

#### Understanding

#### See differently

# Age-related macular degeneration



## **Sight Advice FAQs**

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# **RNIB's Understanding series**

The Understanding series is designed to help you, your friends and family understand a little bit more about your eye condition.

The series covers a range of eye conditions, and is available in audio, print and braille formats.

## **Contact us**

We're here to answer any questions you have about your eye condition or treatment. If you need further information about cataracts or on coping with changes in your vision, then our Helpline is here for you.

RNIB Helpline 0303 123 9999 helpline@rnib.org.uk

Or say, **"Alexa, call RNIB Helpline"** to an Alexa-enabled device.

# What is age-related macular degeneration?

Age-related macular degeneration (AMD) affects a tiny part of the central retina at the back of your eye, called the macula. AMD causes changes to the macula, which leads to problems with your central, detailed vision. AMD doesn't cause pain and doesn't lead to the total loss of sight.

AMD affects the vision you use when you're looking straight at something, for example when you're reading, looking at photos or watching television. Your central vision can become distorted or blurry and over time, a dark or missing area may appear in the centre of your vision.

# Why have I developed AMD?

The exact cause for AMD is not known. Some things are thought to make it more likely you'll develop AMD, such as:

- Your age: AMD develops as people grow older and while it's most often seen in those over 65 years old, it can also develop in people who are in their forties and fifties
- Your gender: More women have AMD than men, probably because women tend to live longer than men
- Your genes: Certain genes have been found 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. However, not all AMD is thought to be inherited
- Your lifestyle: High blood pressure and lack of exercise have been identified as possible risk factors for AMD. Having a higher body mass index (BMI) of over 30 kg/m<sup>2</sup> does increase your risk of AMD progression. Therefore, maintaining a healthy weight and living an active lifestyle with regular exercise is recommended

- Smoking: Smoking greatly increases your risk of developing AMD – you can reduce this risk if you stop smoking
- Sunlight: Some studies have suggested 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. However, 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 diet high in fat and low in omega 3 and 6, vitamins and minerals have also been associated with AMD. At the moment, there isn't an agreement on how much of a risk factor diet can be.

"I'm always losing my glasses, my eyesight isn't very good now. I eat well – lots of oily fish and green vegetables. I do feel what you eat is important, not to have too much junk food or sugar and to go outside for fresh air. I'm lucky as I live by the beach, so can go for long walks for miles and not see many people. I think it's important to have good light, I also practice yoga and relaxation." **Carolyn Milbank**  In general, protecting your eyes from the sun, eating a balanced diet with plenty of fresh fruit and vegetables, stopping smoking, keeping active and maintaining a healthy weight and blood pressure may all help to keep your eyes as healthy as possible.

Unfortunately, because the exact cause of AMD is not known, you may develop AMD even if you don't have any of these risk factors.



# What are the symptoms and when should I seek help?

Everyone can have slightly different symptoms, but usually the first thing you'll notice is that it's harder to see detail, such as small print. You may find that your vision has a small, blurred area in the centre. Straight lines may look distorted or wavy, or like there's a little bump in them. You may also find that you're more sensitive to bright light.

You should have your eyes tested by an optometrist (also known as an optician) if you experience any of these in one or both eyes:

- You have difficulty reading small print despite wearing reading glasses
- Straight lines start to look wavy or distorted. You can check this by looking at door and window frames, or tiles in your home
- Your vision isn't as clear as it used to be.

Your optometrist can measure any changes in your vision and look at the back of your eye. They may see 'drusen' when they examine your retina. Drusen are small deposits under the retina, which they can see as yellow dots. Drusen can be present as a normal part of ageing and are not always a sign that someone has AMD. Your optometrist might say you have early AMD if you have a few medium sized drusen in one or both your eyes.

If your optometrist finds any changes to your macula or any cause for concern, they'll send a letter to your GP or sometimes directly to the hospital. Based on your optometrist's letter, the hospital will judge how quickly you need to be seen by the ophthalmologist (also known as a hospital eye doctor) and arrange an appointment for you.

