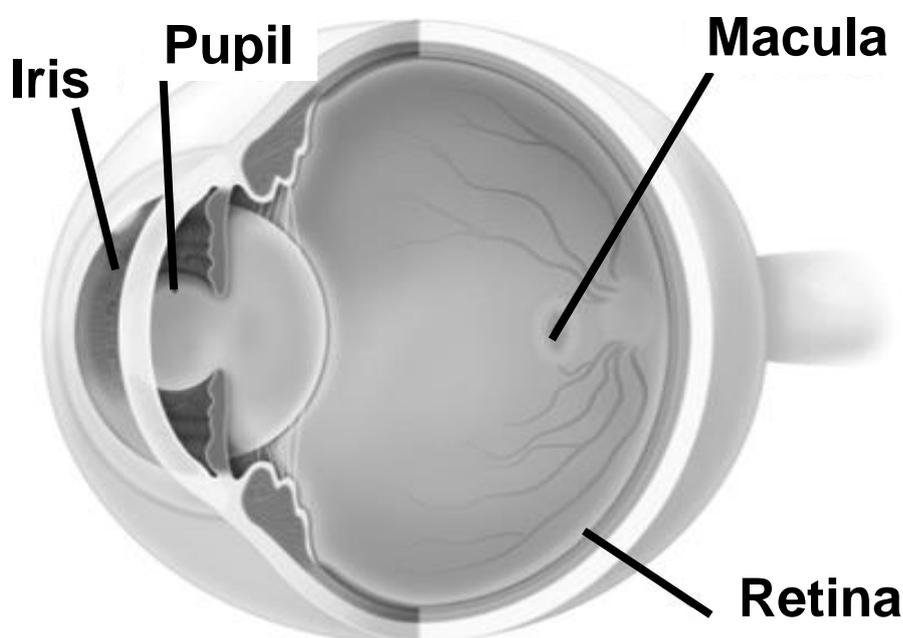


Patient Information

Age Related Macular Degeneration (AMD)

The macular is responsible for what we see straight in front of us, allowing us to see fine detail for activities such as reading and writing, as well as our ability to see colour.



What is macular degeneration?

Sometimes the delicate cells of the macula become damaged and stop working. There are many different conditions which can cause this. If it occurs later in life, it is called Age-Related Macular Degeneration, (AMD.)



Patient Information

There are two types of macular degeneration or AMD, usually referred to as Wet and Dry.

What causes it?

It is generally age related. There is some evidence to support the fact that certain groups of people are more at risk than others, such as:

- If other family members have the condition
- People with blue eyes
- People who smoke
- People with high blood pressure
- People with high cholesterol
- People with vascular diseases and those with Diabetes
- People who have a poor diet
- People who work in very sunny climates



