory Agency (MHRA) and must pass rigorous tests for quality, safety, and effectiveness compared to the original licensed product. The National Institute for Health and Care Excellence (NICE) produces guidance for the use of medicines such as anti-VEGF agents. If NICE recommends the original medicine, the same recommendation applies to the biosimilar medicines.

The ranibizumab agent we are now most commonly using is one known by the trade name Ongavia. When you next come to the eye clinic, the doctor or optometrist you see may discuss your treatment options including switching to a biosimilar medication if this is clinically appropriate for you. You will be able to discuss any questions you have.

Avastin (bevacizumab)

Avastin is the full-length antibody from which Lucentis is made. Although Avastin is a licensed drug and is available for use in disorders such as wet AMD, it is not currently licensed for treating this specific condition. However, it has been shown in trials to be as clinically effective as Lucentis for the treatment of non-AMD blood vessel growth. Avastin, like Lucentis, Eylea and Vabysmo is given as in injection into the eye.

Monitoring of wet AMD and response to treatment

Your retina will be reassessed to check whether you need further treatment. We will tell you how often this needs to be done when you come for your clinic appointment.

A retinal imaging assessment involves having a colour photograph taken of your retina and an OCT scan (optical coherence tomography). We will tell you whether you need further treatment either at the appointment or within a week, by telephone or letter. If you have not received either a phone call or a letter within 10 days of the scan please contact the AMD Coordinator (contact details are inside the front cover of this booklet).

Further treatment will only be recommended if your wet AMD appears active.

What are the risks of having anti-VEGF injections?

Systemic vascular risks such as a heart attack, stroke or transient ischaemic attack (also known as a "mini stroke") are theoretically a potential risk associated with the use of these treatments, particularly if you have had such an event in the 12 months before the injection.

Prior to giving the injection, an antiseptic solution is applied to the eye to reduce the risk of infection. Iodine is usually used as it has been shown to be the most effective at reducing the risk of infection. It is possible that you may notice some temporary discomfort or slight soreness of the eye after the procedure.

The main risks to vision are related to the injection itself. These risks are small, but could result in loss of vision in that eye. They include:

- endophthalmitis – infection in the eye (occurs in approximately 1 in 2,000 injections)
- cataract (clouding of the lens in the eye)
- retinal detachment – when the retina comes away from the back of the eye (occurs in approximately 1 in 7,000 injections)
- retinal pigment epithelial detachment or tear (when the layer which sits underneath the retina at the back of the eye and allows it to function normally comes away or is torn) leading to central visual loss
- bleeding
- inflammation inside the eye
- increase in eye pressure
- watery eye, a feeling that something is in your eye, blurry vision. This can be a reaction to the eye drops and is expected to resolve within 2 to 3 hours.

Although AMD usually occurs in the older age group, if you are female and there is any possibility you could be pregnant, please inform a clinician before having any anti-VEGF injections, in order that any potential risk can be discussed with you.

How many injections will I need?

Due to the lack of long-term data, there is no accurate way of estimating how many injections you might need. Some people have the injections for 5 years or longer.

There is research being carried out to investigate different therapies and other drugs that have a longer lasting effect, including drug combination therapies.

Are there any potential developments for the treatment of AMD?

There is on-going research into the development of drugs that have a longer-lasting effect. Assessment of different ways of giving this treatment is also on-going.

Stem cell work, electronic visual aids/assistive technology and gene therapy are all in research and development programmes.

Your Ophthalmologist can discuss any research initiatives that may be available locally and relevant to you. We have a number of research projects that are being carried out at the Oxford Eye Hospital.

We also have a research registry (a database of individuals interested in being involved in research).

Visit: **ergo@ouh.nhs.uk** or scan the QR code below:

What happens when I come to the AMD clinic?

Appointments for AMD are held at the Oxford Eye Hospital which has clinics at the John Radcliffe (West Wing LG1), and Wantage Community Hospital. Further community-based clinics are expected to be set up in the future. You may be given an appointment at a location that is not necessarily the closest to your home, due to pressures on the service and in order to provide a timely review and/or treatment.

