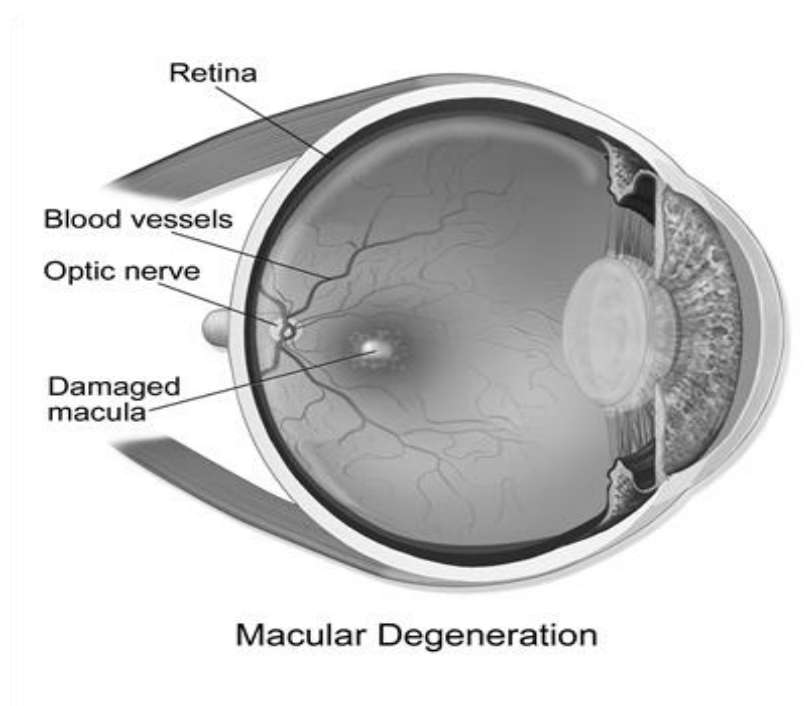


Ophthalmology

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).