# What is the macula?

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

When light enters your eye, it is focused onto your retina at the back of your eye. The retina has several 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 contains a few million specialised photoreceptor cells called cone cells. These cone cells work best in bright light and allow you to see fine detail for activities like reading and writing and recognising colours. When someone develops AMD, the cone cells in the macular area become damaged and stop working as well as they should.

The peripheral retina is further away from the central macula. It is mostly made up of the other type of photoreceptors called rod cells. They allow us to see when light is dim and provide peripheral vision (also known as side vision) outside of the main line of sight. AMD does not affect the peripheral retina, meaning that side vision remains good. AMD does not cause you to lose all your sight.



# What are the different types of AMD?

AMD can be further classified as 'early', 'intermediate' and 'late'. In early and intermediate AMD, there may be no vision loss and there may be no symptoms. Early and intermediate AMD are often picked up in a routine eye examination by the optometrist due to the presence of drusen at the macular area.

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

## **Dry AMD**

This is also known as geographic atrophy, where there is central vision loss because all the cells at the macula have degenerated so much that they no longer work. It is the more common type of AMD.

Dry AMD develops very slowly and causes a gradual change in your central vision. It usually takes a long time – sometimes years, to get to its final stage. At its worst, dry AMD causes a dark or missing area in the centre of your vision in both of your eyes. It doesn't affect your peripheral vision, so it never leads to total blindness. Some people with this stage of AMD may go on to develop the wet form of AMD.

## Wet AMD

About 10 to 15 per cent of people who develop late AMD have wet AMD, often having had dry AMD to begin with. You develop wet AMD when the cells of the macula stop working correctly and your body starts growing new blood vessels to fix the problem. As these blood vessels grow in the wrong place, they cause swelling and bleeding underneath the macula – this is why it's called "wet" AMD. This new blood vessel growth is medically known as neo-vascularisation. It causes more damage to your macula and eventually leads to scarring. Both the new blood vessels and the scarring can damage your central vision.

Wet AMD can develop very quickly, causing serious changes to your central vision in a short period of time, over days or weeks. Treatment is 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 they cause is usually permanent. Wet AMD doesn't affect your peripheral vision, so it doesn't lead to total blindness.

## **Both types of late AMD**

Wet and dry AMD have a few things in common. They usually affect both your eyes, though sometimes one eye may be affected long before the other. If you have AMD in one eye only, the other eye may compensate so you may not notice the blurring of vision in the early stages. Both wet and dry AMD only affect your central vision and won't affect your peripheral vision. Neither type of AMD will cause you to lose all your sight.

Some people diagnosed with dry AMD may find that, with time, new blood vessels grow, and they develop wet AMD. If you have dry AMD and you notice a sudden change in either of your eyes, you should let the hospital or optometrist know as soon as possible. This is because dry AMD can develop into wet AMD, and if this happens, sightsaving treatment may be possible.

Some people may have wet AMD in one eye and dry AMD in the other which doesn't develop into wet AMD. Most people, however, have the same type of AMD in both eyes. People who've had wet AMD for a long time that has caused 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 wouldn't help.

Most people with AMD keep their peripheral vision, which means that you should still be able to get around on your own and make use of this vision.

Some people who have lost a lot of vision because of AMD or another eye condition may experience visual hallucinations – they may see shapes, colours or figures that aren't really there. This condition is known as Charles Bonnet Syndrome (CBS). CBS hallucinations are silent and do not involve any of the other senses. You cannot hear, smell, or touch the images and people are aware that what they are seeing isn't real. You can find more information on CBS on our website, or by calling our Helpline.

# How is AMD diagnosed?

If you have dry AMD, you'll normally be monitored by your optometrist. They may ask you to return for regular appointments so they can monitor any changes to your AMD and to your sight.

