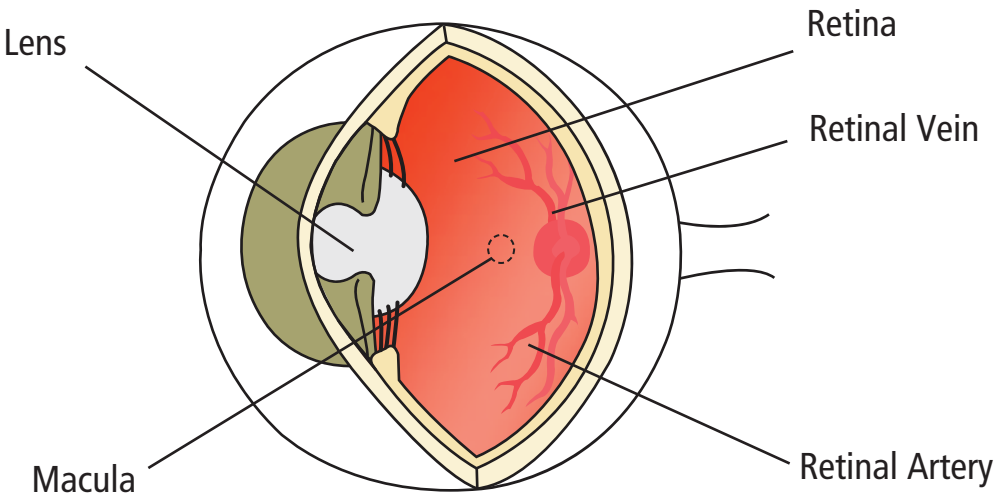
NHS
Royal Cornwall Hospitals
NHS Trust

Age-related macular degeneration

affix patient label

What is the macula?

The tissue at the back of the eye is the retina, it can be thought of as being like the film in a camera. The central part of the retina is called the macula. It provides detailed sharp central vision and the ability to appreciate colour.



What is macular degeneration?

Macular degeneration simply means wear and tear in the macula. When these changes happen due to aging it is called age-related macular degeneration (AMD or ARMD).

What causes macular degeneration?

There is no known cause but cells in the macula break down due to the aging process. Important risk factors are a family history of ARMD and smoking tobacco. Less commonly, macular degeneration can occur in severely shortsighted people or certain genetic conditions.

What are the symptoms?

In the initial stage you may not have any symptoms. As the condition progresses, you may experience blurred vision and distorted images. It affects your ability to see what is directly in front of you. Reading, writing and close work such as knitting is affected the most. Later on, you may experience significant vision loss in the centre and be unable to recognise faces. However, this condition does not affect the side/peripheral vision and so you will never experience complete loss of vision.

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What are the types of macular degeneration?

There are two types of changes that occur in macular degeneration, 'dry' and 'wet'. The terms 'dry' and 'wet' have nothing to do with tears or dry eyes but refer to the way changes progress in the macula. ARMD begins as the Dry type and progresses gradually, with approximately 10% of the patients developing Wet ARMD. So, strictly speaking, Wet ARMD is not a type but a specific abnormality that develops in patients with ARMD.

- **In Dry macular degeneration** – the light-sensitive cells in the macula slowly break down, leading to gradual blurring of the central vision. As it gets worse, the macula becomes increasingly thin and the central blurred patch increases.
- **In Wet macular degeneration** – patients develop fragile and leaky blood vessels. This leads to leakage of fluid and blood in the macula (hence the term 'Wet'). If untreated, it leads to permanent damage to the macula and formation of a scar. Wet macular degeneration can happen suddenly leading to rapid loss of sight.

How is the diagnosis made?

Specialized photographs of the macula are taken to confirm the type of macular degeneration and to decide the appropriate treatment course:

- **OCT retinal scan** – this is a simple test which uses a light beam to build up a detailed picture of the macula as well as blood vessels.
- **Fundus fluorescein angiography** – Some people need this test. A dye is injected in the arm and photographs are taken of the dye as it passes through the blood vessels at the back of the eye.

What is the treatment for dry macular degeneration?

