



# MACULAR DEGENERATION

Often referred to as Age-related Macular Degeneration (AMD)

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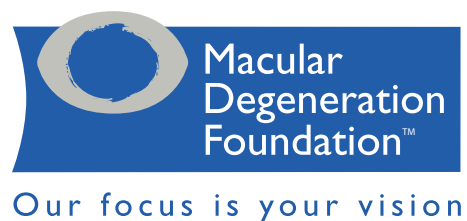
Our focus is your vision

## Contact the Macular Degeneration Foundation

Tel: 1800 111 709

Email: [info@mdfoundation.com.au](mailto:info@mdfoundation.com.au)

[www.mdfoundation.com.au](http://www.mdfoundation.com.au)



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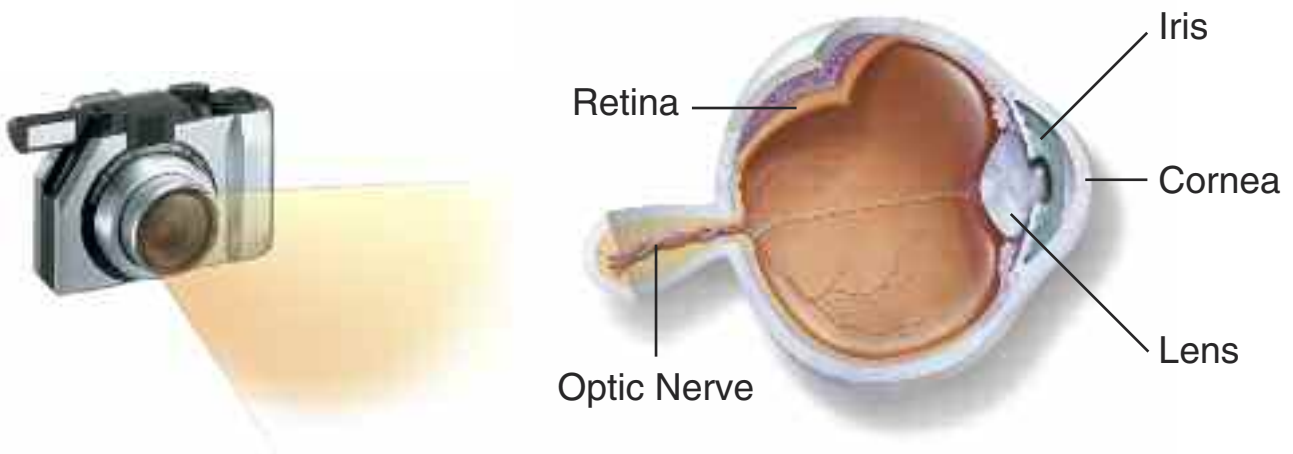
## Introduction

Many people consider sight to be their most precious sense. Vision is the way we access and appreciate the world. We need, as we grow older, to look after and protect our eyes. It is therefore important that we are aware of **Macular Degeneration** (MD), the leading cause of blindness and severe vision loss in Australia.<sup>1,2</sup>

This booklet is designed to provide you with information about MD. It describes how the eye works and why the macula is so important. It will explain all about MD, how it affects your vision and how to reduce your risk. It will also explain how to identify signs and symptoms of MD as well as the treatment options and support services available.