At your appointment your vision will be tested and you will have some eye drops put in, which make your pupils dilate. These will make your vision blurred for up to 4 to 6 hours. The drops take between 20 to 30 minutes to work fully. You will not be able to drive until the effects of the drops have worn off. As such, it is advisable that you do not drive yourself to the appointment and you may wish to ask someone to accompany you.

Please bring your distance glasses with you to the clinic appointment, as you will need to wear them when we check your vision.

You will then be called in to one of our clinic rooms to have an OCT scan of your retina. After the OCT scan, you will be seen by one of the AMD team for a consultation. It is possible that you may require an angiogram which is a test using dye to assess the retina. We have a separate information leaflet to provide more detail on this test.

Please allow between 2 to 3 hours for this appointment, to allow us to carry out all of the tests required, along with your consultation.

If we think that you would benefit from having anti-VEGF injections, an appointment will be booked for the injection clinic, usually within one week and in some cases may be on the same day.

If you are only booked to have retinal imaging (an OCT scan with or without colour photos) at your appointment then you will be contacted by our AMD Coordinator within 3 days with the results of the images, after they have been assessed by a retinal specialist. You will be given an appointment for further follow-up, further treatment or further investigations, depending on the results of the retinal imaging.

Before the anti-VEGF injection procedure

Please do not wear eye make-up or skin foundation on the day of the procedure, as this increases the risk of infection. You can eat and drink as you would normally, and can take your usual medication.

What happens when I come for the anti-VEGF injection procedure?

You are likely to be in the department for two and a half hours for the procedure. If there are any potential delays you will be informed.

When you arrive you will have some pre-injection checks, we will test your vision. Please bring your distance glasses with you for the injection procedure, as you will need to wear them when we check your vision.

You will then be asked to sign the consent form, if this has not already been done.

We will take you to the injection room for the procedure. Unless there are exceptional circumstances, we are unable to accommodate relatives or friends in the injection room due to the strict infection prevention control measures we need to maintain.

You will be asked to confirm which eye is being injected, and a mark will be placed on your forehead above this side. You will be asked to inform the team if you have any allergies.

You will be asked to lie flat on your back and the skin around your eye will be cleansed. We will put anaesthetic drops into your eye, which will make it go numb. We will also put in some antiseptic drops, to help prevent infection.

Once your eye is numb, a trained injector will carry out the injection. At the Oxford Eye Hospital, both medical, nursing, orthoptic and optometry staff members who are trained to inject will carry out the injections.

The actual injection itself takes only a few seconds but the whole process can take up to 20 minutes. This includes our checks as well as cleaning your eye and preparing the equipment.

After the injection, you will be free to go and your next appointment will be made.

What happens after the first course of injections?

You will have scans/pictures taken of your eyes, and/or be seen in the AMD clinic on the day of the last injection of the course prescribed. Based on your vision and these images, the doctor or allied health professional (AHP) seeing you will discuss how often further injections are required. If the changes at the back of your eyes are stable or inactive, we would plan to increase the intervals between your injections.

Who can I speak to about my AMD?

We have Eye Clinic Liaison officers who you can talk to and can help you to register as sight impaired or severely sight impaired, if you are eligible. They can also offer counselling or advice.

The Eye Clinic Liaison officers can give you information about eligibility and the benefits of registering as sight impaired or severely sight impaired. They also have information about support groups, including the MyVision Oxfordshire, the Macular Society, and the Royal National Institute of Blind People (RNIB), Retina UK, Fight for Sight, among others. The contact details for the Eye Clinic Liaison officers and other support groups are at the end of this booklet.

Our Low Visual Aid clinic will show you what is currently available to help if you have low vision. This is based at the Oxford Eye Hospital as well as local outreach clinics. Our Eye Clinic Liaison officers can help to arrange an appointment for you in this clinic, if required.

How to look after your eyes

Making the following lifestyle changes may help to protect your eyes.

If you are a smoker – giving up reduces risk

Smokers are four times more likely to develop age related macular degeneration compared to non-smokers. People with AMD who smoke are more likely to develop faster progression of the disease, compared to non-smokers. If you are a smoker and would like help to give up, please contact your GP or local NHS Stop Smoking Service.

Vitamin supplements and diet

If you have AMD with specific early features, it is possible that taking the Age Related Eye Disease Study 2 (AREDS2) preparation of high dose vitamins may be of benefit. Your Ophthalmologist can discuss the recommendations of these studies and their relevance to you.