Normal Vision

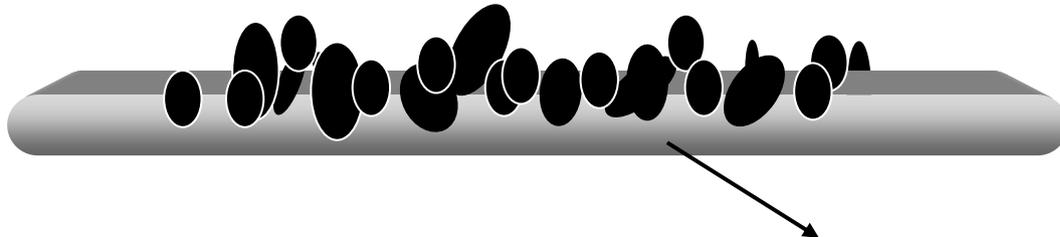


As viewed with Macula Degeneration

Patient Information

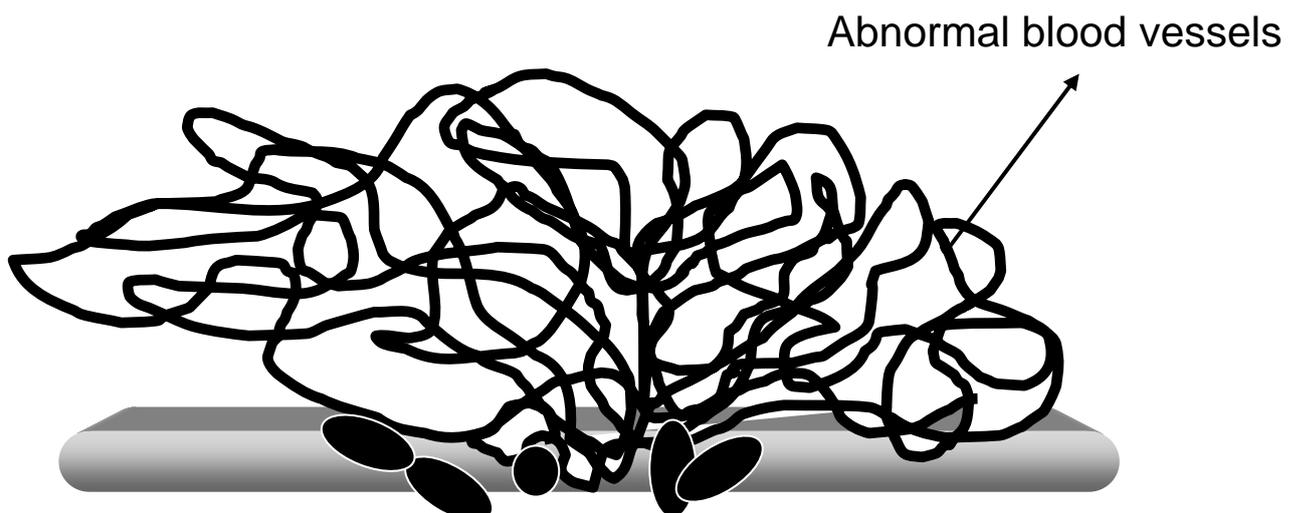
Both types of Age related macular degeneration affects the central vision

In Dry AMD the cells of the macula decay and disintegrate.



The cells start to clump together and disrupt the normal functions of the macular it is a slow process and affects the vision slowly

In Wet AMD due the cells breaking down and disrupting the normal functioning of the macular this can sometimes trigger off a response. Abnormal blood vessels begin to grow in the macular in an attempt to improve the oxygen and nutrient supply to the deprived cells. However the blood vessels get out of control and start to bleed, causing sight to rapidly deteriorate



What to expect: You will be sent an appointment for several tests to assess your condition. You may need to come twice in one week for

Patient Information

tests or they may be carried out in one day with a longer appointment.

- You will have your vision checked by an optician, so bring in your latest glasses prescription.
- You will have drops put into both of your eyes **so do not drive** to your appointments, as you will not be able to drive home.
- Photographs and scans and an eye angiography will be carried out.

Investigations: Eye Angiography

What is an eye angiography?

This is an investigation, which involves having your pupils dilated and having a dye injected into one of the veins, either in the back of your hand, or in the crease of the arm at the front of the elbow.

Why is it performed?

As the dye moves around the circulation system a special camera will be used to photograph the vessels at the back of the eyes.

These tests are very useful for finding leaky or damaged vessels, especially in Wet AMD.

What are the risks involved?

Both procedures are considered safe and are carried out routinely in the Eye Outpatients Department. However, there is the possibility that patients may have some reaction to the dyes.

Fluorescein (orange dye) is a synthetic dye and has few side effects. **Indocyanine** (green dye) contains iodine and some patients who are sensitive to iodine could react to it.

It is important to tell the nurse if:

- **You are taking any medication**
- **You know that you are allergic to iodine**

Patients who have allergies may experience the following during or after the procedure;

- Some patients can have a shock reaction to the dye, but this is extremely rare.
- There is a small chance that you may feel sick but this feeling should pass very quickly.
- There is a very small chance that you may get an itchy rash.
- You will experience a discolouration of the skin and urine for up to 48 hours – (drink plenty of fluids to flush it through your system and everything will return to normal quite quickly).
- If the dye leaks into the surrounding tissues during the injection, it may cause discomfort for a number of days. Any permanent damage to the skin is extremely rare.

