



Understanding Age-related Macular Degeneration



About BID Services

BID Services is a charity dedicated to removing barriers and empowering people who are D/deaf, hard of hearing, sight impaired, deafblind, or living with other disabilities to live full and independent lives.

We deliver a wide range of specialist services across the country, including information, advice and guidance; community services with welcoming social groups and activities; children and young people's services; awareness training and British Sign Language courses; communication support and interpreting services; assessment and rehabilitation for people with sight loss or who are deafblind, including mobility training and independent living skills; hearing aid clinics; and assistive technology and equipment assessments and training.

Self refer online

If you need support or you know someone who does, you can make a referral on our website:

www.bid.org.uk/contact-us

Use the camera on your smartphone to scan this QR code and self-refer online, or go to the end of this booklet for alternative contact information.



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About age-related macular degeneration

Age-related macular degeneration (AMD) is an eye condition that affects a tiny part of the retina at the back of your eye, called the macula. AMD causes problems with your central vision, but does not lead to total loss of sight and is not painful.

AMD affects the vision you use when you are looking directly at something, for example, when you are reading, looking at photos or watching television. AMD may make this central vision distorted or blurry and, over a period of time, it may cause a blank patch in the centre of your vision.



Causes

At the moment, the exact cause for AMD is not known. Some things are thought to increase your chances of developing AMD:

Your age: AMD develops as people grow older and is most often seen in people over the age of 65, although it can develop in people who are in their 40s and 50s.

Your gender: More women have AMD than men, probably because women tend to live longer.

Your genes: Some genes have been identified which seem to be linked to the development of AMD in some people. This has been discovered by looking at families with more than one member who has AMD, but not all AMD is thought to be inherited.

Smoking: Smoking greatly increases your risk of developing AMD. Studies also show that stopping smoking can reduce your risk of developing AMD.

Sunlight: Some studies suggest that exposure to high levels of sunlight (particularly the UV light contained in sunlight) throughout your life may increase your risk of developing AMD, but this has not been proven. Wearing sunglasses to protect your eyes from the UV light in sunlight is a good

idea for everyone throughout their life.

What you eat: A number of studies have looked at diet as a risk factor for someone developing AMD. At the moment there isn't agreement on how much of a risk factor diet is. There is some evidence that vitamins A, C and E and zinc may help to slow the progression of AMD in people who already have the condition.

Although you cannot change your age or genes, current thinking is that protecting your eyes from the sun, eating a balanced diet with plenty of fresh fruit and vegetables, and stopping smoking may all help to keep your eyes as healthy as possible. Unfortunately, you may develop this condition even if you don't have any of the risk factors.

Symptoms

Symptoms vary from person to person, but usually the first problems people notice are with their ability to see detail. You may have problems reading small print, even if you wear your usual reading glasses, or you may find that there is a slight smudge in your sight or that your vision has a small blurred area in the centre. Straight lines may look distorted or wavy or as if there's a little bump in them.

You may also find you become sensitive to bright light or that you see shapes and lights that aren't actually there. Sometimes people may only notice these changes in one eye.

You should have your eyes tested by an optometrist (optician) if:

- You notice any difficulty with reading small print with your reading glasses.
- Straight lines start to look wavy or distorted.
- Your vision isn't as clear as it used to be.

The optometrist will be able to measure any changes in your vision and examine the back of your eye. If they detect any changes to your macula

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or any cause for concern they will arrange an appointment with the ophthalmologist (hospital eye consultant) for further tests.

The macula

AMD affects the macula area of the retina. The macula is a tiny area of your retina which is very important for seeing detail, colour and things directly in front of you.

When light enters your eye it is focused onto your retina at the back of your eye. The retina includes a number of layers but the most important for vision is a layer made up of cells called photoreceptors. Photoreceptors are cells which are sensitive to light.

