

Your guide to

age-related macular degeneration



**No one need face macular degeneration alone.
For information and support call 0300 3030 111.**

Support throughout central vision loss

The Macular Society is the national charity for anyone affected by macular conditions. We have produced this guide to age-related macular degeneration to help explain the condition and how it affects people.

Being diagnosed with macular degeneration can be distressing and worrying but, with the right information and support, people can cope very well. There are now treatments for some types of the condition.

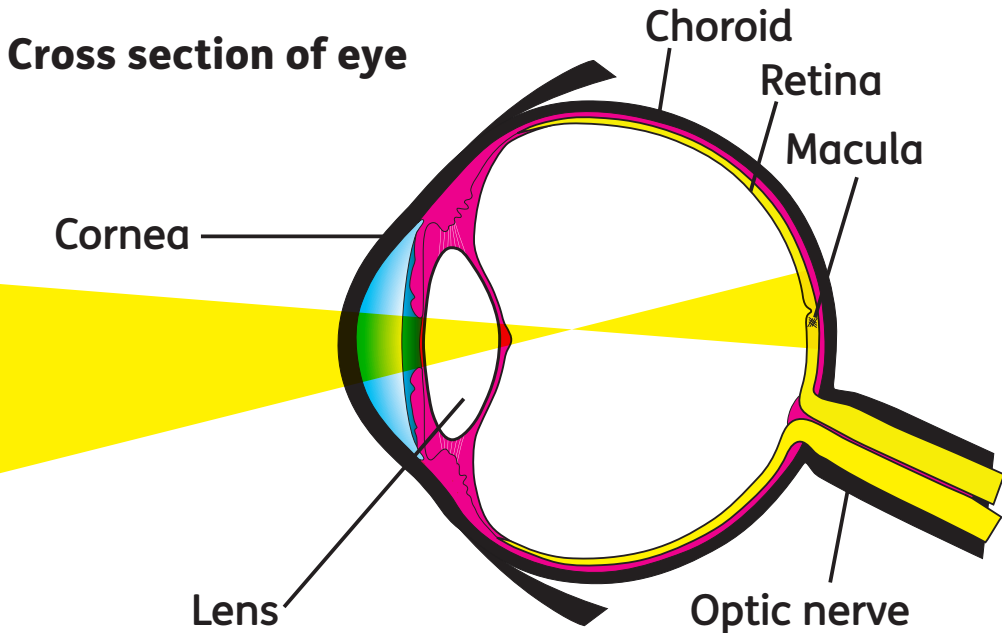
It's also important to remember that, no matter how advanced your macular degeneration is, you will not lose all your sight: macular degeneration is a condition that affects the central vision only. Peripheral vision is not affected. Macular degeneration is painless.

Helpline 0300 3030 111

What is the macula?

The macula is part of the retina at the back of the eye. It is only about 5mm across but is responsible for our central vision, most of our colour vision and the fine detail of what we see.

The macula has a very high concentration of photoreceptor cells – the cells that detect light. They send signals to the brain, which interprets them as images. The rest of the retina processes our peripheral, or side vision.



What is age-related macular degeneration?

There are many forms of macular disease, including age-related macular degeneration or AMD. This usually affects people over 60 but can happen earlier. In the UK around 600,000 people are affected by AMD – the most common cause of sight loss in the developed world. About half are registered as visually impaired.

The older we are the greater our risk of developing the condition. Around one in every 2,000 people has AMD at 60. However by the age of 90 it affects one person in five. We are all living longer so the number of people affected is increasing.

There are two forms of AMD – **dry** and **wet**. Dry AMD is a gradual deterioration of the macula as the retinal cells die off and are not renewed. The term dry does not mean the person has dry eyes, just that the condition is not wet AMD. There is currently no treatment for dry AMD. The progression of dry AMD varies but in most

people it develops over many months or years. Often people carry on as normal for some time.

Wet macular degeneration develops when abnormal blood vessels grow into the macula. These leak blood or fluid which leads to scarring of the macula and rapid loss of central vision. Wet AMD can develop very suddenly. It can now be treated if caught quickly.