Some optometrists may take a photograph of your retina, which can help to monitor any changes to your macula over time. Your optometrist may also be able to take a detailed scan of your macula using OCT (optical coherence tomography) which can detect changes to your macula more reliably and at an earlier stage. Your optometrist should be able to let you know how often they would like to see you for an appointment.

Between your appointments, you may be advised to monitor your vision at home regularly by closing one eye at a time and looking at window/ door frames or tiles to see if there is any distortion. Some optometrists may provide you with a paper-based test called an Amsler grid along with instructions to help you monitor your vision at home. An Amsler grid is made up of horizontal and vertical lines with a dot in the centre of the grid that you use as a focal point when checking for any distortion. This test is done while wearing your reading glasses (ideally not varifocal glasses). If at any time between appointments, you feel like your vision has deteriorated, you should let your optometrist know straight away.

Your optometrist may refer you to the hospital to see an ophthalmologist if they are concerned about your dry AMD possibly starting to convert to wet AMD, or if your vision has worsened and you may be able to be certified with sight loss.

If your optometrist suspects that you have wet AMD, then you'll be referred quickly to an ophthalmologist at the hospital. You should expect to be seen by the eye hospital within two weeks if your optometrist believes you have developed wet AMD.

"I don't have any treatment, I'm on a dietary supplement to hopefully slow it all down and have been for about ten years. The idea is that I go to the opticians every so often and if anything is untoward, they refer me to the hospital." Steve Cottrell



When you are seen at the hospital for AMD, your vision will be checked by reading the eye chart and your pupils will be dilated (made bigger) by putting in eye drops. This allows the ophthalmologist to look at your macula at the back of the eye and spot any changes that AMD may have caused. Your pupils are dilated with drops that take about 30 minutes to work. The drops will make you sensitive to light and cause your vision to become blurry, but they allow the ophthalmologist to see the inside of your eye more easily. Although the light used to examine your eyes is very bright, it cannot damage your eye. The effect of the drops usually wears off after three to six hours, although sometimes, it may take until the next morning for your vision to feel normal again. It is not safe to drive until the effects have worn off, so you should not drive yourself to your appointment.

Sometimes the ophthalmologist can tell you whether you have AMD from just looking at your macula. However, you may need a test called optical coherence tomography (OCT), and sometimes, a fluorescein angiogram, to confirm you have AMD or to find out whether you have wet or dry AMD.

## Optical coherence tomography (OCT) and Optical Coherence Tomography Angiography (OCTA)

An OCT is a scanner that provides a cross section image of the retina, showing the layers of the retina and giving a detailed picture of your macula. This helps the ophthalmologist to find out how much fluid is in your macula, to see if your macula is thicker than it should be and to check for any signs of changes.

You'll need to have some drops to dilate your pupil before the scan. You'll then be asked to sit in front of the OCT machine, look at a target and keep still while your eye is scanned by the machine. It's a painless and very quick procedure, which doesn't involve any physical contact with your eye, and it only takes a couple of minutes to complete.

OCTA is a similar test to an OCT scan and allows your doctor to detect unhealthy blood vessels in the retina without the need to use a dye such as with the fluorescein angiogram.

## Fluorescein angiogram

The network of blood vessels underneath your retina can't usually be seen by looking at the back of your eye. The ophthalmologist can see the damage to your retina, but they can't see the detail of the blood vessels. A fluorescein angiogram is a way of taking pictures of these blood vessels, which allows the ophthalmologist to see if there are any changes to them which could be causing problems.

The test is carried out using a yellow dye called fluorescein that is injected into your arm. The fluorescein travels through your blood stream to your eye. This usually isn't painful, but it can make some people feel nauseous or be sick. This dye makes the blood vessels in your eye show up on the pictures taken.

When the dye has been injected, you'll be asked to look at a special machine. The machine takes pictures of the back of your eye as the dye is travelling through the blood vessels. There will be a series of flashing lights as the pictures are taken, but the test isn't painful. It usually takes about 10 minutes.