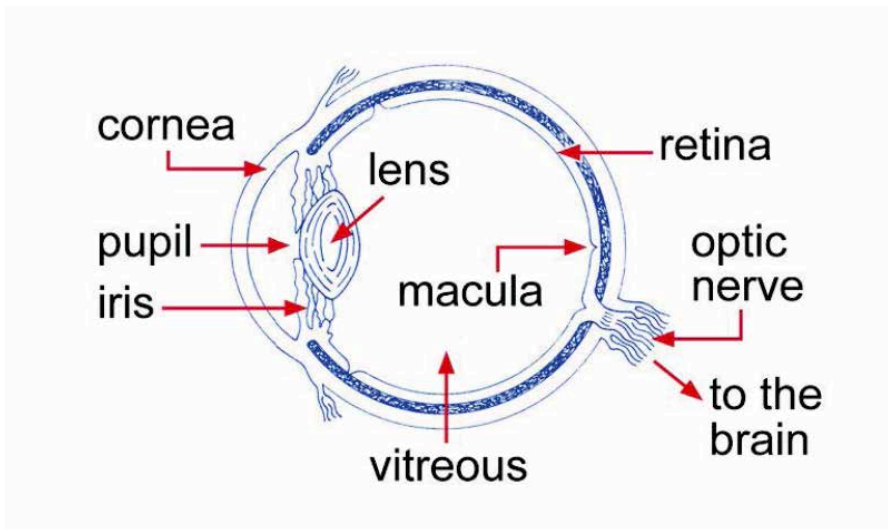
The macula, which is about the size of a pinhead, is a specialised area of the retina that contains a few million specialised photoreceptor cells called cone cells. These cone cells function best in bright light levels and allow you to see fine detail for activities such as reading and writing and to recognise colours.

Away from the central macula is the peripheral retina, composed mostly of the other type of photoreceptor called rod cells. They enable us to see when light is dim and provide peripheral (side)

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vision outside of the main line of sight. Peripheral vision is the sight you have out of the corner of your eye when looking straight ahead.

When someone develops AMD, the cone cells in the macula area become damaged and stop working as well as they should.



Types of AMD

There are two main types of AMD - "wet" AMD and "dry" AMD. They are called "wet" and "dry" because of what happens inside your eye and what the ophthalmologist sees when examining the inside of your eye, not because of how the eye feels or whether you have a watery or dry eye.

Dry AMD

Dry AMD is the more common type of AMD. It usually develops very slowly and causes a gradual change in your central vision. Dry AMD usually takes a long time, maybe a number of years to get to its final stage. At its worst, dry AMD causes a blank patch in the centre of your vision in both of your eyes. But it doesn't affect your peripheral vision, so never leads to total blindness.

Wet AMD

About 10-15% of people who develop AMD have wet AMD. You develop wet AMD when the cells of the macula stop working correctly and the body starts growing new blood vessels to fix the problem. Unfortunately these blood vessels grow in the wrong place and cause swelling and bleeding underneath the macula.

This new blood vessel growth, medically known as neo-vascularisation, causes more damage to your

macula and eventually leads to scarring. Both the new blood vessels and the scarring damage your central vision and may lead to a blank patch in the centre of your sight.

Wet AMD can develop very quickly, making serious changes to your central vision in a short period of time. Treatment is now available for wet AMD, which stops the new blood vessels from growing and damaging your macula. This treatment usually needs to be given quickly before the new blood vessels do too much damage to your macula. If the blood vessels are left to grow, the scarring and the sight loss it causes are usually permanent. Wet AMD doesn't affect your peripheral vision, so it doesn't lead to total blindness.

Both types of AMD

Wet and dry AMD have things in common. They usually affect both your eyes, though sometimes one eye may be affected long before the other. Both wet and dry AMD only affect your central vision and won't affect your vision around the edge of your sight (peripheral vision). So neither type of AMD will cause you to lose all your sight.

Some people diagnosed with dry AMD find that, with time, new blood vessels grow and they develop wet AMD. If you have dry AMD and your sight

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suddenly changes you should always have this checked by your ophthalmologist.

Some people may have wet AMD in one eye and have dry AMD in the other, which doesn't develop into wet AMD. Most people, however, have the same type of AMD in both eyes.

Confusingly, people who have had wet AMD for a long time, causing bad scarring on their retina, may be told that their wet AMD has "dried up." This usually means that there are no new blood vessels growing and that your macula has been badly scarred. At this stage of wet AMD, the treatments available would not help.

