

A guide to Age-related Macular Degeneration

www.FightingBlindness.ie



**FIGHTING
BLINDNESS**
Cure. Support. Empower.

Fighting Blindness: Working to Cure, Support and Empower

Fighting Blindness is focused on helping individuals and families who are affected by sight loss.

Fighting Blindness was set up in 1983 by families affected by retinitis pigmentosa (RP) coming together to support each other. Since then the organisation has evolved to work with many more conditions, including age-related macular degeneration, by investing in vital vision research and expanding services to meet the growing needs of the sight loss community.

For more on how we can help you, please visit www.FightingBlindness.ie or call the team on 01 6789 004.

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About Age-related Macular Degeneration

Age-related macular degeneration is a painless eye condition often referred to as AMD or macular degeneration. AMD is the most common cause of sight loss in people over the age of 50. It affects the macula, a tiny area located at the back of your eye.

The macula is responsible for your detailed and central vision. In AMD, the macula does not function as well as it used to. As a result, you may find your central vision becoming blurry or distorted and colours beginning to fade. Over time, it may cause dark spots to appear in the centre of your visual field.

Therefore, AMD can lead to difficulties with every day tasks and activities such as reading, driving and recognising faces. It is important to remember that your peripheral vision (vision off to the side) is usually not affected and the severity of the condition varies from person to person.

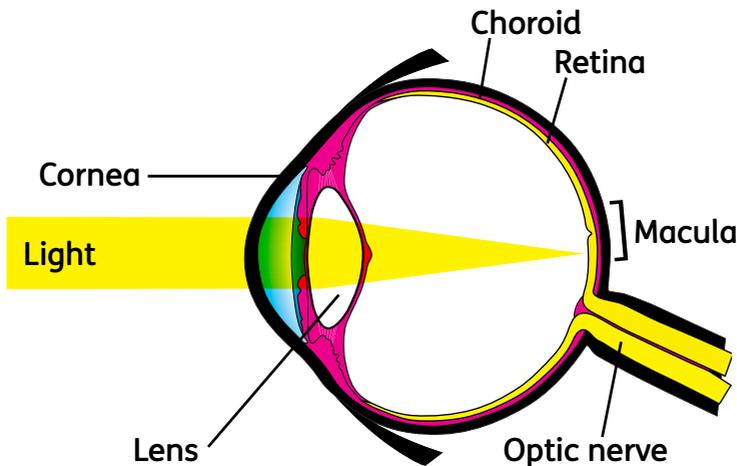
1 in 10 people over the age of 50 will be affected by AMD

The Retina

The retina is an important tissue that lines the back of your eye. When light enters your eye, it is focused onto the retina. Here, special light-sensitive cells called photoreceptor cells, detect this light and send signals to the brain, which interprets them as images.

At the very centre of your retina is a tiny area called the macula. The macula is only 5 mm wide, which is equal to the size of a pinhead. It has a very dense concentration of a type of photoreceptor cell called a cone cell. Cone cells work best in bright light and allow you to see in fine detail, recognise colours and see directly in front of you.

Cross-section of the eye



*Image courtesy of the Macular Society

Outside the area of the macula is the peripheral retina, which is composed mostly of another type of photoreceptor cell called a rod cell. Rod cells work best in dim and low light and allow for your peripheral vision.

Located next to the retina is a pigmented layer of cells called the Retinal Pigment Epithelium (RPE). The RPE serves as a pass-through between the light-sensitive photoreceptors in the retina and a layer of blood vessels, called the choroid. The RPE's role is to provide essential nutrition and waste removal for the photoreceptor cells.

In AMD, cone photoreceptor cells within the macula and the RPE layer do not work as well as they should which can then affect the vision you use when looking directly at something, for example when you're reading or using your mobile phone.

The macula is yellow in colour because it contains a pigment that is also found in coloured fruits and vegetables

Types of AMD

There are two main types of AMD that can affect your sight - Dry AMD and Wet AMD. These names are not related to having dry or watery eyes but instead based on what happens inside your eye. Your eye care professional can tell you which type of AMD you have.

Dry AMD

Dry AMD is an early and more common form of AMD. It develops very slowly and can cause a gradual change in your central vision.

