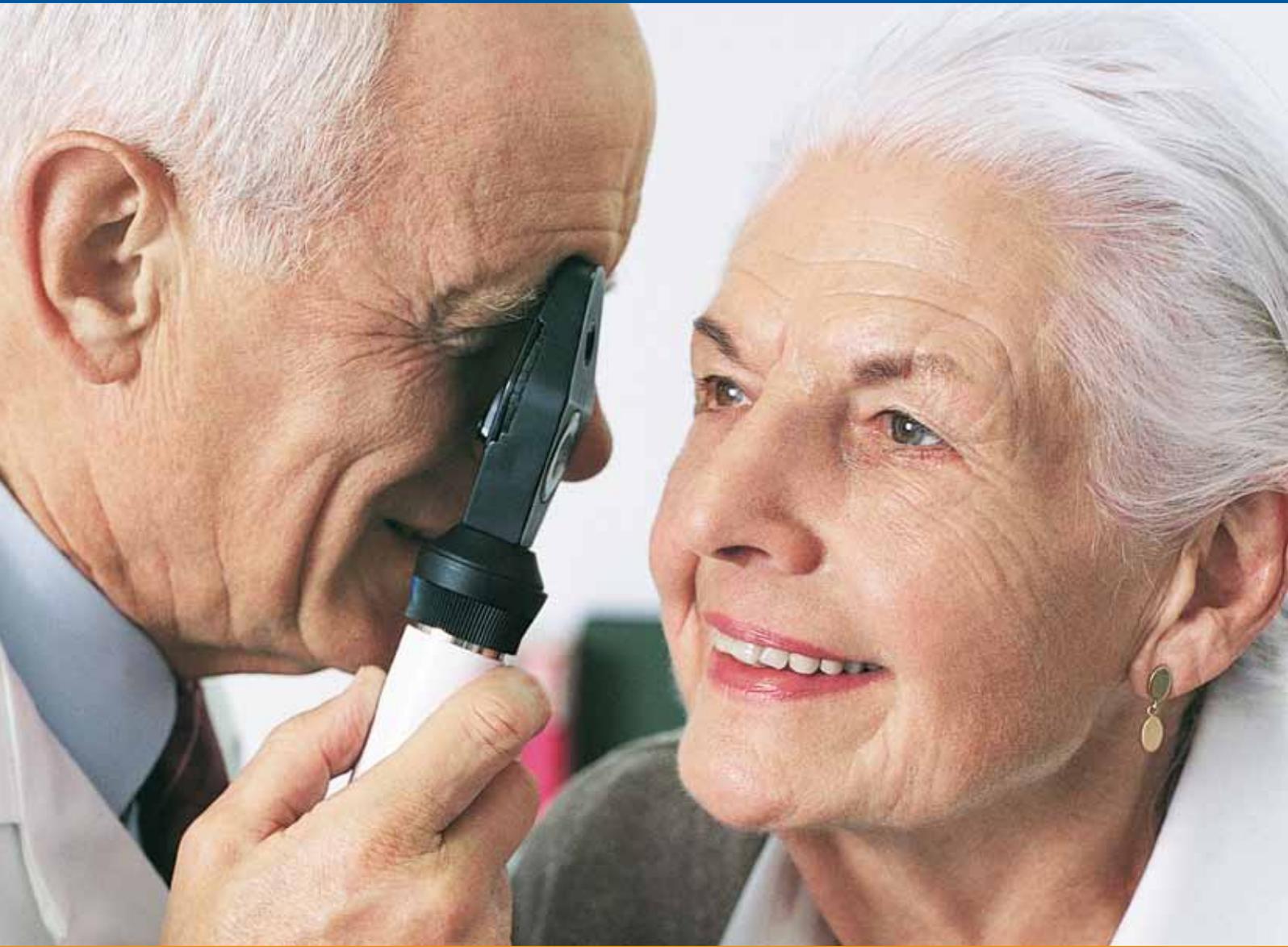


MACULAR DEGENERATION



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

Free information service provided by:



Our focus is your vision

The Macular Degeneration Foundation

The Macular Degeneration Foundation is a national charity established in 2001 with the mission to reduce the incidence and impact of Macular Degeneration in Australia through education, awareness, client services, research and representation.