## How does the eye work?

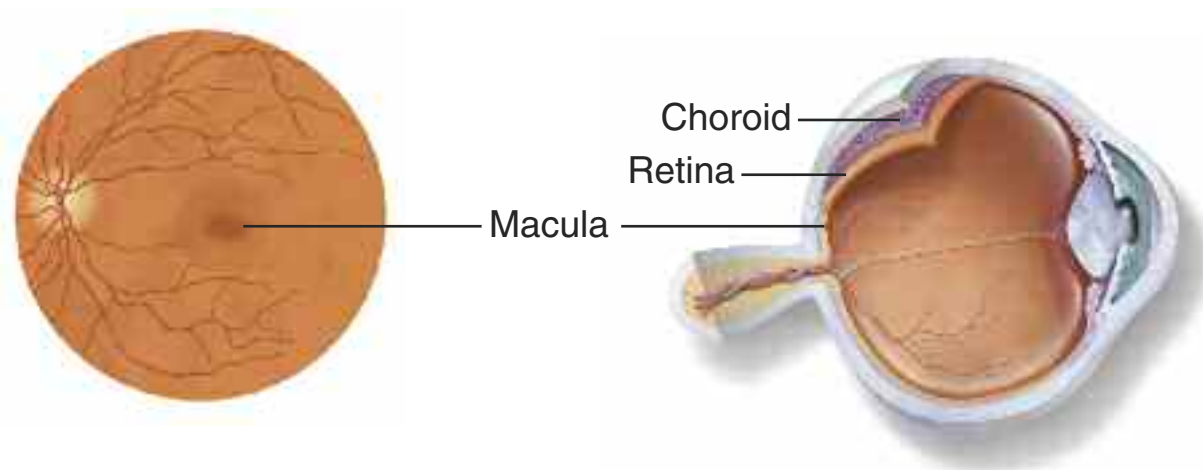
The eye works very much like a camera. The front of the eye, comprising the cornea, iris, pupil and lens focus the image onto the retina, which lines the back of the eye. The retina is sensitive to light and acts like the film in the camera, capturing images and then sending them via the optic nerve to the brain, where the images are interpreted.



## What is the macula?

You are reading this booklet using your macula.

The **macula** is the name given to the area at the very centre of the retina. This region is responsible for detailed central vision and most colour vision. It is responsible for your ability to read, recognise faces, drive a car, see colours clearly and any other activity that requires fine vision. The rest of the retina is called the peripheral retina. It is used to see general shapes and gives you your “get-about” vision, which is also called side vision or peripheral vision.



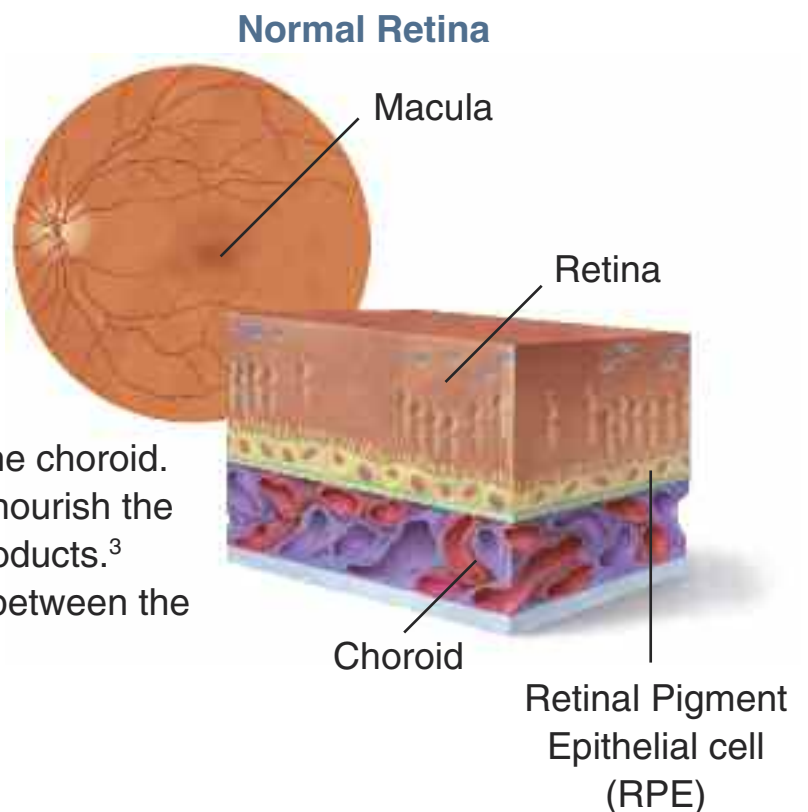
## What is Macular Degeneration?

Macular Degeneration (MD) is the name given to a group of degenerative retinal eye diseases that cause progressive loss of central vision, leaving the peripheral or side vision intact.<sup>1</sup> MD is usually related to ageing and most frequently affects people over fifty years of age. It is commonly referred to as **Age-related Macular Degeneration** or AMD. However, it is important to remember that inherited forms of the disease can also affect young people.