Fast referral to a hospital specialist is essential.

Around 10 to 15 per cent of people with dry AMD develop wet AMD so if you have been diagnosed with the dry form of the disease and notice a sudden change in your vision, contact your optometrist or hospital eye specialist urgently. If you have AMD in one eye, the other eye may be affected within a few years.

Other forms of macular disease include genetic conditions, which affect young people. See our booklet **Juvenile macular dystrophies**.

Symptoms

Macular degeneration affects people in different ways. Symptoms may develop slowly if you have dry AMD, especially if it's only in one eye. However, as the condition progresses, your ability to see clearly will change.

- Gaps or dark spots (like a smudge on glasses) may appear in your vision, especially first thing in the morning.
- Objects in front of you might change shape, size or colour or seem to move or disappear.
- Colours can fade.
- You may find bright light glaring and uncomfortable or find it difficult to adapt when moving from dark to light environments.
- Words might disappear when you are reading.
- Straight lines such as door frames and lampposts may appear distorted or bent.

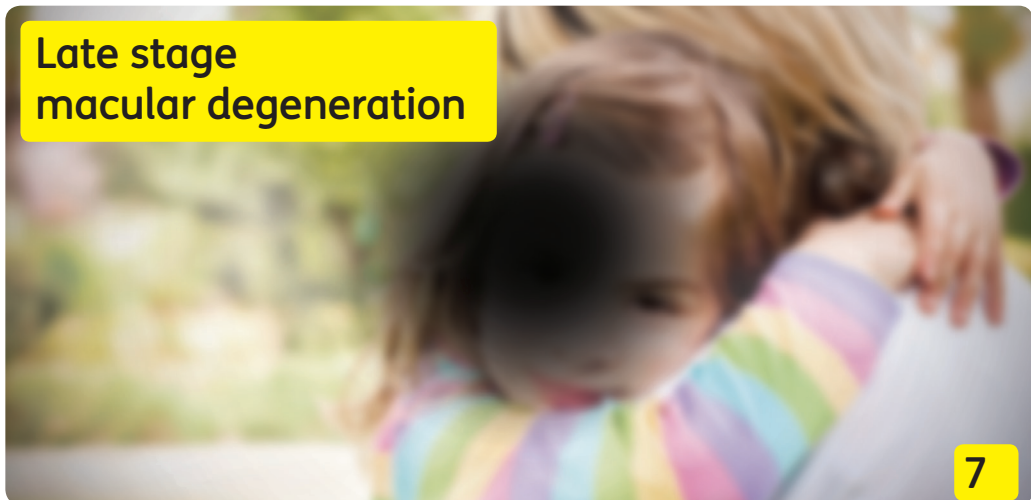
Normal vision



**Vision with
macular degeneration**



**Late stage
macular degeneration**



This distortion can be checked using an Amsler grid (see page 20) or against everyday household grids such as bathroom tiles or a window frame.



Diagnosing AMD

The optometrist at your local optician's practice can test sight, prescribe glasses and check for eye disease. Some optometrists use photography or other imaging to detect early signs of macular degeneration. These might include Optical Coherence Tomography (OCT) scans which create cross-sectional images of the retina. You may be charged for these tests.

There is currently no treatment available for dry AMD so you might not be referred to hospital, unless confirmation of the diagnosis is required or the optometrist thinks you need a hospital low

vision service. If your sight has worsened and you would like to be registered as sight impaired you will need a hospital appointment.

If your optometrist suspects you have wet AMD you should be referred to a retinal specialist at a hospital directly and seen within one to two weeks. You should not be sent to your GP. This causes unnecessary delay.

At hospital further tests will confirm the diagnosis. The specialist may use:

- Eye drops to dilate the pupils to see the back of the eye clearly. These may make your vision blurred and sensitive to light for a short time so consider taking someone with you.
- OCT scans.
- Fluorescein dye angiography. A dye injected into a vein in the arm travels to the eye, highlighting the blood vessels in the retina so they can be photographed. The dye will temporarily change the colour of your urine, so be prepared.