What should you expect when you undergo Eye Angiography?

- You will be asked to sign a consent form to say that you understand the procedure and that you wish to have the procedure done. Then the nurse will then insert a small cannula (tube) into a vein in order to inject the dyes.
- Drops to dilate the pupils will then be given and photographs and a scan will be taken.
- You will be taken into the angiography room where some photographs of the back of your eye will be taken before having the dye injected.
- If you feel unwell or uncomfortable at any point you must tell the nurse.
- If you suffer any serious adverse effects from the dyes during the angiography session, it is unlikely that you will be able to have further dye tests which means that you will not be able to receive the treatment

Eligibility for treatment will depend on the findings of the investigations. The doctor will consider these carefully before making a decision about your treatment. Not all types of Wet AMD can be treated and the decisions made to treat or not to treat are based on national guidelines set by the National Institute of Clinical Excellence (NICE)

If you have Wet age related macular degeneration the treatment information is enclosed separately.

If you are eligible for treatment then this will be discussed with you. Please read the Anti- VEGF treatment leaflet enclosed the drugs are administered as an injection into the eye. Its purpose is to halt the production of the new blood vessels. The procedure is carried out in the clean room. Again its aim is to stabilise your vision and it needs to be repeated regularly, every month in some cases.

Dry age related macular degeneration

There is currently no cure or reliable treatment for this condition. Dry AMD is a slowly progressing eye condition which affects the back of your eye. There is currently no treatment .This condition will affect your ability to read and write, to recognise faces and to see fine details. You will notice that your distance vision will still be fairly good in the early stages of the condition. Central vision loss is the final stage of this condition.

Will the Dry turn into Wet AMD?

If you have Dry AMD in both eyes or if one eye is affected then there is a possibility the dry could turn into wet, in the future. This will depend on whether your AMD is early or a little more progressed. Sometimes the AMD may have reached its final advanced stage, which means the eye condition has gone too far leaving a scar,

Patient Information

therefore the vision cannot get any worse. It is important to check your eyesight for any signs of deterioration. If there are any signs of your eye(s) turning into Wet AMD, then it is better to detect it early.

How will I know if it is turning into Wet?

You can try a simple method of checking at home if your eyesight is worsening or changing, using the Amsler grid which is included in this booklet. Please note you must still visit your opticians for a proper eye examination, as this is not accurate test and may not be suitable for everyone. The grid is used to check for distortion, and it should be used once a week.

How do I use the grid?

While focusing on the dot in the centre of the grid, with one eye covered, ask yourself the following questions:

- Am I able to see the corners and sides of the square?
- Do I see any wavy lines /distortion?
- Are there any holes or missing areas?
- Have I noticed any other changes in my vision

Contact your optician **as soon as possible** or the hospital's Eye Casualty if you do notice any changes.

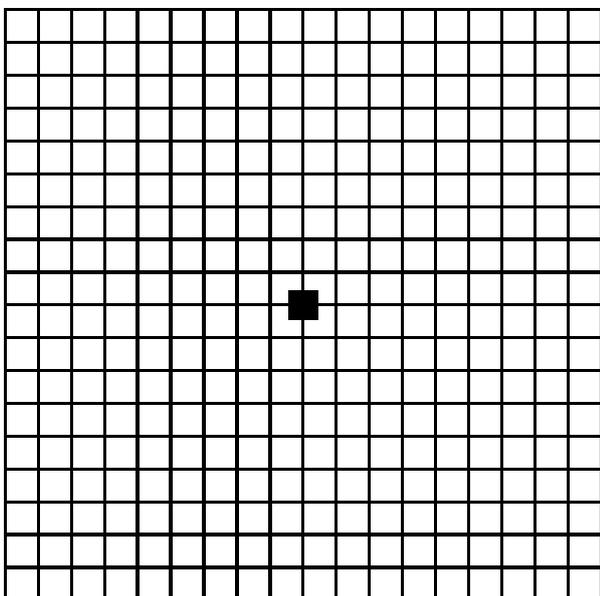
If you cannot use the grid, then you could check each eye for any distortion by looking at the sides of your window frame.