AMD is progressive and painless. It never leads to total or black blindness.

## What happens in AMD?

AMD is not a natural consequence of ageing. It is a disease that affects a special layer of cells in the eye called the **Retinal Pigment Epithelium (RPE)**.<sup>3</sup> The RPE is like a wall that separates the retina from its main blood supply, a vascular layer called the choroid. The major role of the RPE is to nourish the retina and get rid of its waste products.<sup>3</sup> The RPE also acts as a barrier between the choroid and the retina.

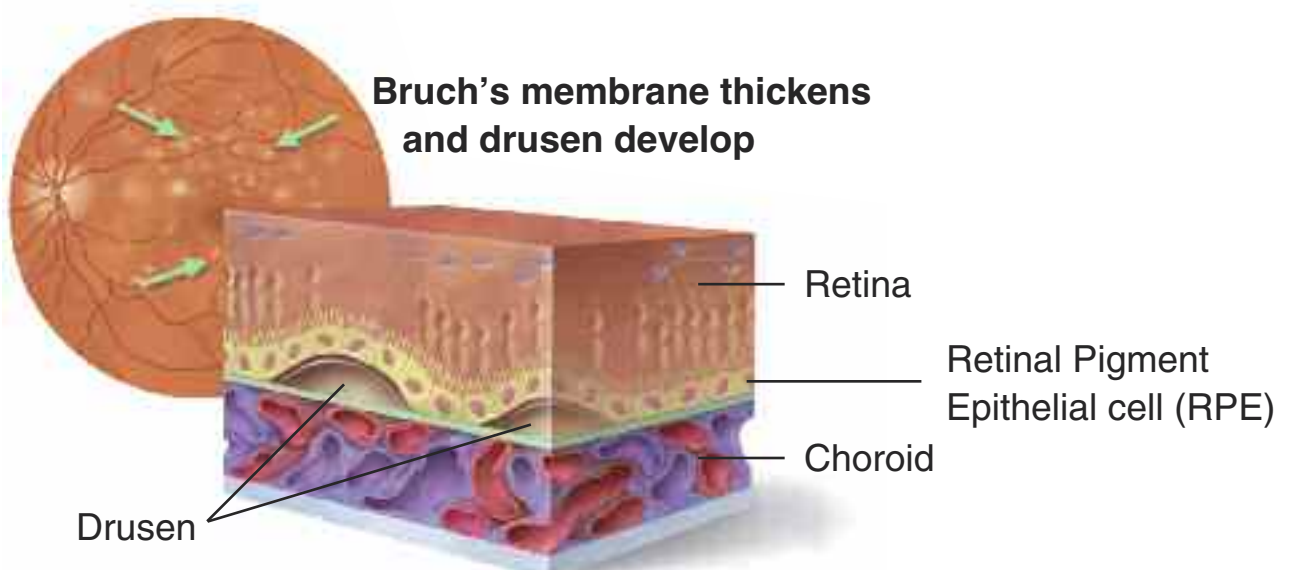


### **Early-stage AMD**

As AMD progresses these waste products from the retina build up underneath the RPE. When your Doctor looks at the back of your eye, he or she may see these deposits as yellow spots called Drusen.<sup>3</sup>

These early signs do not necessarily cause visual symptoms. However, they do increase the chance of AMD-associated vision loss.

### **Early-stages of AMD**



## Late-stage AMD

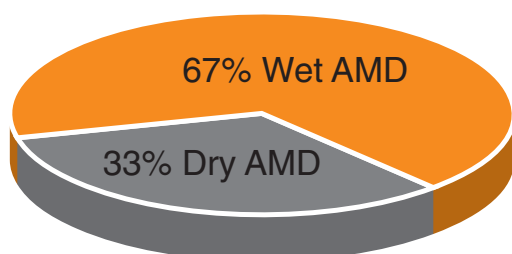
Loss of vision represents the later stage of the disease and occurs because the RPE cells die, or because they fail to keep blood vessels from the choroid out of the retina.<sup>1,3</sup>

When RPE cells die, the retinal cells above them also die, leading to patches of “missing” retina. This is commonly called geographic atrophy or dry AMD. Dry AMD is a slow form of the disease causing a gradual loss of vision.<sup>1,3</sup> It accounts for thirty-three percent of all cases of late-stage AMD.<sup>4</sup> Some patients who have dry AMD can later develop the more aggressive wet form. If you experience any sudden change in vision you should see your eye specialist urgently.