Unfortunately, there is no treatment for dry ARMD. Stopping smoking is certainly beneficial. Wearing sunglasses to protect from the sun's rays and eating a healthy diet rich in antioxidants such as green leafy vegetables and citrus fruits may be beneficial. Age Related Eye Disease Study 2 (AREDS 2) showed that supplements containing vitamins C (500 mg), vitamin E (400IU), lutein (10 mg), Zeaxanthin (2 mg), zinc (80 mg) and copper (2 mg) when taken daily may benefit in slowing down the disease but it does not prevent ARMD from advancing. Smokers or ex-smokers must avoid any supplements containing Beta Carotene due to risk of lung cancer. These supplements can be purchased from health shops or pharmacies.

What is the treatment for wet macular degeneration?

Wet macular degeneration is treated by injection of an anti-vascular endothelial growth factor (anti-VEGF) drug in the eye. Anti-VEGF drugs works on leaky blood vessels to help reduce fluid in the macula. Lucentis and Eylea are the two drugs approved by NICE and used in the NHS. The risks and the benefits of both the drugs are similar.

How is the treatment given?

The treatment is usually started with monthly injections. After 3 months the injections are given every few weeks. The frequency of injections can vary from every month to every 3-4 months depending upon the disease activity. The more stable the condition, the fewer injections are needed.

How successful is the treatment in the beginning?

The treatment stabilises vision in almost 90% of patients. Around 30% of patients experience improvement in their sight. 10% of patients do not benefit from the treatment.

What is the long-term success?

The treatment slows down the progression of vision loss but does not stop it. Despite initial success, patients experience very slow decline in their sight over time. Sometimes a sudden vision loss can occur in spite of the initial success.

How long is the treatment required?

The treatment will continue indefinitely as long as it is helping your eye and the benefit outweighs the risks. The treatment will be stopped if injections are not effective or your sight deteriorates significantly despite treatment.

Are there any other treatment alternatives?

No. The anti-VEGF drugs are the most successful in preventing vision loss. The other options will be considered either as an additional treatment or when anti-VEGF treatment cannot be given. These include laser treatment or photo-dynamic therapy. Both these treatments entail applying laser to the leaky blood vessels. Your doctor will discuss these options with you if appropriate.

How is the injection given?

It is an outpatient procedure and takes only a few minutes:

1. The nurse will instill antiseptic and local anaesthetic drops into your eye and then the eye will be cleaned with an antiseptic solution.
2. The injection is given into the eye. It is not a painful procedure but most people describe it as a brief 'sharp scratch'.
3. You will be asked to wait for a short time before going home to ensure there are no problems.

What are the side effects?

You may experience temporary blurring of vision and minor discomfort for a day. Some patients experience severe pain for a day or two. We advise you to use plenty of lubricating eye drops during this time. You may see a few 'floaters' or 'bubbles' for a few days.

Are there any risks or complications?

As with all procedures, there are some possible risks, but the benefits usually outweigh the risks. An injection carries a small risk (0.3%) of sight-threatening infection in the eye (endophthalmitis). There is a small risk of glaucoma (increased pressure in the eye) and cataract (cloudy lens). With frequent injections there is a small risk (1-2%) of cardiovascular events such as heart attack and stroke. In all cases, there is a very small risk of accidental injury to lens, retina or other eye structures. The risk of total sight loss due to any complication is less than 1 in 1000.

What should I look out for?

If you experience sudden loss of vision after injection, especially associated with severe pain, contact the emergency number: 01872 252324.

What happens next?

If you are attending your first appointment, the doctor will assess your eyes and may suggest some tests to rule out Wet ARMD. If Wet ARMD is confirmed, the treatment will be started immediately. If you are already on the treatment for Wet ARMD you will be assessed regularly and more injections will be given when needed.

Any questions?

This leaflet provides just an overview of macular degeneration. If you have any questions please don't hesitate to speak to us during your clinic visit. Further information can also be obtained by contacting:

Royal National Institute for Blind (RNIB) on 0303 123 9999

Macular Disease Society (MDS) on 0300 3030 111

If you would like this leaflet in large print, Braille, audio version or in another language, please contact the General Office on 01872 252690

Patient copy

CONSENT FORM 1
PROCEDURE SPECIFIC PATIENT AGREEMENT

NHS
Royal Cornwall Hospitals
NHS Trust

NHS number: .....
Name of patient: .....
Address: .....
AFFIX PATIENT LABEL
Date of birth: .....
CR number: .....

