

Treatment of age related macular degeneration

at the Oxford Eye Hospital



Name:

Hospital number:

AMD Coordinator

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

Email: amd.coordinator@ouh.nhs.uk

Telephone: 01865 234 567

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

Eye Casualty

Eye Casualty is in the Oxford Eye Hospital. It runs a walk-in service.

Opening hours: Monday to Friday – 8.30am to 4.30pm

Saturday, Sunday and Bank Holidays – 8.30am to 3.30pm

Closed Christmas Day

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. Please bring it with you to every Oxford Eye Hospital appointment.

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:

<http://www.ouh.nhs.uk/eye-hospital/default.aspx>

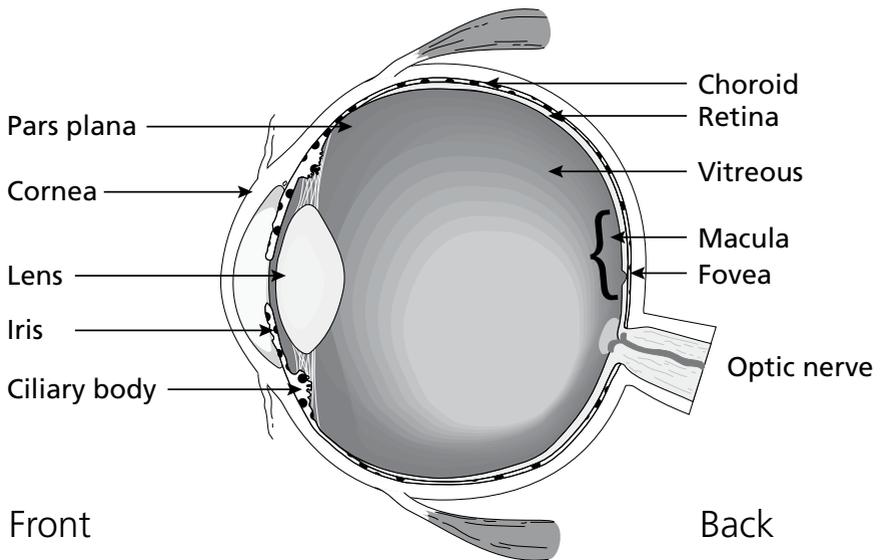
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What is the retina and macula?

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 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 two main forms of AMD, both of which can be identified by an Ophthalmologist or Optometrist:

- dry (non-exudative or non-neovascular)
- wet (exudative or neovascular).

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

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. 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.

Lucentis and Eylea are the most commonly used anti-VEGFs at present in the NHS. 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 has been awarded a licence in Europe and the USA 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 drug to Lucentis but doesn't need to be given as often. It has also been awarded a licence in Europe and the USA for the treatment of wet AMD. Studies have shown that it is equally as effective as Lucentis in treating wet AMD.

If you have recently been diagnosed with wet AMD you will usually be treated with Eylea. You will have a course of 3 injections spaced a month apart, followed by an injection every 2 months for the rest of the first year. After the first year of treatment, we will tell you how often you will need further injections.

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 and Eylea, is given as an 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.

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.

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 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.

What happens when I come to the AMD clinic?

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.

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.

Please allow between 2-3 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, you will be given at least 24 hours to decide whether you would like to have the treatment.

If you would like to have the anti-VEGF injection on the same day, and if it is possible for us to provide this, you will be seen by one of the AMD team, who will organise the treatment for you. If it is not possible for you to have the treatment on the same day or if you decide not to have the injection on the same day, you will be offered an appointment. This will be booked by the AMD Coordinator.

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 at a later date 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. Although the actual injection only takes a short amount of time, you will need to be seen before the injection by a member of the AMD team. 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 and you will be asked if you have any allergies. 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.

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 and antibiotics 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 three injections?

After the first three injections, your eye will be reassessed to check for a response to the treatment. Both of your eyes will usually be checked. Your AMD team member will then discuss with you whether further treatment or monitoring is required.

If you notice any sudden deterioration of your vision while undergoing treatment or monitoring please contact the AMD Coordinator (contact details are inside the front cover of this booklet).

If you have any questions at any point, either during or after the treatment, please speak with the nursing staff. They are available to give information and counselling on what to expect from the treatment.

Who can I speak to about my AMD?

We have two 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 Oxfordshire Association for the Blind, the Macular Society, and the Royal National Institute of Blind People (RNIB). The contact details for the Eye Clinic Liaison officers and other support groups are at the end of this booklet.

There is on-going research into the effectiveness of electronic visual aids. 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 protect your eyes

There are various risks associated with developing age related macular degeneration. Making the following lifestyle changes can 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 that affects one eye, or have certain early features of AMD, it has been shown that preparations of high dose vitamins can reduce the risk of developing advanced AMD. Your Ophthalmologist can discuss the recommendations of these studies with 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 19 and 20). 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 any new change to your vision?
- Do the straight lines show new waviness or distortion?