It's a very common test, and very few people have any major side effects – the most serious but rare side effect is an allergic reaction to the fluorescein used. More commonly, the injection may make your skin look slightly yellow from the dye for 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 it often fades more quickly than that. Some people are dazzled for a while from the flashing lights, but most people find the test straightforward.

These tests show the blood flow through your vessels and will reveal any bleeding, as well as the type and location of the bleed in your eye. It will also help the ophthalmologist to determine which type of AMD you have, and to decide if any treatment is possible.



# What is the treatment for AMD?

Early or intermediate AMD has no treatment. There's some evidence that high doses of vitamin A, C, E, the minerals zinc and copper and the micronutrient lutein when taken together may help slow down the progression of intermediate AMD, particularly if wet AMD has already caused vision changes in one eye. However, there is no evidence that taking high doses of these vitamins can prevent you from developing AMD in the first place.

There are several vitamin products available which have been designed for people with dry AMD and you can usually buy these over the counter or from your pharmacist. A balanced diet with plenty of fresh fruit and vegetables is good for your general health and may also help your eye health.

You can find more information about antioxidant vitamins for AMD on our website or by calling our Helpline for a factsheet.

# **Treating Late AMD**

Unfortunately, at the moment there is no way to treat late dry AMD. Although research is going on to try and find out why the cells of the macula stop working, this has yet to lead to a proven treatment.

# **Treating wet AMD**

## Anti-VEGF

The treatment available on the NHS for wet AMD is a group of medications called anti-vascular endothelial growth factor (anti-VEGF) drugs. As new blood vessels form in your eye, your body produces a chemical which encourages further new blood vessel growth. Anti-VEGF drugs interfere with this chemical and stop the vessels from growing, minimising further damage to your sight.

Anti-VEGF treatments usually have a high success rate, and, in most cases, they stop your sight from getting worse in the short term. In the long term, your vision may gradually worsen even with treatment but much more slowly than those who have not been treated.

## Anti-VEGF procedure

The medication is injected into the vitreous, which is a gel-like substance inside your eye. This is called an intravitreal injection. The injection needs to be given in a sterile way to reduce the risk of infection. You may have the treatment in an operating theatre, though more commonly, it may be given in a room which has been designed for this type of treatment (sometimes called a clean treatment room). Before the injection, you'll be given anaesthetic eye drops to make your eye numb and antiseptic drops to clean the eye and to help prevent you from getting an infection.

The injection shouldn't be painful thanks to the anaesthetic, but your eye may be a little sore after the anaesthetic wears off. There is a slight chance that the pressure inside your eye may rise a little, but it shouldn't cause you any pain or change your vision.

The sight in your treated eye may be blurry because of the treatment, but this should wear off within a day. You may notice a small black circle in the lower part of your vision. This is caused by a small air bubble which will disappear after a few hours. You may also have slight swirls in your vision for a few days following the injection, but this doesn't always happen to everyone. Your eye may water a bit more after the injection and it may be slightly red or irritated. This normally gets better after a few days. If your eye becomes very painful or very red and hot to touch or if you notice any worsening of your vision, then 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 (where the retina at the back of the eye peels away from its normal position) and eye infections. These complications are rare, happening to less than one per cent of people having the injections. There are treatments available if any of these complications happen to you. If you're worried about your eye after the injection, then let your hospital know as soon as possible.



### Frequency of anti-VEGF treatment

Normally, a course of three injections, one a month for three months, is given to start with known as a 'loading dose'. Once you've had these three injections, your eyes will be checked at the hospital every four to eight weeks. You may be given further injections if your ophthalmologist thinks they are needed. Most people will need to have more injections after the first three.

There are different types of anti-VEGF medications, and each may require different monitoring schedules. Monitoring and treatment can go on for several years depending on your level of vision and whether you still have active wet AMD. Your ophthalmologist will let you know how often you need to have your eyes checked.