Wet AMD occurs when the RPE cells fail to stop choroidal blood vessels from growing into the retina. This growth is called Choroidal Neovascularisation (CNV). The rapidly growing vessels are fragile with leaky walls and they ooze fluid and blood into the retina, leading to scarring and vision loss.<sup>1,3</sup>

Wet AMD is the most severe form of the disease with approximately 17,000 new cases diagnosed annually in Australia.<sup>5</sup> Vision changes associated with the wet form are often sudden and severe. If you experience any sudden change in vision you should see your eye specialist urgently as early detection is crucial. The earlier you seek treatment, the more likely you are to have a better outcome, compared to those who wait.

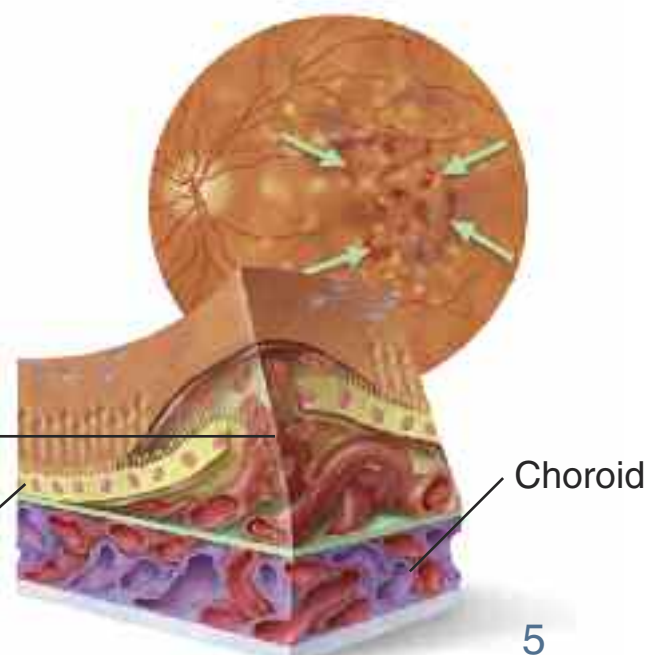
### Proportion of “Dry” AMD vs “Wet” AMD Cases Causing Severe Vision Loss



### Wet AMD

Rapidly growing vessels break through the RPE, leading to leakages and haemorrhage

Retinal Pigment Epithelial cell (RPE)



## What causes MD?

Macular Degeneration affects 1 in 7 Australians over the age of fifty and the incidence increases with age.<sup>6</sup> It is hereditary, with a fifty percent chance of developing MD if a family history of the disease is present.<sup>7</sup> MD is caused by genetic and environmental factors. Risk factors include age, family history, smoking and diet and lifestyle factors.

Studies have shown that those who smoke are three times more likely to develop MD and smokers may also develop the disease ten years earlier than non-smokers.<sup>8,9</sup> Those with a specific genetic predisposition who smoke have a markedly increased risk of developing wet AMD.

You cannot change your family or your age, however the following can help to reduce your risk of developing MD.

## Eye health checklist

- Have your eyes tested and make sure the macula is checked
- Don't smoke
- Keep a healthy lifestyle, control your weight and exercise regularly
- Eat a healthy well-balanced diet. Limit your intake of fats, eat fish two to three times a week, eat dark green leafy vegetables and fresh fruit daily, and a handful of nuts a week
  - In consultation with you doctor, consider taking a zinc and antioxidant supplement
  - Provide adequate protection for your eyes from sunlight exposure, especially when young



Please note: Any changes in diet or lifestyle should be undertaken in consultation with your doctor.