The ingredients of the preparation used in the most recent of these studies (the Age-Related Eye Disease Study 2 (AREDS2)) can be bought as supplements over the counter at chemists.

There are many different over the counter preparations available, so you may want to seek advice from your Ophthalmologist, Pharmacist or Optometrist, particularly if you are already taking other medications or supplements.

AREDS 2 ingredients:

- Vitamin C – 500mg
- Vitamin E – 400IU
- Zinc – 25mg or 80mg
- Copper – 2mg
- Lutein – 10mg
- Zeaxanthin – 2mg

If you eat a diet rich in naturally brightly coloured fruits and vegetables, oily fish (such as salmon, trout, mackerel, etc.) and avoid processed food, you are likely to get the nutrients you need. However, if your eyes have high risk features, we may recommend that you also take these supplements.

Monitor your vision regularly

Check your vision regularly. Check each eye separately. Some people find the Amsler grid helpful for this (see pages 18 and 19). If you notice any changes in your vision you should contact the AMD Coordinator, to be seen within a week.

The following pages explain how to use the Amsler grid.

How to use the Amsler grid to check your vision

Wear the glasses you would normally wear when reading.

- Position the chart approximately 12 inches (30 centimetres) away from your face.
- Cover one eye at a time.
- Look directly at the dot in the centre. Do not let your eye drift from the centre dot.
- Note any change in your vision by drawing it onto the grid.

Ask yourself:

- Is there is any new change to your vision?
- Do the straight lines show new waviness or distortion?

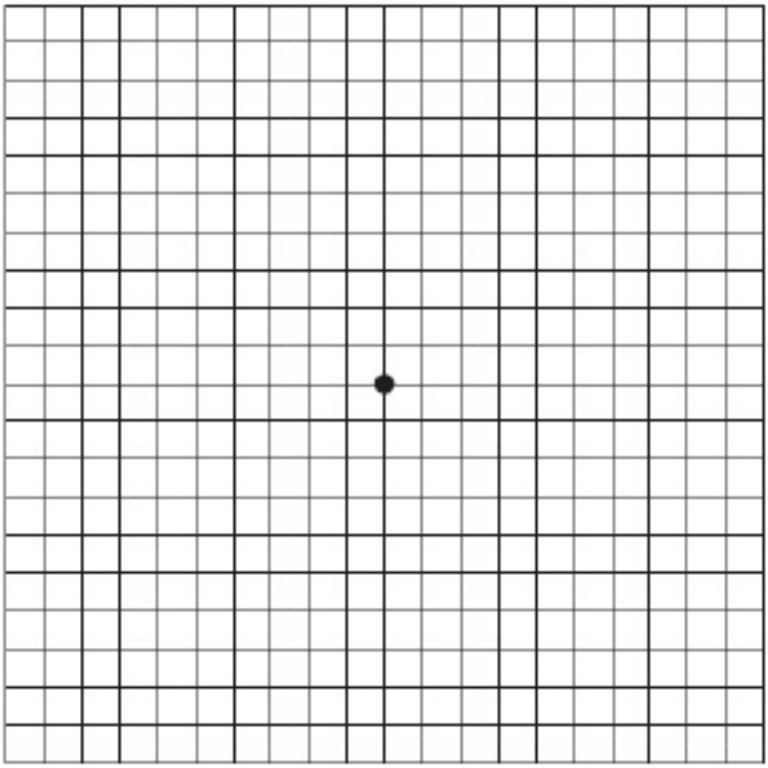
If you notice a change in your vision with the above symptoms, contact the AMD Coordinator (contact details are on page 27).

Monitor your vision regularly – once a week is recommended.