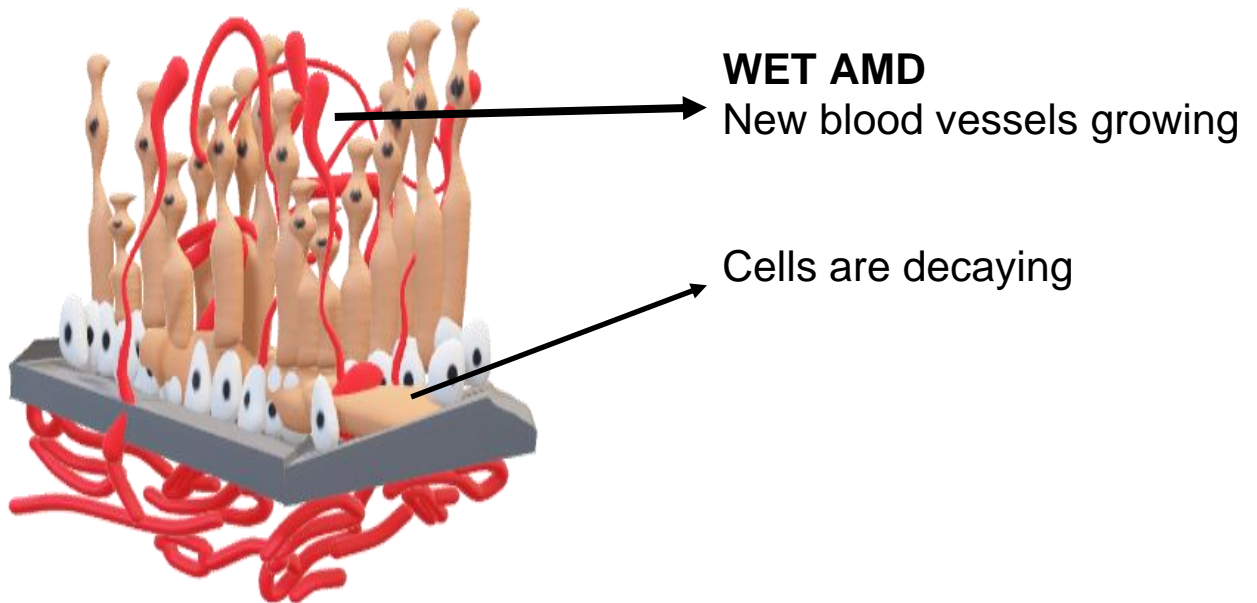
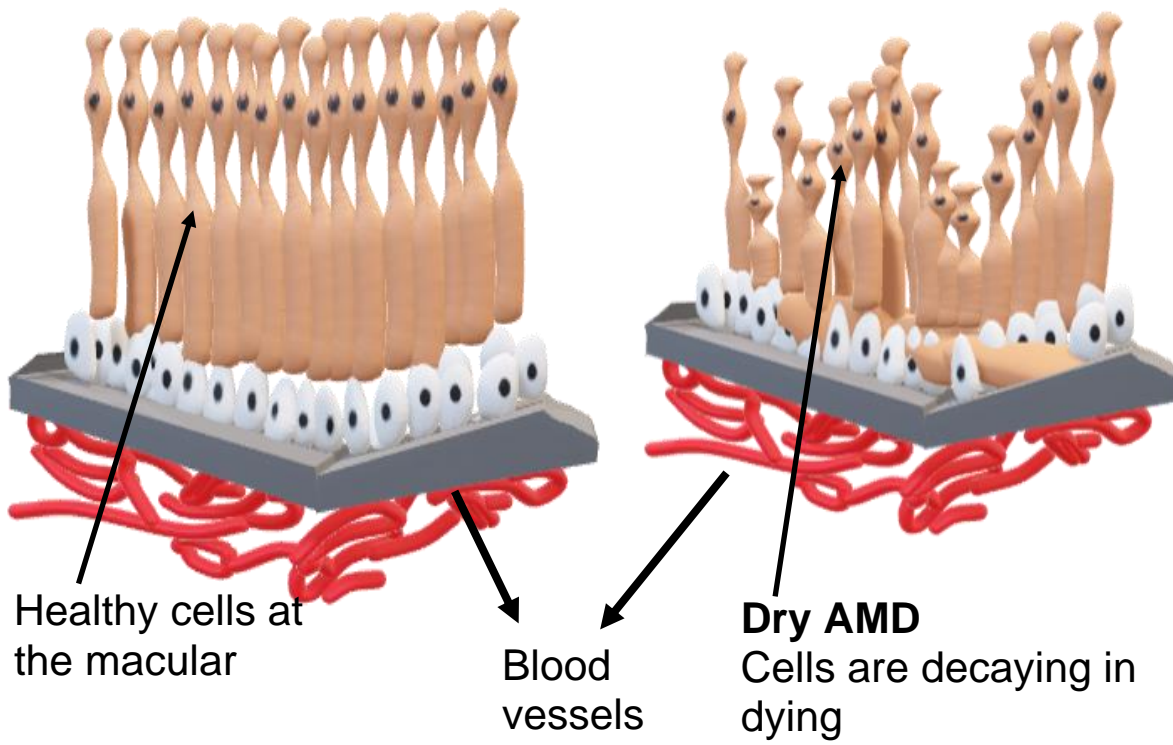
There are two types of macular degeneration or AMD, usually referred to as wet and dry.

In dry AMD the cells of the macular decay and disintegrate and disrupt the normal functions of the macular. It is a slow process and affects the vision slowly.

In wet AMD, when the cells break down at the macular this can sometimes trigger a response. Abnormal blood vessels begin to grow at the macular, attempting to recover the damage.

Unfortunately, the blood vessels are weak and grow out of control. They can start to bleed or leak fluid and cause your sight to deteriorate rapidly.

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What causes macular degeneration?

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

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 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 further investigations such as an angiography may be carried out. (A separate leaflet explaining eye angiography is available)

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Eligibility for treatment will depend on the findings of the investigations. The doctor will consider these carefully before making the 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 are eligible for treatment, then the option of Anti-VEGF injectable drugs which are administered as an injection into the eye will be discussed with you. The injection's purpose is to halt the production of the new blood vessels. The procedure is carried out in the clean room. It aims to stabilise your vision, and it needs to be repeated regularly, every month in some cases. (A separate patient information on the injections is available)

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 is minimally affected 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 and if one eye is affected, then there is a possibility the dry AMD could turn into wet AMD 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, 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 on page 8 of this booklet. Please note you must still visit your opticians for a proper eye examination, as this is not an 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?