"I had six sessions of injections, these seemed to improve my eyesight, so I was pleased and felt confident. I found the treatment okay, and then I had a break for six months, when I just had check-ups. At this point I needed to have treatment in both eyes. I was going for treatment every month and I had nine sessions of injections. I still felt it helped, as the injections stabilised the condition." **Carolyn Milbank** 

## Biosimilar

You may be offered a type of anti VEGF medicine that has only recently become available called biosimilar anti VEGF medicine. The biosimilar medicine is very similar to the known anti VEGF drugs that are currently available on the NHS. It works the same way, is administered the same way, is just as safe and is equally effective. Biosimilars are already in wide use in the NHS for other conditions but the opportunity to use them in the treatment of wet AMD has only recently become available due to the patent protection expiring.

If you're worried or frightened of having injections into your eye, it may help to talk to someone who has already experienced the injections. The Macular Society can put you in touch with a 'treatment buddy' who can support people who are anxious about their injections and offer information and reassurance. More information can be found on the Macular Society website; their details are listed at the end of this information.

You can find more information about anti-VEGF treatment on our website or by calling our Helpline for a factsheet.

# What type of research is being done into AMD?

There are a number of different research approaches that are being investigated into late AMD, both dry AMD and wet AMD. Some of these include stem cell transplant where the damaged cells are replaced with healthy ones, gene therapy where your own eye can make its own anti VEGF, drugs that can protect retinal cells, and eye drops are some areas of research into both forms of the condition.

In wet AMD, trials are ongoing into looking at ways to extend the effectiveness of anti-VEGF medication and reducing frequency of injections as well as visits to the hospital. These include anti-VEGF drugs that are effective for a longer period, thereby reducing the frequency of injections; implants containing anti-VEGF drug that can be placed in the eye which are released over a longer period; delivery systems that are implanted into the eye releasing anti-VEGF and refilled as necessary, among others.

# What help is available?

# Making the most of your sight

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.

We have a series of leaflets with helpful information on living with sight loss, including how to make the most of your sight. You can find out more about our range of titles by calling our Helpline.

## The low vision assessment

Ask your ophthalmologist, optometrist, or GP about low vision aids, such as optical aids (hand and stand magnifiers, magnifying reading glasses, telescopes, etc) and ask for a referral to your local low vision service. Your low vision service or the Macular Society can also provide eccentric viewing training. Eccentric viewing is a technique of reading using an area in your peripheral vision when you have central vision loss. There is further information on low vision and eccentric training on our website or from the Macular Society.

# Assistive technology

There is also technology available that can help with low vision. Many smart phones and tablets are already equipped with in-built software that can enable people with low vision to access information. There are also specific apps and low vision devices that may help too, as well as computer software programmes that can be installed. If you would like to find out more about the assistive technology that is available and how it can help you, our Technology for Life team advisors would be happy to chat to you. You can get in touch with this team by calling our Helpline.

"Reading ordinary print is difficult, but I have got a Kindle that I can read large print on. I can also use a computer, using larger text and I use a magnifying glass. But I rely a lot on Talking Books from RNIB." Steve Cottrell

## Registration

You should also ask your ophthalmologist whether you're eligible to register as sight impaired (partially sighted) or severely sight impaired (blind). Registration can act as your passport to expert help and sometimes to financial concessions. Even if you aren't registered, a lot of this support is still available to you.

#### Social services support

Local social services should be able to give 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.

# Driving

Being diagnosed with AMD does not automatically mean you are no longer able to drive a car. Speak to your optometrist or ophthalmologist about whether you can continue to drive, and if you need to report your eye condition to the Driver and Vehicle Licensing Authority (DVLA). You're required by law to tell DVLA about your eye condition if it affects both eyes or if it only affects one eye and the vision in your other eye is below the minimum standards of vision for driving.

"I can still do things, I get up and go to work, and continue to do all the things that I want to. I know what my boundaries are, but that doesn't mean that I'm not willing to push them every now and then, I know I have to be sensible." Liz Wick

# Coping

It's completely natural to be upset when you've been diagnosed with AMD and it's normal to find yourself worrying about the future and how you will manage with a change in your vision.