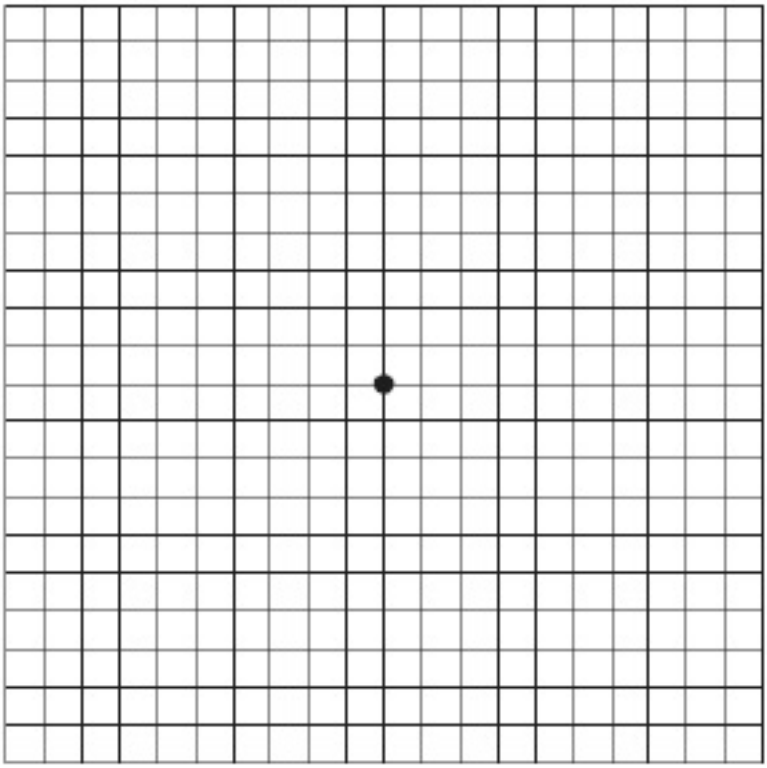
Keep this grid flat in a convenient place. Do not fold, bend or get any other marks on it.

If you need another Amsler grid they are available online or you can contact the Eye Clinic Liaison officer at the Oxford Eye Hospital for copies.

Amsler Grid – Right Eye



Amsler Grid – Left Eye



Instructions after the injection

Please follow these important instructions to help prevent infection or complications:

- Avoid touching your eye if possible.
- If you do have to touch your eye, wash your hands carefully first.
- Use a disposable tissue to clean your eye area, rather than a handkerchief or flannel, to avoid contamination.
- Continue to use your usual prescribed eye medications (drops), unless advised otherwise by a healthcare professional.
- Avoid wearing eye make-up and getting water in your eyes for 48 hours after the injection.

Some blurring of your vision is normal immediately after the injection. Some individuals notice seeing black bubbles or spots floating in the eye. These new 'floaters' usually disappear within 24 to 48 hours.

Your eye may feel a little gritty or mildly uncomfortable after the injection, which is usually due to the cleaning fluids. This should start to improve over the next 24 hours.

If you feel this is not happening or you experience any of the followings symptoms, please come to the **Oxford Eye Emergency Department as soon as possible**:

- eye pain
- your eye becoming more red
- swollen eyelids
- a new significant worsening of your vision.

Eye Emergency Department

Do not attend the eye emergency department without calling by telephone first.

Please call **01865 234 567** and select option 1, followed by option 1.

You will be able to speak to an eye specialist who will advise you on what action to take.

Opening Hours Monday to Friday – 8:30am to 4:30pm
Saturday, Sunday and Bank Holidays – 8:30am to 3:30pm
Closed Christmas Day

The Eye Emergency Department is in the Oxford Eye Hospital in the West Wing on level LG1.

If you have an eye emergency outside of these hours, please call NHS 111 who will advise you.

AMD appointments

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For further information please contact:

Oxford Eye Hospital Eye Clinic Liaison Officer

Telephone: 01865 231 137
Monday to Friday, 8.00am to 4.00pm
Email: eyeclinicliasonofficer@ouh.nhs.uk

AMD Coordinator

Telephone: 01865 234 567; select option 1, followed by option 7 and ask for the AMD Coordinator
Email: amd.coordinator@ouh.nhs.uk

MiVision Oxfordshire

Telephone: 01865 725 595
Email: info@MyVision.org.uk
Website: www.myvision.org.uk

Macular Society

Telephone: 0300 30 30 111
Email: help@macularsociety.org
Website: www.macularsociety.org

Royal National Institute of Blind People (RNIB)

Telephone: 0303 123 9999
Email: helpline@rnib.org.uk
Website: www.rnib.org.uk

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Authors: Susan Downes, Samantha De Silva, Ali Northover
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Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

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Oxford Hospitals Charity

Leaflet reference number: OMI 77603