Treating AMD

Wet AMD can be treated if caught early. Drugs are injected into the eye to stop the growth of the abnormal blood vessels. Following diagnosis people will usually have a number of injections in the first few months. A patient will then be assessed to see if more are required.

The injections are not as bad as they might sound. The patient's eye is anaesthetised and the needle goes into the corner of the eye so the patient does not see it.

Some people do not respond to the injections and may be offered a form of laser treatment instead. There are a range of treatments and options although not all are available on the NHS. Further information is available in our leaflet **Treatment for macular conditions**.

Causes of age-related macular degeneration

The cause of AMD is not known but there are a number of factors associated with the development of the condition.

Age

Age is the main risk factor. As we age, cell regeneration reduces. This increases the risk of developing the condition.

Genetics

A family history of macular degeneration will increase your chances of developing AMD.

Smoking

Smoking damages blood vessels and the structure of the eye. Smokers are up to four times more likely to develop macular degeneration than non-smokers. If you also have the particular gene for AMD you are twenty times more likely to develop the condition.

Diet

A poor diet low in fruit and vegetables may increase the risk of AMD. Antioxidants and other substances in fruit and vegetables protect the body against the effects of 'free radicals'. These are unstable molecules that damage cells or prevent cell repair.

Alcohol destroys antioxidants. Obesity and a diet with lots of sugars and hydrogenated or saturated fats also increases the risk of developing AMD.

Blood pressure

People with high blood pressure are one and a half times more likely to have AMD than those with normal blood pressure.

Sunlight

Macular cells are sensitive to the ultra violet (UV) radiation and visible blue light, which occurs naturally in sunlight. Cell damage from blue light may cause deterioration of the macula.

Gender

More women than men are diagnosed with AMD.

Protecting your eyes

You cannot change your age or family history but lifestyle changes may help protect your eyes.

- Maintain a healthy weight and blood pressure.
- Wear lenses that block UV and blue light, and reduce glare.
- Wear a hat with a brim or visor to shade eyes from direct sunlight.
- Have regular eye tests to spot problems.
- Monitor your vision to check for changes.
- Eat a diet low in saturated fats and rich in omega 3 fatty acids (e.g. oily fish, walnuts) and fresh fruit and vegetables.
- Don't drink alcohol to excess.
- **Do not smoke.** This is the most important self-help measure you can take. If you would like help to stop smoking speak to your GP.

Nutrition

A good diet is important for eye health because certain nutrients protect the body from damaging substances called oxidants. In the eye oxidants may contribute to the development of AMD because they speed up cell degeneration.

Antioxidants like Vitamins A, C and E and a group of substances called carotenoids reduce this damaging effect. Two important carotenoids for people with AMD are lutein and zeaxanthin, which are found in dark green leafy vegetables like spinach and kale.

Eating two to four servings a week of vegetables high in lutein and zeaxanthin may help reduce the risk of AMD. Some experts recommend eating at least 10mg of lutein a day.

Eggs also contain lutein and zeaxanthin and zeaxanthin is found in orange and yellow fruits and vegetables such as sweetcorn and orange bell peppers.

Nutritional supplements

Two large studies in the USA, the Age-Related Eye Disease Study (AREDS) 1 and 2 have found that certain nutritional supplements can slow down the progression of AMD in people already showing signs of the condition.

AREDS supplements are available in the UK but they are not suitable for everyone. Your ophthalmologist or GP can advise you. There is also further information and guidance in our leaflet **Nutrition and eye health**.

Please talk to your GP before taking supplements or making major changes to your diet, especially if you take other medications.

Living with AMD

Macular degeneration is a very frustrating condition which can greatly affect your day-to-day life. However, there is plenty of support and information available. Even if your sight is still good and you are having treatment, it's important to know how to look after your vision and what to do if your AMD reaches a stage where you struggle with daily tasks.

Here are some ideas to help you manage AMD.

- Improve the lighting in your home and workplace. A person with normal sight needs twice as much light at 65 as they did when they were 21. A person with AMD will need even more. Control glare and keep general lighting levels bright and even.
- Use adjustable, cool to the touch task lighting for reading and close-up tasks.
- Bright and contrasting colours can help differentiate between objects.