AMD is not painful and it never leads to a complete loss of vision. Most people with AMD keep their peripheral vision (everything around the edge). This peripheral vision will mean that you should still be able to get around on your own and make use of this vision every day.

Changes in your vision

If you notice a sudden change in your vision, you should always have your eyes examined by an eye health professional. Usually this is an optometrist in the high street. However, if your sight changes very quickly then you can attend the Accident and Emergency Department at your nearest hospital, where an ophthalmologist will be able to check your eyes.

If you have slight changes in your vision then you should arrange for an eye examination with an optometrist. They are trained to detect any eye problems and, if necessary, can refer you to your GP for a further appointment with the ophthalmologist at the hospital.

If you have dry AMD and you notice a sudden change in either of your eyes you should let the hospital know. This is because dry AMD can develop into wet AMD and, if this happens, sight saving treatment may be possible if treated early.

If you have AMD in one eye and you notice a sudden change in either eye, you should let the hospital know as soon as possible. This is because you can have different types of AMD in each eye and treatment might now be of help to you.

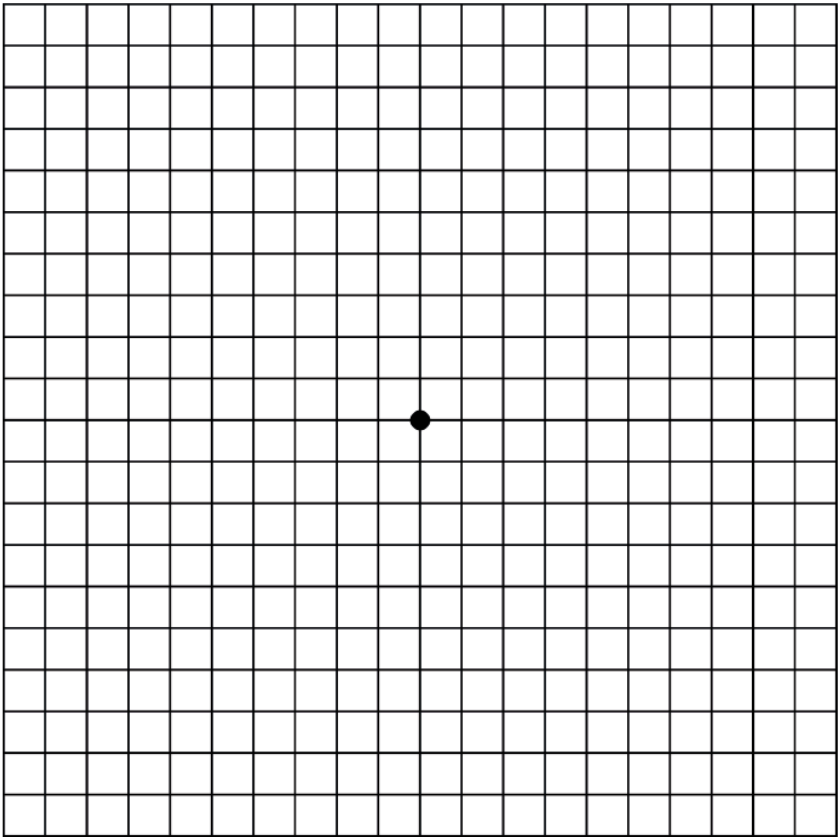
Amsler grid

Use an Amsler grid on the next page 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) and 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.



Eye examination

To diagnose AMD you need to have your eyes examined by an ophthalmologist. This is done at the hospital once your optometrist or GP has referred you.

At the hospital, your vision will be checked and your pupils dilated to allow the ophthalmologist to look at your macula. Your pupils are dilated with drops that take about 30 minutes to work. They will make you sensitive to light and cause your vision to be blurry.

The drops allow the ophthalmologist to see the inside of your eye more easily. The effect of the drops usually wears off in about six hours, though sometimes it can happen overnight. It is not safe to drive until the effects have worn off.