Patient Information

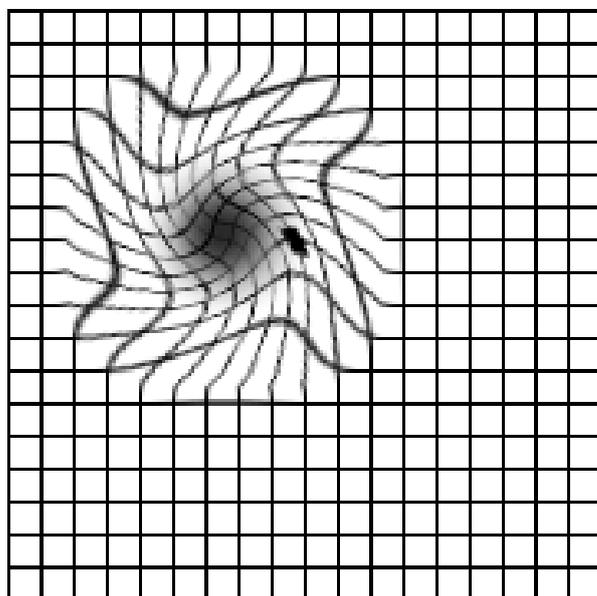
You may already have distortion of your vision or other symptoms due to the Dry AMD and detecting changes can be difficult so it is important to keep your appointments with the opticians

Remember do not delay as in some cases early action is vital.

The Amsler Grid



- **Amsler Grid**
Areas appear to be missing



- **Amsler Grid**
As it might appear to someone with age-related macular degeneration

Will spectacles help?

If you imagine that your eye is a camera. The back of your eye film is
A new spectacle prescription may help to magnify things in some cases. You will need to discuss your needs with an optician, or you may be referred to a low vision clinic.

Patient Information

A **Low Vision Assessment** is not about what you cannot see, but assesses what you can see. There are a number of ways that the Low Vision Clinic may help you to find aids and ways of adapting things to suit your needs.

Will I go blind?

You will retain the vision around the outside, your peripheral vision. You will not lose the ability to do things; you can be helped to find different ways of adapting in order to do them. If you have been diagnosed by the hospital then we can refer you to the Sensory Impairment Team, and to the Low Vision Clinic. The clinic also has an Eye Clinic Liaison Officer (ECLO) who can discuss any support or make referrals to any teams to support you. If you would like any advice on what support is available please ask a member of the medical team to refer you to these services.

The Sensory Impairment Team have **Rehabilitation Officers for Visual Impairment** who will offer you an assessment to identify any support or information you might need to remain as independent as possible at home. Advice can also be given on crossing roads, lighting levels at home and alternatives to reading. Please talk to the nurse if you find that you are struggling with reading, writing (signing pension or cheque books) cooking or making a cup of tea and getting out and about without help. There may be something that we can do to help. If you would like to receive this service please ask to

Patient Information

be referred to the Eye Clinic Liaison Officer or the Sensory Impairment Team who will try to support you to stay as independent as possible.

Registering as partially sighted or severely sight impaired?

You may be able to register as partially sighted and be eligible for certain financial benefits. For this you will need to be assessed by the eye consultant to identify your current level of vision. In order to be registered your vision would need to be at a level to meet the registration guidelines. Information on registration are available from the following sources:

- RNIB – helpline number 0303 123 9999 www.rnib.org.uk
- Macular Society 0300 3030 111 www.macularsociety.org

Can I drive?