- A wide variety of low vision equipment is available including magnifiers. You may be able to buy or borrow them from your local low vision service.
- Try spectacles with filters that block UV and blue light. They help protect the eye and reduce glare.
- Computers have options that can read text and emails as speech. E-readers, such as the Kindle or iPad, mean you can read books in large format.
- Buy or borrow large print books, audio books, newspapers and magazines.
- Use talking equipment such as watches, wall clocks, microwaves and kitchen scales. Audible liquid level indicators warn when a cup or jug is full.
- Tactile bumps help you find settings on appliances like washing machines.
- Use large face clocks and watches, large print stickers for keyboards, telephones with large numbers.

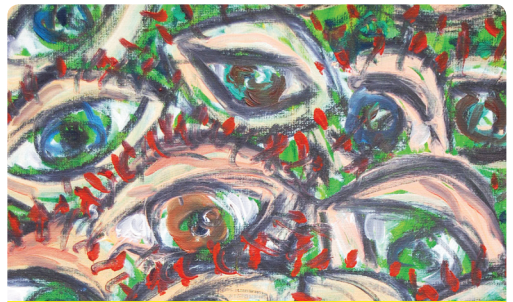
It's hard to know what equipment to buy but there are plenty of organisations to advise and help. These include low vision clinics, social service sensory impairment teams and local societies for visually impaired people.

Charles Bonnet syndrome

Up to half of all people with macular degeneration are thought to experience visual hallucinations at some time. The condition is called Charles Bonnet syndrome. These images might be of people, animals, landscapes or just patterns.

People who haven't heard of it often worry they are developing a mental illness, but it is a normal response of the brain to sight loss.

As fewer messages reach the brain, the cells that normally process vision can



An example of a visual hallucination

become hyperactive and create images of things that are not there.

Not everyone with vision loss has hallucinations. For some people they may occur once or twice or continue for several years or longer. If you would like to speak to someone about hallucinations call 0300 3030 111.

There is further information on living with macular degeneration in several Macular Society leaflets.

Leaflets available include:

- Diabetic macular oedema
- Nutrition and eye health
- Smoking and sight loss
- Visual hallucinations

Call our helpline

0300 3030 111 or visit

www.macularsociety.org/resources



Amsler grid

Use an Amsler grid to monitor your vision in case it changes. It is important to spot early signs of dry AMD becoming wet or wet AMD becoming more active.

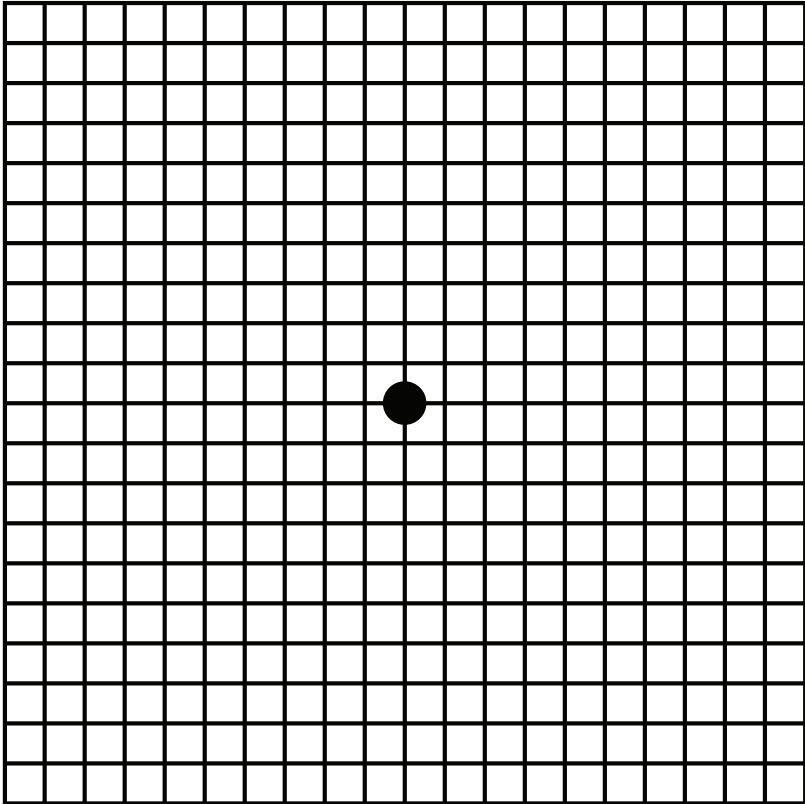
Wear any reading glasses you normally use (but not varifocals).