The ophthalmologist will look at the inside of your eye using a special microscope called a slit lamp. You place your chin on a rest and the ophthalmologist will sit opposite you. The ophthalmologist will ask you to look in particular directions while shining a light into your eye. This allows them to see your retina and any changes that AMD may have caused. Although very bright, the light cannot damage your eye.

Sometimes the ophthalmologist can tell you whether they think you have AMD or not from this examination. However, you may need a test called a fluorescein angiogram to find out for certain if you have AMD or to find out whether you have wet or dry AMD.

Fluorescein angiogram

This test helps the ophthalmologist find out more about your AMD and whether you have wet or dry AMD. Usually the network of blood vessels underneath your retina can't be seen by examining your eyes with a slit lamp. The ophthalmologist can see the damage to your retina but they can't see the detail of the blood vessels this way. A fluorescein angiogram is a way of taking pictures of these blood vessels, which allows the ophthalmologist to see if there are any changes which could be causing problems.

Before a series of pictures is taken, a yellow dye is injected into your arm, which then travels through your bloodstream to your eye. This usually isn't painful but can make some people feel sick. This dye makes the blood vessels visible on the pictures taken.

Once the dye has been injected, you will be asked

to position yourself and look at a special machine. The machine takes pictures of the back of your eye as the dye is travelling through the blood vessels.

You will experience a series of flashing lights as the pictures are taken, but the test is not painful. It usually takes about ten minutes.

It is a very common test and very few people have any serious side effects. The injection may give your skin a slight yellow tinge from the dye which lasts up to a day or two. Your urine may also appear a darker yellow than normal (possibly for up to two to three days) but often it fades quicker than that. Some people are dazzled for a while after the flashing lights but most people find the test straightforward.

These tests help the ophthalmologist decide which type of AMD you have and if any treatment is possible.



Treatment

A number of treatments are available for wet AMD. These mainly work by stopping the growth of new blood vessels. This means that treatments usually need to be given fairly quickly once the blood vessels start to grow in your eye. If the blood vessels are allowed to grow for too long, they may scar and this scarring cannot be treated.

There is no treatment for dry AMD. This is because dry AMD does not involve new blood vessels growing. Although research is going on to try and find out why the cells of the macula stop working, this hasn't yet led to a treatment.

Treatments for wet AMD

Anti-VEGF treatment

The most recent treatment available on the NHS for wet AMD is with anti-vascular endothelial growth factor (anti-VEGF) drugs. As new blood vessels form in your eye, your body produces a chemical that stimulates further new blood vessel growth. Anti-VEGF drugs interfere with these chemicals and stop the vessels from growing. By stopping blood vessels growing and leaking, further damage to your sight is prevented.

This medicine has to be injected into the vitreous,

the gel-like substance inside your eye. This is called an intravitreal injection. This injection needs to be given in an operating theatre or a “clean room” to avoid infection. A clean room is a sterile room, which may not have the full facilities of an operating theatre.

Before the injection, you will be given anaesthetic eye drops to make your eye numb, an antibiotic drop to help prevent you getting an infection and a drop to dilate your pupil.

The injection shouldn't be painful but your eye may be a little sore after the anaesthetic wears off. Because the injection goes into the gel in the centre of your eye there is a slight chance that the pressure inside your eye may rise a little. This should not cause you any pain or change your vision, but will need to be checked shortly after you have the injection.

The sight in the treated eye may be blurry because of the drop to dilate your pupil, but this should wear off in a day. Some people find that they have slight swirls in their vision for a few days following the injection.

You may find that your eye waters a bit more after the injection and that your eye may be slightly red

or irritated, but this normally gets better after a few days. If your eye becomes very painful or very red and hot to touch, or you notice any worsening of your vision, you should let your hospital know as soon as possible.

The main complications of this treatment are the chance of a rise in pressure in your eye, retinal detachment and eye infections. These only happen to a very small minority of people (less than 1% of people having the treatment) and there are treatments available if any of these complications happen to you.

Usually you will need more than one injection of anti-VEGF medication. Normally a course of three monthly injections is given to start with and then you should be monitored every four to eight weeks, depending on which particular drug was given to check that the treatment is working. There are different anti-VEGF medications being used and each may require different monitoring schedules. Your ophthalmologist will advise you how often you need to have your eyes checked. Many people go on to have more injections after the initial three.