As we get older, the retina begins to show signs of aging. Changes in its pigmentation may take place while yellow deposits called drusen may form and accumulate. Drusen are often found in the eyes of older people, but an increase in the size and number underneath the retina can be an early sign of AMD. Over time, these drusen deposits lead to deterioration of the macula and the loss of RPE and photoreceptor cells. You may find that colours begin to fade or your central vision becomes distorted or blurry. However, your peripheral vision will not be affected.

Progression of Dry AMD varies from person to person, but in most people it develops over many months or even years.

The early stages of Dry AMD have no symptoms and can only be detected through an eye test. This is why regular eye tests by an eye health care professional is so important.

If you have Dry AMD and notice a sudden change in your eyes, you should contact your eye doctor straight away. This is because, in some cases, Dry AMD can progress into an advanced form of AMD. However, not everyone with early AMD will develop advanced AMD.

Geographic Atrophy (GA)

Some people with advanced or late-stage Dry AMD may develop geographic atrophy (GA). GA occurs when photoreceptor cells within regions of the retina start to die or waste away (known as atrophy) and are not replaced. When your eye care professional is examining your eye, sometimes these regions of atrophy look like a map, hence the term geographic atrophy.

Regions of atrophy can cause blank spots to appear in your central vision. For example when reading, one or two letters may be 'missing' from a word. In some cases, the region of atrophy may extend to a larger area of the eye over a number of years and result in a significant loss of vision. You should however still retain peripheral vision.

Wet AMD

Wet AMD is a less common form of AMD but can develop more quickly and cause a rapid loss of vision. Because Dry AMD can sometimes progress into Wet AMD, you may also find Wet AMD referred to as Late or Advanced AMD.

Wet AMD occurs when cells within the macula stop working and your body starts growing new blood vessels to fix the problem. Your eye doctor (ophthalmologist) may refer to this new blood vessel growth as neo-vascularisation. As these new blood vessels grow in the wrong place, they cause swelling and bleeding underneath the macula, hence the name Wet AMD.

This leads to eventual scarring of the macula and can result in a sudden change in your central vision such as images appearing distorted, or objects looking smaller than normal. Although Wet AMD can develop quickly, it is treatable. In the majority of cases, if diagnosed and treated early, deterioration in vision can be stopped and some people may even see an improvement.

Around 10-15% of people with Dry AMD go on to develop Wet AMD

Symptoms

AMD can cause changes in your central vision, which can affect your ability to carry out day-to-day activities. Some symptoms you may notice include:

- Straight lines such as door frames appearing wavy or distorted.
- A smudge or shadow appearing in your field of vision.
- Difficulty in reading small print, even with glasses.
- Difficulty in recognising or distinguishing faces.
- Difficulty in seeing different textures or slight contrasts.
- Gaps in your field of vision.
- Poor recognition of colours or colours beginning to fade.
- Decreased levels of vision in low lighting or darkness.
- Glare in bright light.

If you notice any change in your vision, you should make an appointment to see your eye doctor, optometrist or GP as soon as possible.

Diagnosis

To detect the earliest signs of AMD it's recommended that you have an eye examination every one or two years by an optometrist or an eye doctor. This is particularly encouraged if you are over 50 years of age, if you have a family history of AMD, or both.

The following tests may take place during your eye examination:

- A photo may be taken of the back of your eye to look for any unusual features associated with AMD.
- You may be asked to look at an Amsler Grid. You will find an Amsler Grid and instructions for using it on page 26 and 27 of this booklet.
- You will be asked to read letters off an eye chart (Snellen chart).
- They may shine a small light into the back of your eye to detect presence of drusen, yellow retinal deposits which are often a feature of Dry AMD.

If it is suspected that you have AMD, you will be referred to an eye doctor for a thorough diagnosis and follow-up.

Early diagnosis can result in the effective treatment of AMD and prevention of sight loss.

An eye doctor (ophthalmologist) will perform a detailed eye examination using a variety of tests to help diagnose AMD. These tests are also used to monitor progression of AMD over time.

