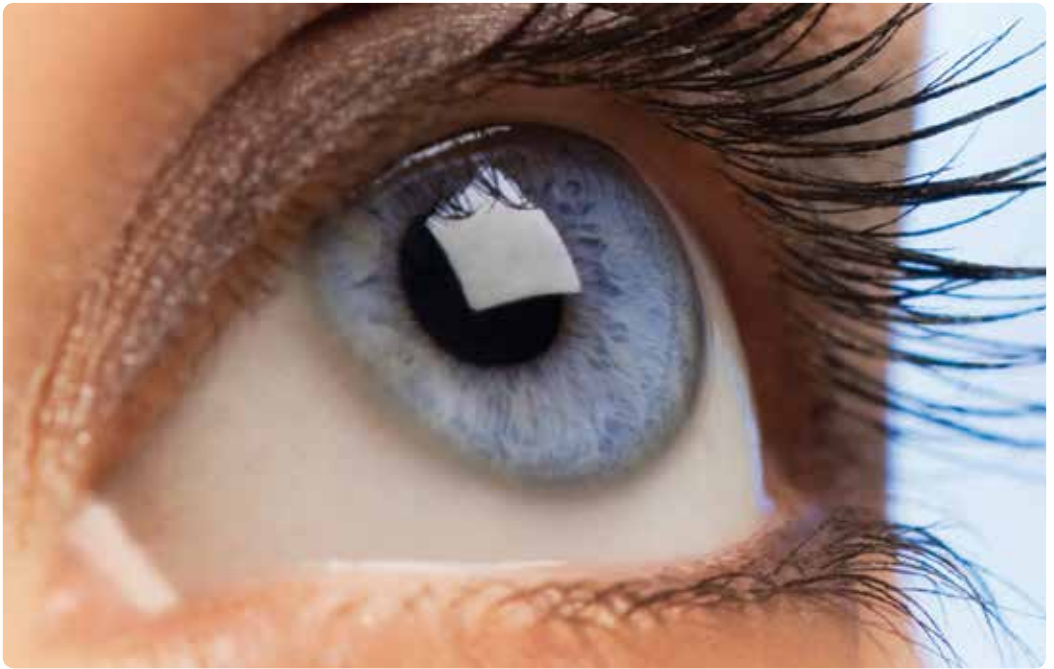


Your guide to

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 a 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.

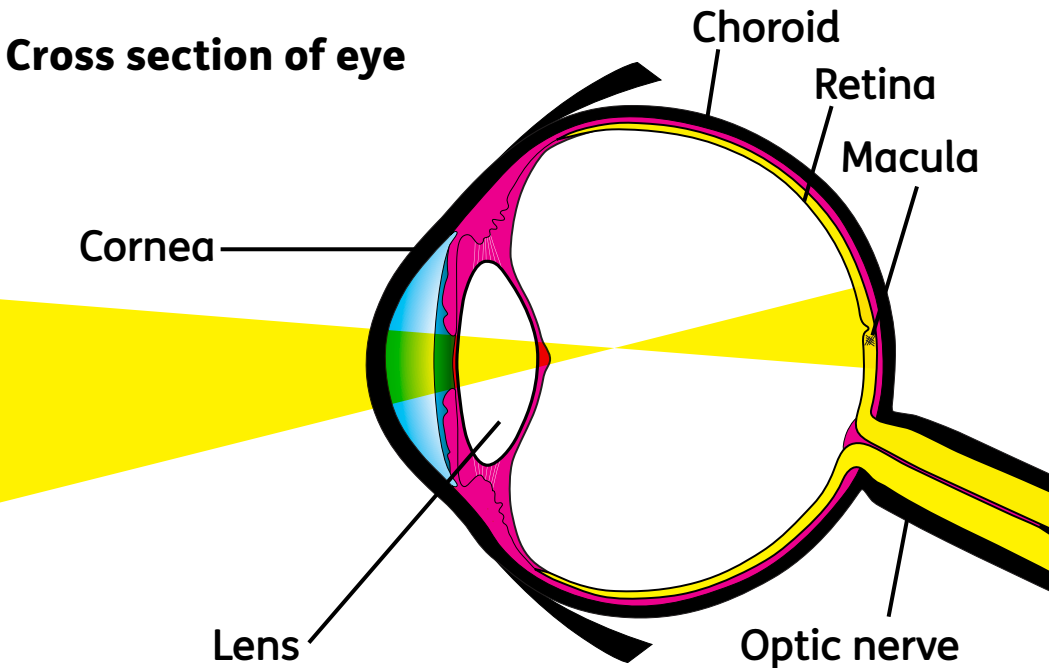
Being diagnosed with macular degeneration can be distressing and worrying but, with the right information and support, people can cope very well. There are now treatments for some types of the condition.