## How do I know if I might have MD?

Key symptoms can include one or more of the following:<sup>5</sup>

- Distortion, where straight lines may appear wavy or bent
- Difficulty in reading or any other activity which requires fine vision
- Distinguishing faces becomes a problem
- Dark patches or empty spaces appear in the centre of your vision

The need for increased illumination, sensitivity to glare, decreased night vision and poor colour sensitivity may also indicate that there is something wrong. These symptoms should not be dismissed as part of just getting older. Remember, the earlier treatment is sought, the greater likelihood of a better outcome compared to those who wait.



Metamorphosia  
(distortion)



Loss of  
visual acuity



Loss of contrast  
sensitivity



Scotoma  
(central blind spot)

It is essential to have your eyes tested and the macula checked by an eye care professional. However you should arrange to see an eye specialist if you experience any symptoms of MD or if you are in any way concerned about your vision.

Early detection and prompt treatment are crucial to saving sight.

## Amsler Grid Eye Exam

An Amsler Grid is an important management tool used to detect changes in your vision. These changes may include wavy or bent lines, dark or missing patches and any distortion. The Amsler Grid should not be relied upon for medical diagnosis, and is not a substitute for regular eye examinations.

A magnetised Amsler Grid has been attached to the inside back page for use.

**Your eyesight is vital. Don't take chances with your eyes.**

## What treatments are available?

There is no cure for MD, although there are treatments that aim to keep you with the best vision for as long as possible, and in some cases may potentially provide vision improvement.

There are currently no treatments available to reverse the effects of **dry AMD**. However, studies have shown that vitamins, minerals and antioxidants may slow its progression.<sup>10</sup>

There are a number of proven treatments available for **wet AMD**. These treatments target the blood vessels that grow abnormally into the retina and cause bleeding, leakage and scarring.

## Treatments

*Proven to be effective by controlled trials published in peer review journals.*

An excessive growth of blood vessels in Wet MD causes bleeding, leakage and scarring which results in severe loss of vision. The blood vessels are prompted to grow by a protein called Vascular Endothelial Growth Factor (VEGF). In the case of anti-VEGF drugs, an antibody, called an anti-VEGF, is injected into the eye cavity where it spreads to the retina and blocks the growth of blood vessels.

### 1. Lucentis (ranibizumab)

Lucentis is an anti-VEGF drug which is injected into the eye at four week intervals. The two-year results of two separate trials have been reported and show this treatment is extraordinarily effective. Roughly 7 to 8 out of 10 patients maintain their vision or notice improvement. Over one third still have vision in the affected eye that would enable them to legally drive a car.

Lucentis appears to be equally effective for all the types of Wet MD and for all lesion sizes. This treatment is available in Australia and is registered under the TGA (Therapeutic Goods Administration). Lucentis was listed from 1 August 2007 on the Pharmaceutical Benefits Scheme (PBS).

Patients should discuss details of the injections with their doctor.

Phase 3 trials are being constructed on Lucentis in Australia. The trial is looking at varying the frequency of administration and using it in combination with Photodynamic Therapy with Visudyne.

## **2. Photodynamic Therapy (PDT) / Visudyne Therapy**

This is a two step process combining a light-activated drug (Visudyne) and the light from a cold laser directed on to the abnormal retinal area. Once activated, the drug causes the blood vessel to close off. PDT treatment does not cause direct damage to the surrounding retina. It therefore can be used to treat new vessels that are under the centre of vision (the fovea).

PDT is a course of therapy and several treatments are needed to keep the leaking blood vessels closed and stop the progression of Wet MD. Close follow up and monitoring with the attending eye doctor is needed to determine if further treatment is required.

Unlike Lucentis in which the vision is usually maintained, patients having PDT continue to lose vision in the first six months. Their vision then stabilises so that the eye does not progress to severe vision loss. Patients with large, poorly outlined CNV respond poorly to PDT.

## **3. Laser Photocoagulation**

This treatment consists of a concentrated light beam of high energy thermal light which is directed on to the retina to destroy and seal the leaky blood vessels. A contact lens is placed onto the eye. The doctor will give instructions on where to look, so that the eye remains still while the laser is focused on the area being treated. This is not a painful procedure.