The Foundation funds world leading research into Macular Degeneration, its prevention and treatment and ultimately seeks to find a cure for this chronic disease.

As a charity, the Foundation relies upon donations, bequests and fundraising efforts to support its work. If you would like to donate to support the Foundation or its research grants program, or arrange for a bequest, please contact the Foundation.

For further information, support and guidance, or to register to receive newsletters and invitations to national education sessions please contact the Foundation.

Macular Degeneration Foundation

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Introduction

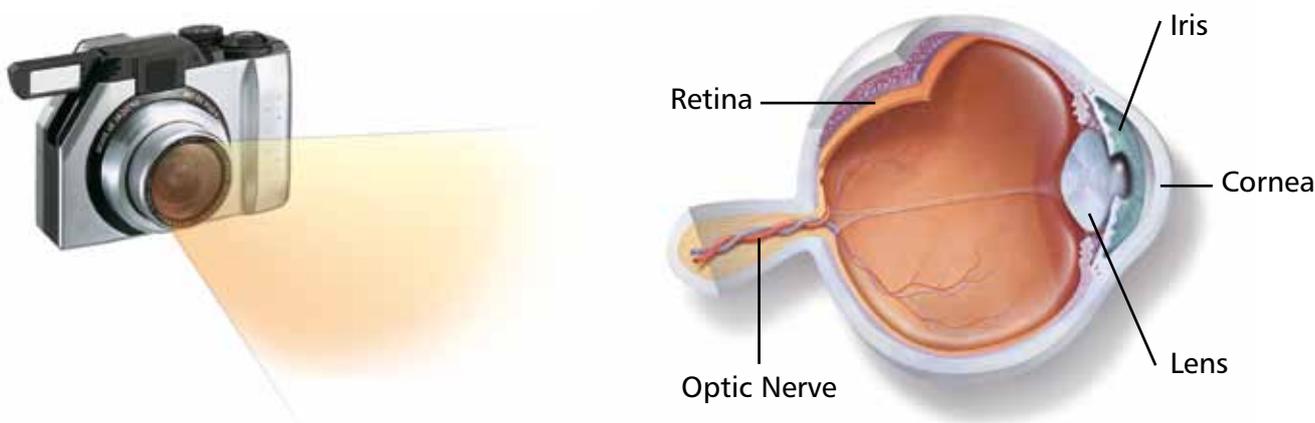
Sight is a precious sense. Vision is the way we access, appreciate and interpret the world. We need to look after and protect our eyes, especially as we grow older. It is therefore important to be aware of **Macular Degeneration (MD)**, the leading cause of blindness* and severe vision loss in Australia.

This booklet is designed to provide general information about Macular Degeneration. It describes how the eye works and why the macula is so important. It explains all about Macular Degeneration, how it affects vision and how to reduce risk. It also explains how to identify signs and symptoms of the disease as well as the treatment options and support services available.

This publication is one of a series produced by the Macular Degeneration Foundation as a part of the work undertaken in education and awareness to reduce the incidence and impact of this disease in Australia. Further resources are listed at the back of this publication.

How does the eye work?

The eye works very much like an old-style film camera. The front of the eye, comprising the cornea, iris, pupil and lens, focuses 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.