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 the size of a grain of rice 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 genetic conditions, which affect young people. (See our booklet *Juvenile Macular Dystrophies*). When macular disease appears in later life it is called age-related macular degeneration or AMD. It usually affects people over 60 but can happen earlier. AMD is the most common cause of sight loss in the developed world. In the UK around 600,000 people are affected. About half are registered as visually impaired.

The older we are the greater our risk of developing AMD. 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 by AMD 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, for example by continuing to drive.

In **wet** macular degeneration 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 percent of people with **dry** AMD develop **wet** AMD so if you have **dry** AMD but notice a sudden change in your vision, contact your optometrist or hospital eye specialist urgently. If you have AMD in one eye it may affect the other eye within a few years.

Symptoms

Macular degeneration affects people in different ways. You may not notice any change in your vision in the early stages, especially if you have AMD in only one eye. However, as the condition progresses, your ability to see clearly will change.

- Gaps may appear in your vision or dark spots like a smudge on glasses, 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 lamp posts may appear distorted or bent.

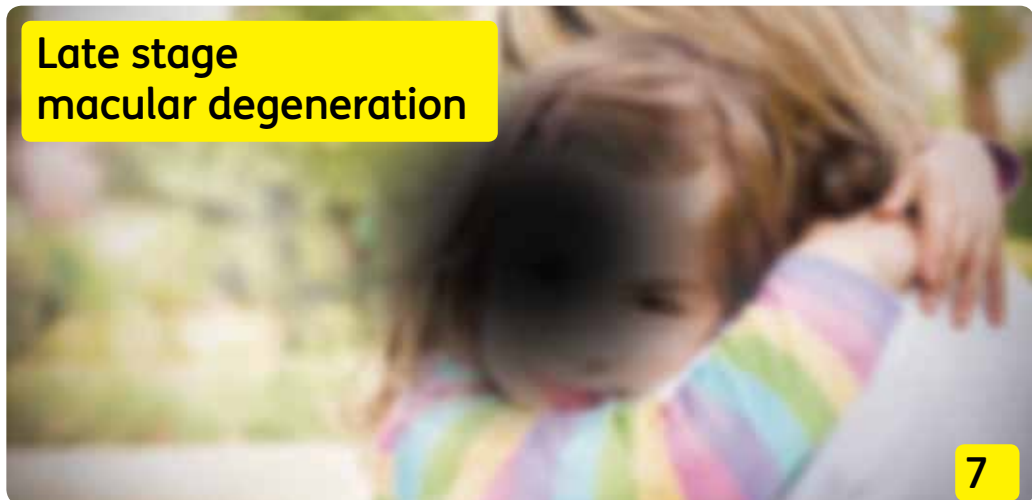
Normal vision



**Vision with
macular degeneration**



**Late stage
macular degeneration**



This distortion can be checked using an Amsler grid (see page 22) or against everyday household grids such as looking at 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.

If you have dry AMD you may not be referred to hospital as there is no treatment available yet. You may be referred for confirmation of the diagnosis or if 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.

If you are referred to hospital, more tests will be done to confirm the diagnosis. The hospital specialist, the ophthalmologist may use:

- eye drops to dilate the pupils to see the back of the eye clearly. The drops may make your vision blurred and sensitive to light for a short time so consider taking someone with you;
- OCT scans;
- fluorescein dye angiography. The dye is injected into a vein in the arm. It 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 injection treatments in the first few months. Subsequent check-ups will then be needed to assess when more injections are needed. The interval between injections varies among patients, however, six to eight injections in the first year is not uncommon.

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.

The treatment cannot restore sight if there is already significant scarring of the macula. Some people do not respond to the injections. A few people may be offered a form of laser treatment instead.



Causes of age-related macular degeneration

There are a number of factors associated with the development of AMD. Unfortunately, because the exact cause is not known, you may develop the condition even if you reduce your risk factors.

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.

