

Understanding age-related macular degeneration



supporting blind and
partially sighted people



RCOphth

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.

Other titles in the series include:

Understanding cataracts

Understanding eye conditions related to diabetes

Understanding glaucoma

Understanding nystagmus

Understanding retinal detachment

Understanding retinitis pigmentosa

All these leaflets are available in audio, print and braille formats. To order please contact our Helpline on 0303 123 9999 (all calls charged at local rate), email helpline@rnib.org.uk or visit rnib.org.uk/shop.

In 2010, three new titles are being added to the series:

Understanding Charles Bonnet syndrome

Understanding dry eye

Understanding posterior vitreous detachment

Visit rnib.org.uk/shop for more details.

Contents

- About age-related macular degeneration 4
- Causes 5
- Symptoms 7
- Types of AMD 10
- Changes in your vision 13
- Hospital eye examination 14
- Treatment 17
- Coping 22
- Useful contacts 24

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, which is 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're looking directly at something, for example when you're 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 forties and fifties
- your gender: more women have AMD than men, probably because women tend to live longer than men
- 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. 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, because the exact cause of AMD is not known you may develop this condition even if you don't have any of these 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 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 the 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.

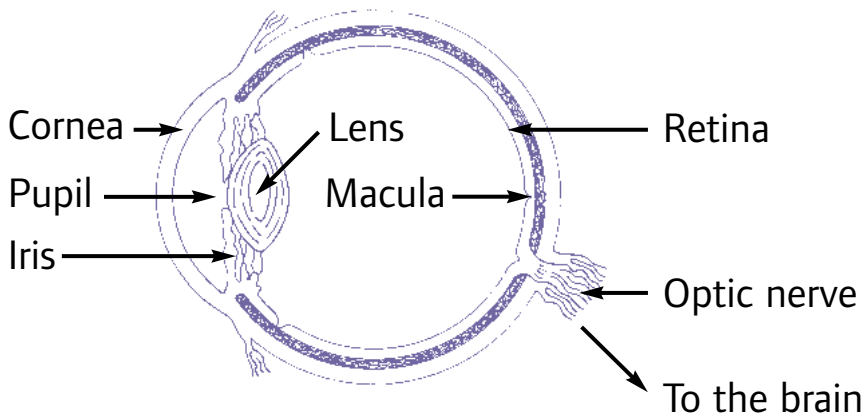
Photoreceptors are cells which are sensitive to light.

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) 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.

A cross section of the eye



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 (hospital eye doctor) 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 worse, 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 per cent 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 damages 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 is 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. 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 suddenly changes you should always have this checked by your ophthalmologist (hospital eye doctor).

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 wouldn't 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 everyday.

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 test with an optometrist (optician). 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 type AMD can develop into wet AMD and if this happens sight saving treatment may be possible.

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.

Hospital eye examination

To find out whether you have AMD and what type of AMD you have, the ophthalmologist will have to perform a number of tests.

At the hospital, your vision will be checked and your pupils dilated to allow the ophthalmologist to look at the 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 effects of the drop usually wear off in about six hours though sometimes it can happen overnight. It is not safe to drive until the affects 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 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'll experience a series of flashing lights as the pictures are taken, but the test isn't painful. It usually takes about 10 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 and it soon passes into your urine, which 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 the blood vessels may scar the retina and this scarring cannot be treated.

At the moment there is no treatment for dry AMD. This is because dry AMD doesn't involve new blood vessels growing. Although research is continuing to find a treatment for dry AMD, nothing is available yet.

Treatments for wet AMD – Anti-VEGF treatment

The most recent treatment available on the NHS for wet AMD is with an anti-vascular endothelial growth factor (anti-VEGF) drug, called Lucentis. As new blood vessels form in your eye, your body produces a chemical which 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.

Lucentis has to be injected into 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 shouldn't 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 one per cent 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 Lucentis. Normally a course of three monthly injections is given to start with and then you should be monitored every four weeks to check that the treatment is working. Many people go on to have more injections after these initial three.

Usually anti-VEGF treatments have a high success rate and in most people they stop sight getting worse. About 40 per cent of people also see an improvement in their vision.

RNIB has more information available on this treatment if you check our website or call our Helpline on 0303 123 9999.

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. 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.

Treating dry AMD

Unfortunately at the moment there is no way to treat dry AMD. Although research is going on to try and find out why the cells of the macula stop working, this hasn't yet lead to a treatment.

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 because of AMD in one eye.

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.

You can find more information about nutrition and the eye on our website or by calling our Helpline on 0303 123 9999.

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. RNIB can help, with our telephone Helpline and our emotional support service. Your GP or social worker may also be able to help you find a counsellor if you think this would help you.

The Macular Disease 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 that they can use everyday and using your vision won't make your AMD worse.

There are lots of things that you can do to make the most of the vision you have. This may mean making things bigger, using brighter lighting or using colour to make things easier to see. Ask your ophthalmologist, optician or GP to refer you to your local low vision service, which can provide you with magnifiers to help with reading, advice on lighting and tips on how to make the most of your peripheral vision for everyday tasks to help make the most of your sight.

Local social services should also 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.

Our Helpline can also give you information about the low vision services available, and our website offers lots of practical information about adapting to changes in your vision and products that make everyday tasks easier.

Useful contacts

Royal National Institute of Blind People

105 Judd Street, London WC1H 9NE

t: 0303 123 9999

helpline@rnib.org.uk

www.rnib.org.uk

Macular Disease Society

PO Box 1870, Andover SP10 9AD

t: 0845 241 2041

www.maculardisease.org

Royal College of Ophthalmologists

17 Cornwall Terrace, London NW1 4QW

t: 020 7935 0702

www.rcophth.ac.uk

Driver and Vehicle Licensing Agency (DVLA)

Drivers Customer Services (DCS)

Correspondence Team DVLA

Swansea SA6 7JL

t: 0300 790 6801

www.dvla.gov.uk



We value your feedback

Please help us improve the information we supply by sharing your comments on this publication.

Please complete the form and return to:

FREEPOST RSCB-GJHJ-HLXG

RNIB Publishing

105 Judd Street

London WC1H 9NE

(There is no need to use a stamp.)

Alternatively, you can email publishing@rnib.org.uk.

1. Where did you receive your copy of this leaflet?

2. Did you find that the information was presented in a way that was easy to read and easy to understand? Please give details of anything you feel could be improved.

3. Is there any information you would have found helpful, or were expecting to find, that was missing?

4. Further comments. Please use the space below for any other comments you have on the information in this leaflet or any aspect of your contact with RNIB.

Information sources

We 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.

The information used in RNIB's Understanding series of leaflets uses:

- Royal College of Ophthalmologists guidelines for treatment
- clinical research and studies obtained through literature reviews
- information published by specific support groups for individual conditions
- information from text books
- information from RNIB publications and research.

For a full list of references and information sources used in the compilation of this leaflet email publishing@rnib.org.uk or call 020 7391 2006.

RNIB Helpline

0303 123 9999

helpline@rnib.org.uk

If you, or someone you know, is living with sight loss, we're here to help.

This leaflet has been produced jointly by the Royal College of Ophthalmologists and Royal National Institute of Blind People.

© RNIB and RCOphth
RNIB reg charity no. 226227
RCOphth reg charity no. 299872



Printed August 2010. Review date September 2011.

ISBN: 978 1 85878 697 1

PR10006