Usually anti-VEGF treatments have a high success rate, and for most people it can stop their sight

getting worse. About 25-30% of people also see an improvement in their vision.

Photodynamic therapy

Anti-VEGF treatments are usually the first treatment offered to people with wet AMD. However, sometimes it may be necessary to try a different treatment called photodynamic therapy (PDT). This is a type of laser treatment, which uses a combination of a light sensitive drug and a low energy (cold) laser to stop new blood vessels growing.

You will be given an injection, usually in your arm, of a light sensitive drug called Verteporfin (Visudyne). Once this drug has made its way to the new blood vessels which grow in wet AMD, your ophthalmologist can target a very bright light (a cold laser) onto these blood vessels. The laser causes a reaction with the drug, which seals off any new blood vessels that may be growing.

This treatment also needs to be given at the early stages of the blood vessel growth, so that it can prevent the new blood vessels causing damage.

There is some evidence that high doses of vitamin A, C, E and the minerals zinc and copper when taken

together may help slow down the progression of dry AMD, particularly if someone already has changes to their vision in one eye because of AMD.

There are a number of vitamin products available, which have been designed for people with dry AMD and you can usually buy these over the counter from your pharmacist.

However, there is no evidence that taking high doses of these vitamins can prevent you developing AMD in the first place. A balanced diet with plenty of fresh fruit and vegetables is good for your general health and may also help your eye health.

Coping

Being diagnosed with an eye condition can be very upsetting. You may find that you are worried about the future and how you will manage with a change in your vision. All these feelings are natural.

Some people may want to talk over some of these feelings with someone outside their circle of friends or family. BID Services can help, offering practical and emotional support, access to information and social groups and signposting you to other organisations who may be able to support you.

The Macular Society has local groups which meet throughout the country and also offer a telephone counselling service. Sometimes it can help to talk about your feelings or share with people who may have had similar experiences.

Help to see things better

Both types of AMD can cause severe problems with your central vision. However, most people with AMD have some vision and there are a lot of things you can do to make the most of your remaining vision. This may mean making things bigger, using brighter lighting, or using colour to make things easier to see.

Ask your ophthalmologist, optometrist or GP about low vision aids, such as a magnifier, or get in touch with BID Services to see if we offer services and support in your area.

You should also ask whether you are eligible to register as sight impaired (partially sighted) or severely sight impaired (blind). Registration can help you access support and financial benefits. Even if you are not registered, a lot of this support is still available to you.

Local social services should be able to offer you

information on staying safe in your home and getting out and about safely. They should also be able to offer you some practical mobility training to give you more confidence when you are out.

BID Services offers services across England to support those with sight loss from emotional support to practical advice such as equipment and technology which can help you in your day to day life.

To find out if we offer services near you, please check our list of regional services below or contact us on **0121 246 6100**. You can also send an email to **info@bid.org.uk**

List of regional services

Birmingham Advice and Support Service

Leicester, Leicestershire & Rutland Sensory Services

Coventry Deaf and Hearing Loss Support Service

Lincolnshire Sensory Services

Cumbria Deaf and Hearing Loss Services

Milton Keynes Sensory Services

Leeds Sensory Services

Northumberland Sensory Services

Useful contacts

The Royal College of Ophthalmologists

Tel 020 7935 0702

Website www.rcophth.ac.uk

Royal National Institute of Blind People (RNIB)

Tel 0303 123 9999

Website www.rnib.org.uk

Driver and Vehicle Licensing Agency (DVLA)

Tel 0300 790 6801

Website www.gov.uk/contact-the-dvla

Macular Society

Tel 0300 3030 111

Website www.macularsociety.org

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Did you know?



You can access our **Information Library online**, where you'll find a wide range of helpful resources. Topics include communication tips, health and wellbeing, finding and staying in work, and living independently with a disability.



To access the Information Library, visit
www.bid.org.uk/resources

If you require this booklet in an alternative format (e.g. large print, audio or Braille), please contact us.

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