Hold the grid about 12 inches (30 cm) from you, where it is best in focus.

Cover each eye in turn and look at the central dot.

If you have AMD the lines of the grid may appear wavy or broken. Parts of the grid may be blurred or missing.

If you see **any changes** to your vision, contact your ophthalmologist immediately. Do this check as often as your optometrist or ophthalmologist recommends.

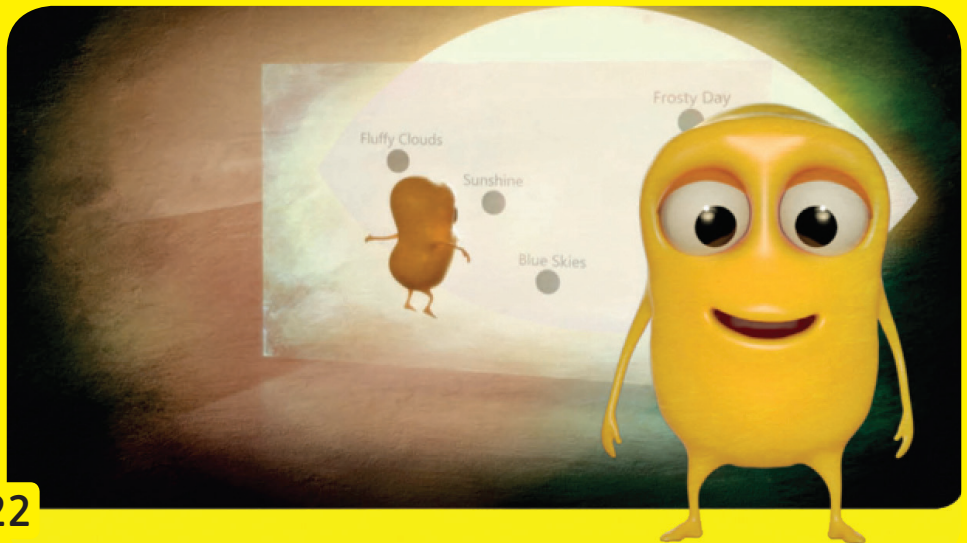


Explaining AMD to family and friends

Explaining AMD isn't easy, from a medical point of view or an emotional one. For anyone affected by macular disease this can be frustrating and upsetting, as they'll need to be understood and will need support from their family and friends.

We'd like as many people as possible to understand AMD and to raise awareness of the support the Macular Society is able to offer. To help with all the above, we've made a short video, featuring a character we've created called Mac.

This film can be seen at
www.macularsociety.org/mac



How we help

We are the national charity for anyone affected by central vision loss. We provide free information and support to improve lives today. We fund research so that one day we can overcome macular disease.

All our services are free to those with macular conditions, their family and friends.

**Helpline 0300 3030 111 Monday to Friday
9am – 5pm help@macularsociety.org**

Counselling – Talk, in confidence, to a professional counsellor.

Support Groups – We have over 300 local groups.

Befriending – Your befriender will call regularly for a friendly, social chat about anything you like including, but not always, macular disease.

Gadget Guides – help people adapt to living with sight loss by showing them gadgets and technology which can help.

Skills for Seeing – Our training programme can help you make best use of remaining sight.

Six months free membership

If you would like to receive regular updates about living with macular conditions, treatments and medical research to find a cure then membership is for you.

Join for free today by calling 01264 350 551 or go to www.macularsociety.org/6months



Macular Society

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Macular Society

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