It can sometimes be helpful to talk about these feelings with someone outside of your circle of friends or family. At RNIB, we can help with our telephone Helpline and our Sight Loss Counselling team. Your GP or social worker may also find a counsellor for you if you feel this might help.

Your eye clinic may also have a sight loss adviser (also known as an Eye Care Liaison Officer or ECLO), who can be on hand to provide you with further practical and emotional support about your eye condition.

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 your experience with people who may have had similar experiences.

# **Other Sources of Support**

#### Macular Society PO Box 1870 Andover SP10 9AD 0300 3030 111 macularsociety.org

#### Driver and Vehicle Licensing Authority (DVLA) Drivers' Medical Enquiries Swansea SA99 1TU 0300 790 6806 dvla.gov.uk

# Further help and support

# **RNIB** Helpline

If you need someone who understands sight loss, call our Helpline on **0303 123 9999**, say **"Alexa, call RNIB Helpline"** to an Alexa-enabled device, or email **helpline@rnib.org.uk**. Our opening hours are weekdays from 8am – 8pm and Saturdays from 9am – 1pm.

# **Connect with others**

Meet or connect with others who are blind or partially sighted online, by phone or in your community to share interests, experiences and support for each other. From book clubs and social groups to sport and volunteering, our friendly, helpful and knowledgeable team can link you up with opportunities to suit you. **Visit rnib.org.uk/connect** or call **0303 123 9999**.

## About The Royal College of Ophthalmologists

The Royal College of Ophthalmologists champions excellence in the practice of ophthalmology and is the only professional membership body for medically qualified ophthalmologists.

The College is unable to offer direct advice to patients. If you're concerned about the health of your eyes, you should seek medical advice from your GP or ophthalmologist.

## rcophth.ac.uk

# **RNIB Booklet Series**

# About the Starting Out series

Essential information about living with sight loss. Titles include:

- Benefits, Concessions and Registration
- Emotional Support
- Help from Social Services
- Making the Most of Your Sight

# About the Confident Living Series

Information to build confidence and independence. Titles include:

- Reading
- Shopping
- Technology
- Travel

# About the Understanding Series

More about your eye condition. Titles include:

- Age Related Macular Degeneration
- Cataracts
- Charles Bonnet Syndrome
- Dry Eye
- Eye Conditions Related to Diabetes
- Glaucoma
- Nystagmus
- Retinal Detachment
- Inherited Retinal Dystrophies including Retinitis Pigmentosa
- Posterior Vitreous Detachment

For audio, print or braille versions of these booklets please contact our Helpline or visit **shop.rnib.org.uk** 

For a list of information sources used in these titles and to provide feedback on the Starting Out and Confident Living Series, email **ckit@rnib.org.uk**. To provide feedback on the Understanding Series, email **eyehealth@rnib.org.uk**.

# **Information sources**

RNIB and The Royal College of Ophthalmologists do all we can to ensure that the information we supply is accurate, up to date and in line with the latest research and expertise.

This publication uses information from:

- The Royal College of Ophthalmologists' guidelines for treatment
- clinical research and studies obtained through literature reviews
- specific support groups for individual conditions
- medical textbooks
- RNIB publications and research.

For a full list of references and information sources used in the compilation of this publication, email **eyehealth@rnib.org.uk** 

# We value your feedback

You can help us improve our information by letting us know what you think about it. Is this booklet useful, easy to read and understand? Is it detailed enough or is there anything missing?

How could we improve it? We would also like your views on the pictures and diagrams, are they appropriate, helpful and are there places where a diagram might have helped?

Send your comments to us by emailing us at **eyehealth@rnib.org.uk** or by writing to the Eye Health Information Service, RNIB, The Grimaldi Building, 154A Pentonville Road, London, N1 1JE.



# rnib.org.uk

# **RNIB Helpline**

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