Your eye doctor may use eye drops to dilate your pupils. This allows the doctor to see the back of your eye clearly. The drops may make your vision blurred for a short time after the test so it is important to consider taking someone with you. You may also need to wear sunglasses until the eye drops wear off as you may become more sensitive to sunlight.

Your eye doctor may also perform non-invasive imaging tests such as Optical Coherence Tomography (OCT). OCT takes a cross-section picture of your retina and allows your eye doctor to study each layer of the retina in more detail. Measuring the layers helps with diagnosis but also provides guidance to treatment options, if applicable.

To assist with a diagnosis of Wet AMD, your eye doctor may perform a Fluorescein dye angiography. A harmless dye is injected into a vein in your arm that travels to the eye. This dye highlights the blood vessels in the retina so they can be photographed and studied in detail.

It is important to note that all of these tests are safe and carried out with care.

Cause

The exact cause of AMD is unknown. However, extensive research efforts over the last decade are playing an important role in uncovering some of the clues as to what may be causing the disease.

Some risk factors that are believed to increase your chances of developing AMD are as follows:

- Being over the age of 50
- Family history of AMD
- Fair skin and light eyes
- Exposure to prolonged periods of sunlight
- Smoking or exposure to second-hand smoke
- Being overweight
- Having a poor diet
- High blood pressure

Unfortunately, because the exact causes of AMD are not yet known, you may develop AMD even in the absence of these risk factors.

However, there are simple steps which you can take today to help protect your sight. Many of these choices are part of living a healthy lifestyle. Please see the 'Living with AMD' section on page 20 for more information.

Treatments

Currently, there are no medical treatments available for Dry AMD or GA, but research efforts are on-going to develop therapies to prevent or treat these conditions. Wet AMD, on the other hand, can be treated if diagnosed early.

Supplementation and Lifestyle

Age-Related Disease Studies (AREDS1 and AREDS2) have shown that a combination of vitamins and antioxidants may help reduce the risk of progression of early AMD to late-stage AMD. Supplements containing vitamins C and E, zinc & copper, and lutein and zeaxanthin are recommended. To find what supplements may work best for you and your condition, speak to your eye doctor. In addition, your eye care professional will suggest lifestyle changes that may help slow the progression of AMD, such as stopping smoking and eating a healthy diet.

Anti-VEGF Drugs for Wet AMD

Treatment for Wet AMD is most often through a series of injections into your eye using a drug called anti-VEGF (anti-vascular endothelial growth factor). This works by reducing the growth of new blood vessels. Response to treatment is usually better in the early stages of Wet AMD, although even later stages

can be stabilised. In some cases, individuals may notice improvements in their vision. However, if the damage has been left for a long time and scarring has already taken place, these treatments may not work well.

If suitable for anti-VEGF treatment, you will usually start by having three injections once a month; this is known as a loading dose. After that, your eye doctor will monitor your sight and determine how well you have responded to treatment. Further injections will be administered if required. Frequency of injections and time scale between appointments will vary for each person. Your eye doctor will discuss the most suitable treatment plan for you.

Before each injection, an anaesthetic will numb the eye for about half an hour. As the anaesthetic wears off, you may notice some initial discomfort. If you experience any significant pain after the injection, please contact your clinic.

Research

There are many layers and approaches to AMD research with efforts focused on enhanced understanding of disease, improved early diagnosis and the development of therapies that have the potential to prevent, delay or treat Dry and Wet AMD.

Internationally, researchers are trying to understand what causes AMD and why some people are affected and others are not. Since people with a close relative who has AMD may have an increased risk of getting the disease, researchers are closely looking at the role of genetics. Scientists are also investigating the involvement of oxidative stress and inflammation as a potential cause of disease and what part our immune system plays in disease progression.

Another key area of research is looking at ways of preventing the early stages of macular degeneration such as drugs that may slow the build up of toxic material. Neuroprotective compounds are also being investigated to see if they can protect the cells of the retina.

There are also considerable research efforts being made to develop new and effective treatments for all

forms of AMD, some of which are currently in human clinical trial.

These include gene therapeutic approaches or the use of cell replacement therapies that might one day restore lost sight. Researchers are also designing ways to deliver medication to the eye using less invasive methods than current methods.