Hold the chart at a comfortable reading distance. 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?

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- Do I see any wavy lines /distortion?
- Are there any holes or missing areas?
- Have I noticed any other changes in my vision

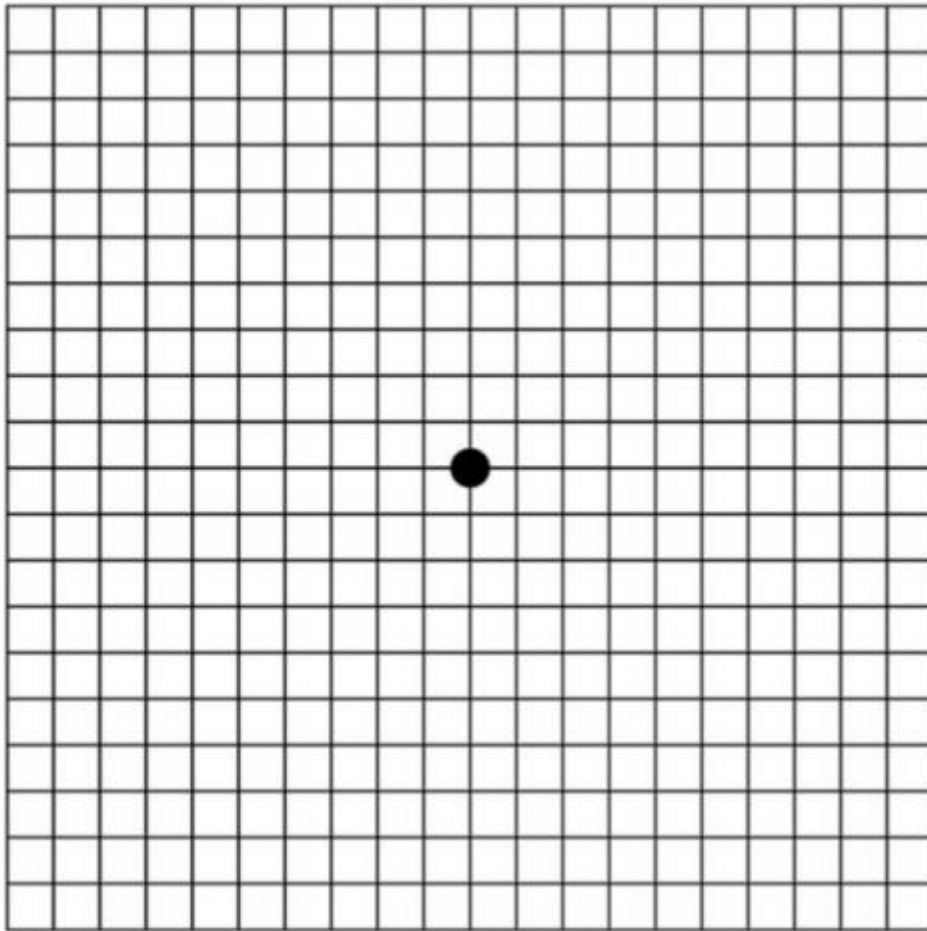
Contact your optician **as soon as possible** if you notice any changes.

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

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



Will spectacles help?

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.

A **low vision assessment** is not about what you cannot see but assesses what you can see. There are several 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 your peripheral vision, also known as your vision around the outside. You will not lose the ability to do things. You can be helped to find different ways of adapting to do them. If you have been diagnosed by the hospital, 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 be referred to the Eye Clinic

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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. To be registered your vision would need to be at a level to meet the registration guidelines. Information on registration is 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?

Having macular degeneration does not automatically mean you have to stop driving. Many people still meet the legal requirements and can continue to drive safely and legally.

However, if your eye specialist says you have any sight condition in both eyes which cannot be corrected with prescription glasses, you have a legal duty to inform your driving licence authority. If you don't, you could be breaking the law, and this can result in a fine of up to £1,000.

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You should also inform your car insurance provider. This is the case even if you feel your sight is still good.

Assessing your vision

When you contact the licensing authority you will be sent a questionnaire about your vision. You may also be asked for permission for your GP to pass on information about your sight. You may be asked to see an eye specialist for sight tests.