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).
- Eat lots of fruit and green 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

Research suggests that nutrition may play an important role in AMD. The macula is thought to be protected from sun damage by a yellow substance called macular pigment. People with low levels of macular pigment may be more likely to get AMD. The pigment is made up of antioxidants called carotenoids, especially lutein and zeaxanthin. These can only be obtained by eating food containing them.

The best food sources of lutein and zeaxanthin are 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. People who struggle to shop for or prepare food may find that difficult.

mg of lutein per 100g fresh vegetable

Kale	11.4 mg	Leek	3.6 mg
Red pepper	8.5 mg	Broccoli	3.3 mg
Spinach	7.9 mg	Peas	1.7 mg
Lettuce	4.7 mg		

Two large studies in the USA, the Age-Related Eye Disease Study (AREDS) 1 and 2 have found some benefit in taking nutritional supplements. The first study looked at the antioxidant vitamins A (as beta-carotene), C and E together with zinc and copper. This preparation reduced the risk of a person developing late-stage AMD by around 25%. The second added lutein, zeaxanthin and omega 3.

Although the overall analysis did not show any additional benefit, taking lutein and zeaxanthin did appear to benefit people who had lower levels of lutein in their diet. Omega 3 did not appear to benefit any group (although some other studies have reported a benefit). The supplements were tested on people who already had AMD so the results do not prove that the supplements can actually prevent AMD.

The ingredients of the AREDS 1 and 2 studies can be bought as commercially available supplements. The AREDS 2 study appears to confirm an increased risk of lung cancer in smokers taking beta-carotene and the

investigators recommended that beta-carotene is removed from AREDS preparations. AREDS 2 also used less zinc without any apparent effect on the benefits of the supplement.

AREDS 2 ingredients

Vitamin C	500 mg	Zeaxanthin	2 mg
Vitamin E	400 IU	Zinc	25 or 80 mg
Lutein	10 mg	Copper	2 mg

More research into this area is needed and experts advise that supplements should not be a substitute for a healthy diet.

Because there are so many supplements on the market you may want to speak to your ophthalmologist, pharmacist, GP or optometrist who can give advice about products and any side effects. It is especially important to ask for advice if you are taking other supplements or medicines.

Avoid products that claim to cure or reverse sight loss caused by AMD. There is no evidence that existing supplements can do that.

Living with AMD

Macular degeneration is a very frustrating condition which can greatly affect your day-to-day life. However, there is support and information to help. 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. Daylight bulbs can be helpful.
- 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 audio. 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 is hard to know what equipment to buy as everyone is different so get advice.

- Go to a low vision clinic, who will assess your needs and give you advice about equipment and how to use it. Health professionals can refer you to a clinic.
- Ask for a referral to an adult social care sensory impairment team. These give practical advice and help with daily living skills, such as getting around safely or making adaptations at home.
- If you are working, ask your employer about 'access to work' schemes to help you stay in employment. Many visually impaired people continue to work very successfully.
- Your local society for visually impaired people, Action for Blind People or RNIB office may have facilities where you can try out or buy equipment.
- If your sight has deteriorated you may consider being registered as sight impaired. This entitles you to claim services and benefits for visually impaired people. Your hospital consultant will need to issue a certificate for you to be registered.

Charles Bonnet Syndrome

Some people with AMD experience visual hallucinations called Charles Bonnet Syndrome. These images might be of people, animals, landscapes or just



An example of a visual hallucination

patterns. People who haven't heard of Charles Bonnet Syndrome often worry they are developing a mental illness. However, it is actually a normal response of the brain to sight loss. As fewer messages reach the brain, the cells that normally process vision can 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. They can be a nuisance, even distressing, although some people say they enjoy them. If you would like to speak to someone about hallucinations call 0300 3030 111.

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.