To learn more about the various areas of AMD research or clinical trials, please visit our website at www.FightingBlindness.ie or scan the QR barcode at the back of this booklet.

Frequently Asked Questions

What is the difference between an optometrist and an eye doctor (ophthalmologist)?

An optometrist provides primary vision care ranging from sight testing and correction of visual changes to the detection of disease.

An ophthalmologist is a medical eye doctor who has undertaken extensive further specialist training and study in matters relating to the human eye. They examine, diagnose and treat diseases and injuries of the eye.

How is a diagnosis of AMD made?

If it is suspected that you have AMD, you will be referred to an eye doctor for a thorough diagnosis and follow-up.

What happens after a diagnosis of AMD?

After making a diagnosis of AMD, your eye doctor will be able to advise what the best course of action is for your particular condition, which will include monitoring, and treatment options, if applicable.

How often should I get my eyes tested?

If you have been diagnosed with AMD, you should have your eyes tested every year or two years, as recommended by your eye doctor.

Questions you may want to ask during your appointment are:

- Do I have the Dry or Wet form of AMD?
- Do I have signs of AMD in both eyes? If not, what steps can I take to protect the unaffected eye?
- Is there a therapy for my condition? If so, how will the therapy treat my condition, how will it be given and how often will I receive it? How much will this therapy cost?
- What lifestyle changes can I make to try and slow the progression of AMD?
- Are there any supplements I can take?
- What should I do if I notice a change in my vision or if my vision gets worse?

Remembering every question you want to ask can be tricky. A good tip is to write down your questions before your appointment.

Will I lose all my vision?

AMD never leads to a complete loss of vision on its own. Most people with AMD will keep their peripheral vision and therefore still be able to continue with most day to day activities. With regards driving, you should always seek advice from your eye doctor.

Living with AMD

This section is designed to provide you with some useful tips on looking after your eyes and little changes that could make day to day activities easier.

Regular Eye Tests

Regular eye examinations are recommended every one or two years as advised by your eye care professional. Even if you have been diagnosed with AMD, you should still have your eyes checked for other conditions which may be treatable.

Healthy Eating

A healthy diet forms part of a healthy lifestyle. Eating a diet low in saturated fats and rich in omega 3 fatty acids (e.g. oily fish, walnuts) is recommended.

Vegetables are important for a healthy diet and more importantly, play a vital role in protecting your eyes.

Green leafy vegetables such as spinach and kale contain antioxidants like vitamins C, E and zinc which are great for your eyes.

Eggs and brightly coloured fruit and vegetables contain nutrients (lutein, zeaxanthin and beta carotene) which help protect the macula. You should aim to eat at least 5 servings of fruit and vegetables per day.

Vitamin Supplementation

Two large studies in the USA, the Age-Related Eye Disease Study (AREDS) 1 and 2 have found that certain nutritional supplements can slow down the progression of AMD in people already showing signs of the condition. Please talk to your GP before taking supplements or making major changes to your diet, especially if you take other medications.

Stop Smoking

Smoking reduces the amount of oxygen in the bloodstream and your eyes are an organ which needs plenty of oxygen to survive and work well.

Exercise

Along with healthy eating, regular exercise is essential for a healthy lifestyle. It is recommended that adults should engage in 150 minutes of medium-level activity every week. This may include activities such as brisk walking, swimming and light jogging.

Wear sunglasses

Wearing sunglasses and a wide-brimmed hat to protect your eyes from the UV light in direct sunlight is a good idea for everyone throughout their life.

Around the home

Having bright, uniform lighting and walls can help brighten up the home environment. Daylight type bulbs

can be helpful in improving lighting. Use bold colours to make it easier to identify objects around the home. You could also put stickers with bumps on them (tactile) or add tape to objects to make them easier to find. Talking devices and utensils may also be available and can be helpful around the home.

Reading and writing

Optometrists and rehabilitation offices can suggest optical devices for reading or writing. For reading, they may suggest magnification devices which can make print look larger and add lighting while you read.