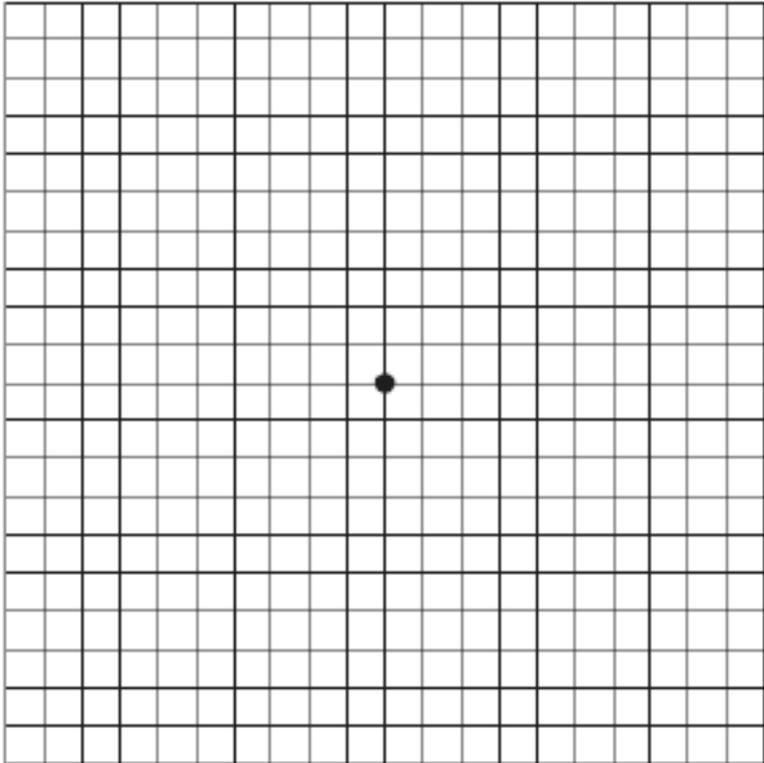
If you notice a change in your vision with the above symptoms, contact the AMD Coordinator (contact details are inside the front cover of this leaflet).

Monitor your vision regularly – once a week is recommended.

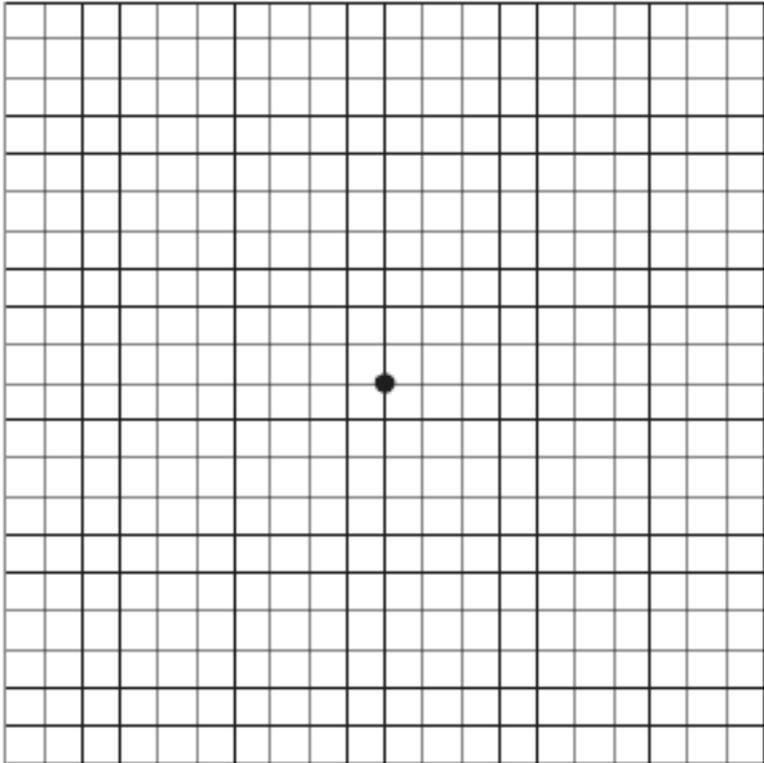
Keep this grid flat in a convenient place. Do not fold, bend or get any other marks on it.

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:

- Wash your hands before touching your eye.
- Use a disposable tissue to clean your eye area, rather than a handkerchief or flannel, to avoid contamination.
- 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. This is often described as 'seeing black bubbles or spots floating in the eye'. These new 'floaters' usually disappear within 24-48 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 Casualty as soon as possible:**

- eye pain
- your eye becoming more red
- swollen eyelids.

The Oxford Eye Casualty opening hours are inside the front cover of this booklet. Outside of these hours, please visit your nearest Accident and Emergency department.

For further information please contact:

Oxford Eye Hospital Eye Clinic Liaison Officer

Tel: 01865 231 137

Monday to Friday, 8.00am to 4.00pm

Email: eyeclinicliaisonofficer@ouh.nhs.uk

AMD Service Lead (Professor Susan Downes)

Tel: 01865 234 735

Monday to Friday, 8.00am to 4.00pm

Email: amd.coordinator@ouh.nhs.uk

Oxfordshire Association for the Blind

Tel: 01865 725 595

Email: admin@oxeyes.org.uk

Web: www.oxeyes.org.uk

Macular Society

Tel: 0300 30 30 111

Email: help@macularsociety.org

Web: www.macularsociety.org

Royal National Institute of Blind People (RNIB)

Tel: 0303 123 9999

Email: helpline@rnib.org.uk

Web: www.rnib.org.uk

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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