You must be able to read in good daylight with the aid of glasses or contact lenses if worn, with both or with the unaffected eye an old style standard vehicle number plate at a distance of 20.5 metres (67 feet) or a new style number plate at a distance of 20 metres (65 feet) where narrower characters are displayed. New style number plates were introduced on 1st September 2001 and start with two letters e.g. AB51 ABC. If you are not sure then ask your eye specialist.

Visual Hallucinations

Some people with sight loss experience visual hallucinations which is also known as Charles Bonnet Syndrome. It is thought that the areas of the brain which process what we see are starved of the visual signals that the macular is responsible for when it is damaged as in AMD. It would be expected that the area of the brain that is starved would work less, but in some cases these brain cells become hyper active and start to create their own images in place of the real ones. It is thought that at least 20%-60% of people with macular degeneration will experience visual hallucinations.

This syndrome is called Charles Bonnet Syndrome, named after the Swiss Scientist who first described it.

This syndrome is not related to any mental illness, it is a side effect of sight loss. The images people see can be simple geometric shapes or people, animals or landscapes. Sometimes people see quite frightening images of distorted faces or giant insects, e.g. the person may think there is an animal on the floor but it could be a shadow which they can't quite make out due to the impact upon their vision.

People frequently keep quiet about their hallucinations for fear that people will think they are losing their minds. There are some drugs and other medical problems, which can cause people to see things: Parkinson's disease, Alzheimer's, strokes and other brain conditions

Patient Information

which effect that part of the brain concerned with seeing. Having CBS does not mean that you are more likely to develop any other conditions. People with CBS quickly learn that the hallucinations although interesting are not real. On the other hand people with a mental health difficulties have trouble telling the difference between their fantasies and reality and will often come up with complicated explanations for the things they are seeing (sometimes called delusional).

Is there a cure for Charles Bonnet Syndrome?

Unfortunately at the moment there is no known cure or treatment for CBS. However, just knowing that it is a condition resulting from poor vision and is not a mental illness or stroke, often helps people come to terms with it. In most people the syndrome will fade over time although there are some reports of people experiencing CBS over many years.

The Macular Society recommend using eye movements to activate visual parts of the brain, i.e. shut the eyes or look away from the image, switch on room lights and these movements may stop certain types of hallucinations. Esme's Umbrella is a charity which offers advice and support for anyone affected by CBS Helpline: 0345 051 3925.

What can I do to help my eyesight?

There is research being carried out, looking at the effect of vitamins on the retina. Whilst the results are not conclusive, a healthy diet may help slow the progression of your eye condition down. Some research suggests that the pigments in vegetables and fruit, such as lutein, and zeaxanthin may be helpful, as these are the pigments found in the healthy macula and protect the macular from damage. These are known as antioxidants. Certain vitamins such as E and C and beta carotene and the mineral zinc have also been found to be beneficial. Ensure you have a varied healthy diet containing a wide range of fruit and vegetables.

Lutein and Zeaxanthin are yellow plant pigments which give certain foods their colour. Green leafy vegetables such as kale and spinach contain the highest amounts of lutein, and eggs are also a good source.

Vitamin supplements

If you are unable to eat this many vegetables, low dose multivitamin tablets may help, but too many vitamins may be harmful. Consult your dietician or GP for advice.

Before taking any doses of vitamins it is best to talk to your GP, dietician or your ophthalmologist

Patient Information

Medical Secretary

Rugby St Cross Macular Degeneration Co-ordinators

Vickey Lacey : 01788 663338

Kate Barns 01788 663390

Support Numbers

- Macular Society Helpline: 03003030111
www.macularsociety.org
- Royal National Institute of Blind people (RNIB)
- Helpline 0303 123 9999 www.rnib.org.uk
- Coventry Sensory Impairment Team: 02476 785269
- Coventry Resource Centre: 02476 717522
- Warwickshire Association for the Blind: 01926 411331
- Esme's Umbrella: 0345 051 3925

The Trust has access to interpreting and translation services. If you need this information in another language or format please contact 024 7696 6474 and we will do our best to meet your needs.

The Trust operates a smoke free policy

Document History

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