The laser not only destroys the new vessel (CNV) but also destroys the retina adjacent to the new vessel. Therefore it should only be used for treating new vessels that are not under the central vision. This is only a small percentage of patients who present with Wet MD.

Close follow up and monitoring with the attending eye doctor is needed to determine if further treatment is required, as there is a fifty percent recurrence rate.

#### **4. Retaane (anecortave acetate)**

This drug also inhibits the abnormal growth of blood vessels. It is an angiostatic cortisone derived from the steroid molecule. It is modified to remove the chemical groups responsible for the development of cataracts and elevated intraocular pressure leading to glaucoma, while preserving potency against angiogenesis.

This drug is administered through a tube called a cannula that is inserted behind the eyeball. It needs to be repeated every six months to maintain efficacy. The treatment appears to be as effective as PDT for some types of CNV. There are Phase 3 trials being recruited to examine the use of Retaane in combination with one of the anti-VEGF drugs.

Retaane has now been listed on the Pharmaceutical Benefits Scheme (PBS).

#### ***Experimental treatments***

##### **1. Avastin (bevacizumab)**

Avastin is an anti-VEGF drug, like Lucentis, that is injected into the eye. It was not designed for use in the eye. It was primarily tested and approved for the treatment of cancer.

Avastin has been used worldwide in the past two to three years for treating patients with Wet MD. Many case reports suggest that it is highly effective, but it remains unproven with regards to both safety and efficiency. Like Lucentis, it appears that Avastin needs to be injected repeatedly to maintain its effect. It is still not clear as to how often the injection should be given.

##### **2. Triamcinalone (Kenacort)**

A slow release steroid designed for injection into joints, the drug has been used 'off label' by some retinal specialists to supplement CNV treatments particularly PDT. It seems to have a beneficial effect when used in conjunction with PDT but has been shown in a controlled trial to be ineffective as a sole treatment. It is injected into the eye but promotes cataract formation and in a third of patients increases the intraocular

pressure often necessitating glaucoma treatment. The effect of one injection lasts a few months. Side effects increase with repeated injections.

***Treatment options for Wet Macular Degeneration should be discussed with your ophthalmologist.***

## **Coping with vision loss due to Macular Degeneration**

### **The challenge**

It takes time to adjust to new circumstances and vision loss is no exception. People can experience different feelings from acceptance to disbelief. Some people newly experiencing vision loss may find daily activities challenging. However with support, assistance and the right advice, these challenges can be overcome in order to maintain quality of life and independence.

Moving forward with vision loss begins with taking control of the situation. The more a person knows about their condition, its effects and options for dealing with the challenges presented by low vision, the more confident they will feel.

### **The low vision pathway**

It is important to map a low vision pathway in order to maintain quality of life and independence. A positive attitude, perseverance and the ability to seek help and support has enabled many people with low vision to fulfill their aspirations and to maintain quality of life and independence in work, home and social settings.

There is help and support available that will cater for individual requirements.

### **Assessment**

A low vision assessment is the best way to get started. It is essential in order to find the best strategies and support options for individual needs.

## **Guidance, advice and support**

Low vision services can provide advice, help, information and solutions for managing everyday tasks. Individual counselling, group programs and support groups are important services that can be accessed if needed. Low vision services can provide equipment solutions and practical assistance. This includes orientation and mobility training.

## **Vision aids and adaptive technology**

Daily living aids, electronic magnification units and audio technology can enhance the quality of life and maintain independence for the vision impaired. The technological landscape is rapidly changing to meet the needs of people with low vision. Even for those who have not formally used computers or audio devices, new technology is now making it simple, accessible, affordable and beneficial.

### **Low Vision - A Guide**

The Macular Degeneration Foundation produces a booklet titled *Low Vision - A Guide* which contains general information on low vision, advice for the newly diagnosed, coping strategies, information on mobility, low vision tips and information on depression. It also contains a helpful directory of services, contact details of major organisations and providers of adaptive technology and other useful information.

### **Family, Friends and Carers - A Guide**

The Macular Degeneration Foundation produces a booklet titled *Family, Friends and Carers – A Guide* which gives information on support and assistance to carers and those who have a friend or family member with vision impairment.