Reading machines make words look bigger and display them on a screen. Small, portable hand-held readers which come with a screen to help with magnification are available. If you enjoy reading newspapers or magazines, it may be possible to obtain large print or audio versions which you can enjoy in your home. You can use large face clocks and watches, large print stickers for keyboards or telephones with large numbers.

Advanced technology

If you use computers, you may find screen magnifiers and voice software useful. Smart phones, which can also come with voice technology, have many apps to help with reading, navigation as well as other tasks.

Useful Resources and Supports

Receiving a diagnosis of AMD can be overwhelming for anyone, but this is not a journey that you have to make alone. The following organisations and resources are available to provide information about AMD, give advice on treatments, and discuss what steps can be taken following a diagnosis:

Fighting Blindness

3rd Floor, 7 Ely Place, Dublin 2

01 6789 004, research@fightingblindness.ie

www.FightingBlindness.ie

Provides information and research news on AMD and other sight loss conditions. The annual Retina Conference gives an opportunity to engage with leading clinicians, researchers, other people affected by sight loss and learn more about AMD.

Insight Counselling Service

3rd Floor, 7 Ely Place, Dublin 2

01 6746 496, insight@fightingblindness.ie

www.FightingBlindness.ie

A professional and confidential counselling service, and peer to peer support groups, for people and families affected by sight loss (Telephone counselling available for those who are unable to travel).

Technology Exchange Club

01 6746 496, insight@fightingblindness.ie

www.FightingBlindness.ie

For people living with different levels of vision loss to meet and help each other to get the best use of assistive technologies. This includes discussions on computers, laptops, phones and other devices.

These meetings are free to attend and held in the Fighting Blindness office on Mondays (11am-1pm) and in Cork City Library most Saturdays (11am and 12:30pm, no meetings on second Saturday of month or on bank-holidays). You can also attend these meetings over the phone.

NCBI (National Council for the Blind in Ireland)

Whitworth Road, Drumcondra, Dublin 9

01 8307 033 or 1850 334 353, info@ncbi.ie

www.ncbi.ie

Provides support and services to people living with sight loss, including emotional support, guidance on living an independent life and assistance with devices and technologies. They also offer employment assistance and have a number of training programmes and activities available.

MIST: Macular Impairment Support and Togetherness

086 730 2009, brenda-323@hotmail.com

<https://mistsupportgroup.wordpress.com/>

A social and peer support group meeting on the last Wednesday of every month in Wynn's Hotel in Dublin city centre. The group organises outings throughout the year including a number of walks. Everyone affected by macular degeneration is welcome.

Other useful websites:

Information on AMD

www.amd.ie

Irish College of Ophthalmologists

www.eyedoctors.ie

Macular Society

www.macularsociety.org

Retina International

<http://retina-amd.org/menu/eye-disease-amd/>

How to test with the Amsler Grid

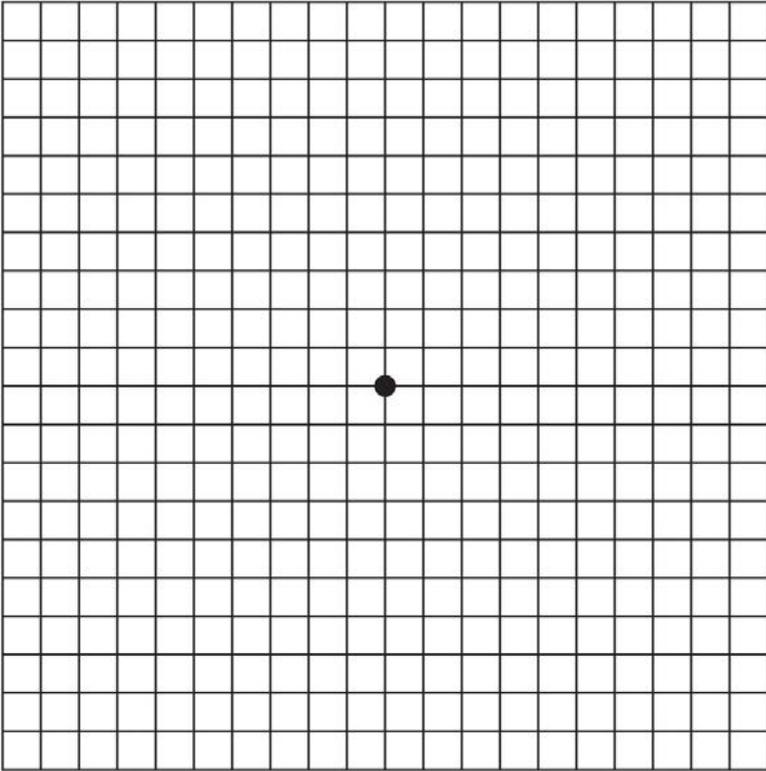
- Hold the grid at reading distance, about 12 inches (30cm) away from your face.
- If you wear reading glasses, leave them on. Do not take the test while wearing varifocal or distance glasses.
- Cover one eye and focus on the centre dot.
- Make sure you can see all four corners of the grid.
- If the lines appear missing or wavy, you may have AMD. Contact your doctor immediately.