Age-related macular degeneration

Intravitreal injection of therapeutic drug

STATEMENT OF HEALTH PROFESSIONAL (to be filled in by health professional with appropriate knowledge of proposed procedure, as specified in consent policy)

Procedure: Intravitreal injection (injection in to the jelly of the eye)

Drug to be injected: Lucentis ☐ Eylea ☐
Beovu ☐ Other (please specify): _____

Eye: Right eye ☐ Left eye ☐

I have explained the procedure to the patient. In particular, I have explained the intended benefits:

- *Prevent rapid vision loss*

Significant, unavoidable or frequently occurring risks

- *Temporary blurring of vision, minor discomfort, seeing a few 'floaters' or 'bubbles', cataract formation, glaucoma (build up of pressure in the eye), severe pain or discomfort lasting 2-3 days*

Uncommon but more serious risks:

- *Accidental injury to structures (lens, retina) inside the eye*
- *Severe intraocular inflammation at the back of the eye causing sight loss (Beovu only)*

Rare but serious risks:

- *Infection in the eye causing total sight loss*
- *Cardiovascular event such as stroke and heart attack*

Any extra procedures which may become necessary during the procedure:

- *Other procedure (please specify):*

I have also discussed what the procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient.

I have given and discussed the Trust's approved patient information leaflet for this procedure: Age Related Macular Degeneration CHA4225 which forms part of this document.

I am satisfied that this patient has the capacity to consent to the procedure.

This procedure will involve: ☐ General and/or regional anaesthesia ☐ Local anaesthesia ☐ Sedation

Health Professional signature: ..... Date: .....

Name (PRINT): ..... Job title: .....

STATEMENT OF INTERPRETER (where appropriate)

I have interpreted the information above to the patient to the best of my ability and in a way in which I believe he/she can understand.

Interpreter signature: ..... Name (PRINT): ..... Date: .....

CHA4225 V3
Revised 02/2021 Review due 02/2024

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Age-related age macular degeneration consent form

STATEMENT OF PATIENT

Please read this form carefully. If your treatment has been planned in advance, you should already have a copy of the patient information leaflet which describes the benefits and risks of the proposed treatment. If not, you will be given a copy now. If you have any further questions, do ask - we are here to help you. You have the right to change your mind at any time, including after you have signed this form.

I agree to the procedure or course of treatment described on this form.

I understand that you cannot give me a guarantee that a particular person will perform the procedure. The person will, however, have appropriate experience.

I understand that I will have the opportunity to discuss the details of anaesthesia with an anaesthetist before the procedure, unless the urgency of my situation prevents this. (This only applies to patients having general or regional anaesthesia).

I understand that any procedure in addition to those described on this form will only be carried out if it is necessary to save my life or to prevent serious harm to my health.

I understand that tissue samples will only be taken in relation to the procedure explained to me. No samples will be taken for quality control, clinical education or research purposes.

I have been told about additional procedures which may become necessary during my treatment. I have listed below any procedures **which I do not wish to be carried out** without further discussion.

.....

I have received a copy of the Consent Form and Patient Information leaflet: Age Related Macular Degeneration CHA4225 which forms part of this document.

Patient signature: ..... Name (PRINT): ..... Date: .....

A **witness** should sign below if this patient is unable to sign but has indicated his or her consent.
Young people / children may also like a parent to sign here (see guidance notes).

Witness signature: ..... Name (PRINT): ..... Date: .....

CONFIRMATION OF CONSENT (to be completed by health professional when the patient is admitted for the procedure, if the patient has signed the form in advance).

On behalf of the team treating the patient, I have confirmed with the patient that they have no further questions and wish the procedure to go ahead.

Health Professional signature: ..... Date: .....

Name (PRINT): ..... Job title: .....

Important notes (tick if applicable):

☐ See advance decision to refuse treatment ☐ Patient has withdrawn consent (ask patient to sign/date here)

Patient signature: ..... Name (PRINT): ..... Date: .....

File copy

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