Sight tests

Your optician should carry out a sight test. A **visual acuity test** measures the sharpness of your vision. To be able to drive a private car or motorbike, you must have binocular visual acuity of at least 6/12. This means that when you use both eyes together, with glasses or contact lenses if necessary, you can see at 6 metres what a person with normal vision can see at 12 metres.

Visual hallucinations

Some people with sight loss experience visual hallucinations. This 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.

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It would be expected that the area of the brain that is starved would work less, but in some cases the brain becomes hyperactive and start to create their own images in place of the real ones. It is thought that at least 20% to 60% of people with macular degeneration will experience visual hallucinations. This syndrome is called Charles Bonnet Syndrome.

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. 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 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 mental

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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, there is currently 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 the following which may help a hallucination to fade:

- Put on the TV or radio
- Stand up and move around
- Look directly at the image or reach out to touch it may cause it to fade
- Moving your eyes or blinking rapidly can also help.
- Lighting conditions in certain rooms may also mean that you see the hallucinations more often in one room than another.
- If your hallucinations happen in dim light, then opening the curtains, turning on a light or the television may help. If your

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hallucinations happen when there's a lot of light, then switching off a light may help

- Try a type of eye exercise where you move your eyes from left to right every second for 15-30 seconds, without moving your head. If the hallucinations continue, have a rest, and try again. It's unlikely to work if you've tried 4 to 5 times and the hallucination is still there. You might want to try again another time for a different type of hallucination.
- CBS hallucinations are worse when you are tired or stressed. Making sure you have enough sleep at night and having time to relax can help with this.

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

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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 GP before taking any doses of vitamins.

Smoking and sight loss

It has been proven that smoking increases the risk of getting AMD. Smoking increases the risk of macular degeneration about 3 times and increases the chances of the condition worsening over a short period of time.

If you already have the condition in one eye, smoking increases the risk of getting it in the other eye by 50%. Macular degeneration occurs 10 years earlier in smokers. Overall smoking accounts for 32% of macular degeneration.

Taking care of your general health and trying to keep your blood pressure down may also help to slow down the loss of your central vision.

Useful contact numbers are:

Retinal Specialist Nurse, Sister Mann (Jas) **024 7696 4000**
(switchboard) and ask them to bleep **2828** or Macarthur Calica on
bleep **5836** and stay on the phone until you are connected
Mr Manjunatha/Mrs Mukherjee: **024 7696 6496**
Mr Pagliarini secretary: **024 76 966497**

Rugby St Cross

Vicky AMD injection co-ordinator **01788 663338**
Diabetic injection co-ordinator **01788 663992**

Eye clinic liaison officer:

Sue Grewcock
Monday, Wednesday, and Thursday University Hospital
Coventry
Mobile: 07834147178 (please leave voicemail)
Tuesday and Friday Rugby St Cross: 01788 663004 (ext 33004)

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

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- 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.

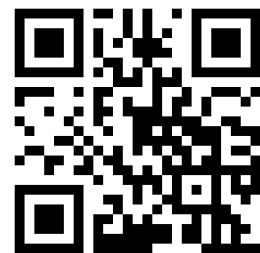
The Trust operates a smoke free policy.

Did we get it right?

We would like you to tell us what you think about our services. This helps us make further improvements and recognise members of staff who provide a good service.

Have your say. Scan the QR code or visit:

www.uhcw.nhs.uk/feedback



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Emergency eye appointments: new booking system



Scan the QR code or visit uhcw.nhs.uk and search Eye Emergency Referral Service with University Hospital, Coventry.

You will be spoken to by an expert clinician who will give you specialist advice on the next steps to take.

Please provide a phone number which you can be contacted on for the consultation. Please also be aware that you will be phoned as close to the allotted time as possible, although at busy times unfortunately there may be a delay.

In the event that you feel you cannot wait to speak to someone or do not have online access then you may call 0247 696 4800.

This phone line is open 9am - 1pm; 1.30pm - 5pm (Monday - Friday, excluding bank holidays) and 9am - 12pm (Saturday).

Please only attend the Eye Outpatient department if you have had a telephone consultation in advance and have been advised to attend.

Out of hours there is a reduced emergency eye service available via the Accident and Emergency Department.