If you have any questions about AMD the Fighting Blindness team are here to help.

While we cannot provide specific medical advice, we are happy to share general information, research news and resources.

Contact Fighting Blindness on 01 6789 004 or visit www.FightingBlindness.ie

Amsler Grid



If you notice any wavy or distorted lines or any blurry or dark spots in your vision, you should have your eyes checked by an eye care professional.

Acknowledgements

In designing this patient booklet, we received guidance from members of the public living with AMD to ensure all relevant content and supports were included.

Thank you to members of the MIST group who provided insight and feedback into ensuring this booklet is designed in a way that is most accessible and user friendly. This is a prime example of public and patient involvement in research.

Fighting Blindness also consulted with a number of ophthalmologists and researchers ensuring that the information provided is of the highest quality and most relevant to those reading it. Thank you also to the clinicians and researchers (Dr Julie Silvestri and Dr Alison Reynolds) who reviewed the content.

Thank you to Bayer who provided an unrestricted educational grant enabling the development of this important and necessary resource.

Many thanks also to Pharmed for assisting with distribution of this booklet.

Become a Fighting Blindness Member

Fighting Blindness membership is open to anyone who is interested in our work. This includes people who are affected by vision impairment or blindness, and their families, Fighting Blindness supporters and fundraisers, scientists, medical professionals, and the general public.

You can sign up as a member by:

- Completing the form overleaf and returning it to: Fighting Blindness, 7 Ely Place, Dublin 2
- Or sign up online at www.FightingBlindness.ie
- Or please contact the team directly on 01 6789 004 or membership@fightingblindness.ie

Some benefits of Fighting Blindness membership include:

- Opportunity to participate in consultations and focus groups about the future of vision research and therapy development
- Subscription to quarterly member newsletter 'Visionaries' and Fighting Blindness news
- Free entry to the annual Retina Conference
- Voting rights at the Annual General Meeting

Membership is incredibly valuable as the more members we have, the stronger our voice is. We represent our members in matters of health policy and raise important issues at a national level.

Fighting Blindness Membership Form

Please return this completed form to Fighting Blindness, 7 Ely Place, Dublin 2.

Membership Options: (please tick)

- Individual Membership for One Year €25
- Family Membership for One Year €30
- Individual Membership for Three Years €60
- Family Membership for Three Years €70

Payment and Contact Details:

My cheque or postal order (made payable to Fighting Blindness) is enclosed, **or** please debit my:

Visa

Visa Debit

Mastercard

Card Number:

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Name:

Address:

Email:

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Signature:* Date:

*Your signature above is used as an authorisation for Fighting Blindness to process your payment and subscribes you to receive Fighting Blindness news and information sent to our membership from time to time. If you prefer not to be contacted further please email fundraising@fightingblindness.ie or call 01 6789 004.

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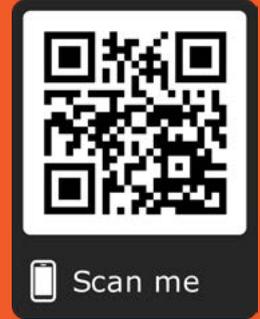


All information current as of August 2018.

To request additional copies of this document please contact info@fightingblindness.ie or 01 6789 004.

This publication is also available online at www.FightingBlindness.ie

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