# Macular Degeneration Foundation

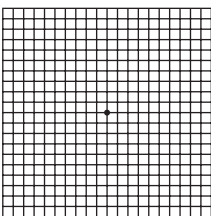
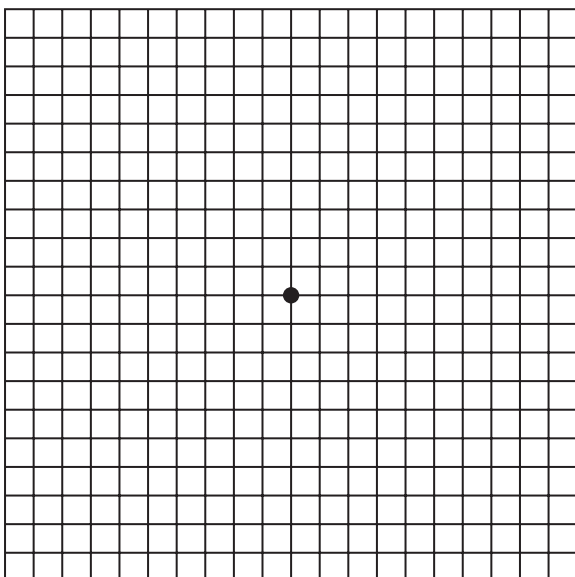
The Macular Degeneration Foundation aims to reduce the incidence and impact of Macular Degeneration in Australia through education, awareness, research, support services and representation. For further information and resources free of charge, contact the Macular Degeneration Foundation on:

**1800 111 709**

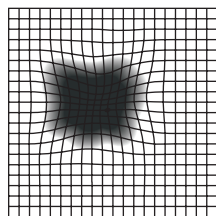
How's Your Macula?

## The Amsler Grid

This can be used to test for the symptoms of Macular Degeneration (MD)



Normal Vision



Consult your eye care provider immediately

### What do I do?

1. Do not remove glasses or contact lenses you normally wear for reading
2. Stand approximately 33cm from the grid in a well-lit room
3. Cover one eye with your hand and focus on the centre dot with your uncovered eye. Repeat with the other eye.
4. If you see wavy, broken or distorted lines, or blurred or missing areas of vision you may be displaying symptoms of Macular Degeneration. and should contact your eye care professional immediately

Key symptoms of MD may include:

- Difficulty in reading or doing any other activity which requires fine vision
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The need for increased illumination, sensitivity to glare, decreased night vision and poor colour sensitivity may also indicate that there is something wrong.

### EARLY DETECTION IS CRITICAL IN ORDER TO SAVE SIGHT

For more information phone the MD Foundation on

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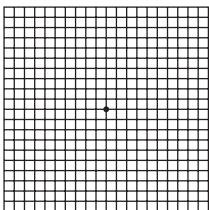
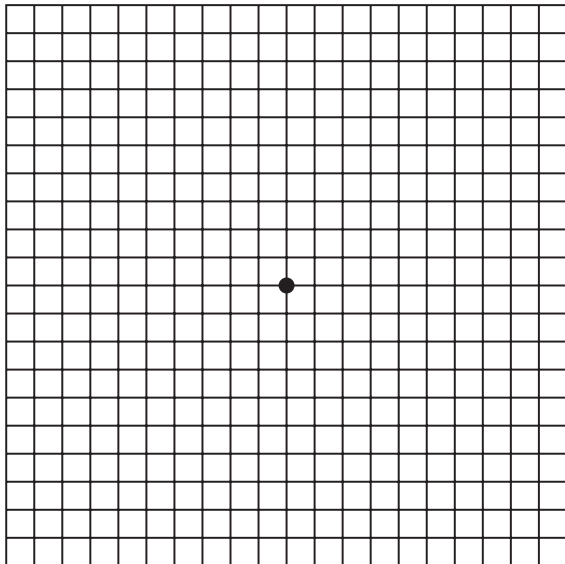
**DO NOT DEPEND ON THE AMSLER GRID  
FOR DIAGNOSIS**

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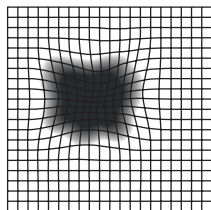
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