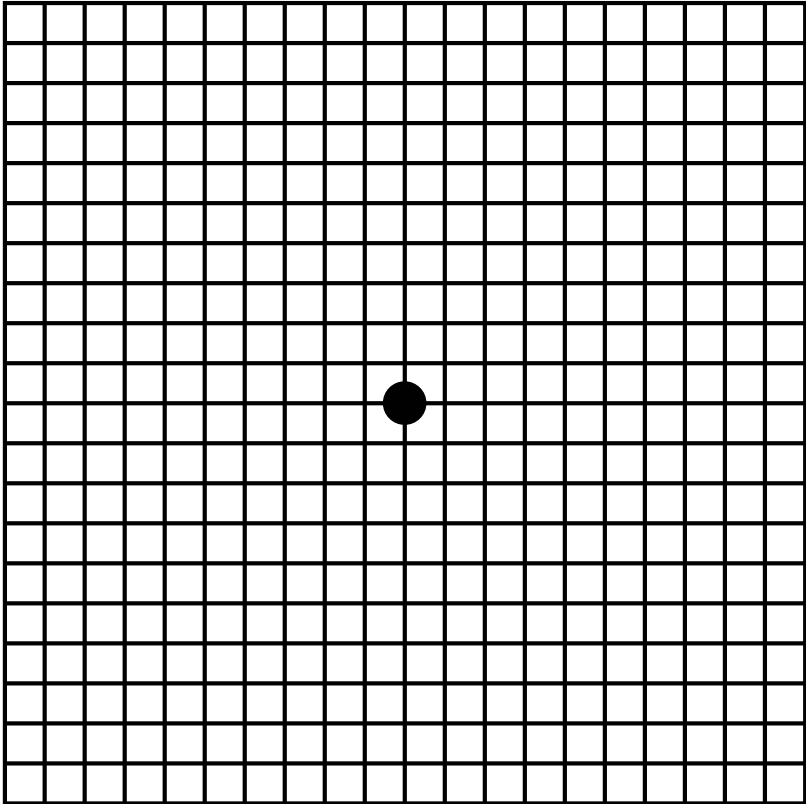
Wear any reading glasses you normally use (but not varifocals).

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.



Macular Society services

The Macular Society has been supporting people with macular conditions for over 25 years. We offer information and support while we fund research to find a cure so that one day we can overcome macular disease.

All our services are free so that no one has to face macular disease alone.

Helpline

0300 3030 111

Monday – Friday

9am – 5pm

Information

We have a wide range of information on living with macular degeneration including leaflets on:

Your guide to age-related macular degeneration

- nutrition
- lighting
- treatments
- low vision aids
- using technology
- visual hallucinations.



These are available in large print, audio or online
www.macularsociety.org

Support groups

You may like to join a local Macular Society group where people with AMD, their family and friends offer each other companionship and support. People with AMD are the experts on living with it! There are groups around the country – including groups for younger people with macular conditions.

Befriending

This telephone service may be especially helpful if you cannot get to a group but would like to talk to someone who has experience of AMD.

Skills for seeing

Many people who have lost their central vision can learn to use their peripheral vision more effectively. Our trainers help you learn this technique called “eccentric viewing”.

Counselling

Having macular disease can leave people upset and worried about the future. Sometimes it helps to speak, in confidence, to a professional counsellor. If you would like to speak to one of our trained telephone counselling team please ask the helpline.

Our helpline can put you in touch with all our services:

0300 3030 111

help@macularsociety.org



Join us

You can join the Society for just £18 a year. We are the only national charity especially for people with macular conditions. We campaign for better care. Through the generosity of our members and supporters we are able to fund vital research to improve lives and search for a cure.

As a member you'll get our quarterly magazine, **Sideview**, and **Digest**, an annual report on new research. Members are invited to special events, such as conferences and seminars, and have a say in how the Society is run. Many people join us because they have found our services valuable and want to help ensure they are available to others in future. Many join to support our research work to find new treatments and a cure for macular disease.

**Join now. Call 01264 350 551,
return the form opposite
or go online www.macularsociety.org**

Membership

UK – £18 a year. Overseas – £30 a year.

- I want to join the Society. I enclose a cheque payable to the Macular Society for £ _____
- I wish to donate £ _____
- Please call me to give me more information.
- We send all our information Articles for the Blind. Tick the box if you wish to opt out.
- I don't wish to join yet but please send me regular news.

Name

Address

Postcode

Telephone

Email

Date of birth

giftaid it

For every £1 of your membership fee or donation we can claim at least 25p more at no extra cost to you. To allow this, sign the declaration below.

Please treat all donations I make to the Macular Society today and in the future as Gift Aid donations until I notify you otherwise.

I understand that I must pay income tax and/or capital gains tax at least equal to the amount the Society will reclaim on my donations.

Signature

Date

Macular Society
PO Box 1870
Andover
SP10 9AD



AMD causes more than half of all blindness in Britain. In the UK 600,000 people have AMD and another 200 people are diagnosed every day.

We urgently need to find a cure and you can help today. Your donation will help people struggling to cope with AMD and move us closer to a cure.

To make your vital donation call us today or go online.


Macular Society

Support throughout central vision loss

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