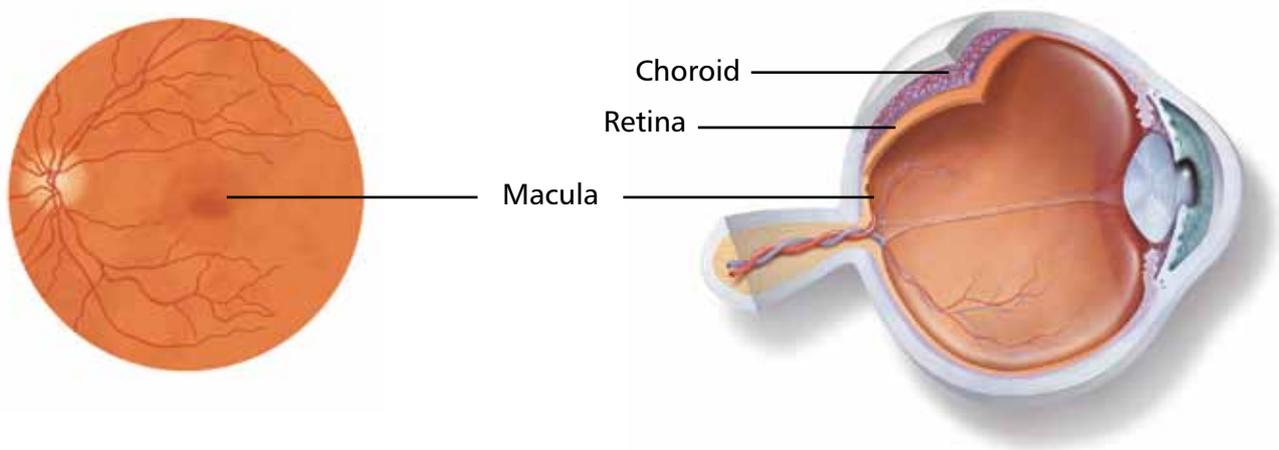


*legal blindness

What is the macula?

Reading this booklet uses the 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 the ability to read, recognise faces, drive a car and 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 provides '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 chronic, degenerative retinal eye diseases that cause progressive loss of central vision, leaving the peripheral or side vision intact.

MD is usually related to ageing and most frequently affects people over 50 years of age. It is commonly referred to as **Age-related Macular Degeneration** or AMD. However, it is not a normal or inevitable consequence of ageing. Certain forms of the disease can also affect younger people.

MD is progressive and painless and although MD can lead to legal blindness, it does not result in total or 'black' blindness.

How common is Macular Degeneration?

About one in seven Australians (1 million people) over the age of 50 has some evidence of MD. Approximately 17% of these people (170,000 Australians) experience vision impairment. MD is the leading cause of legal blindness in Australia and is responsible for 50% of all cases of blindness.

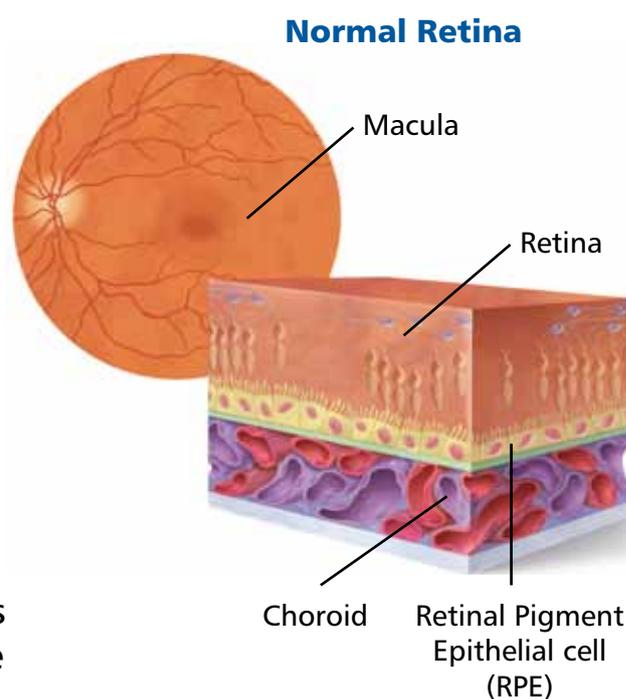
What happens in Macular Degeneration?

Macular Degeneration is a disease that affects a special layer of cells in the eye called the **retinal pigment epithelium (RPE)**.

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. The RPE also acts as a barrier between the choroid and the retina.

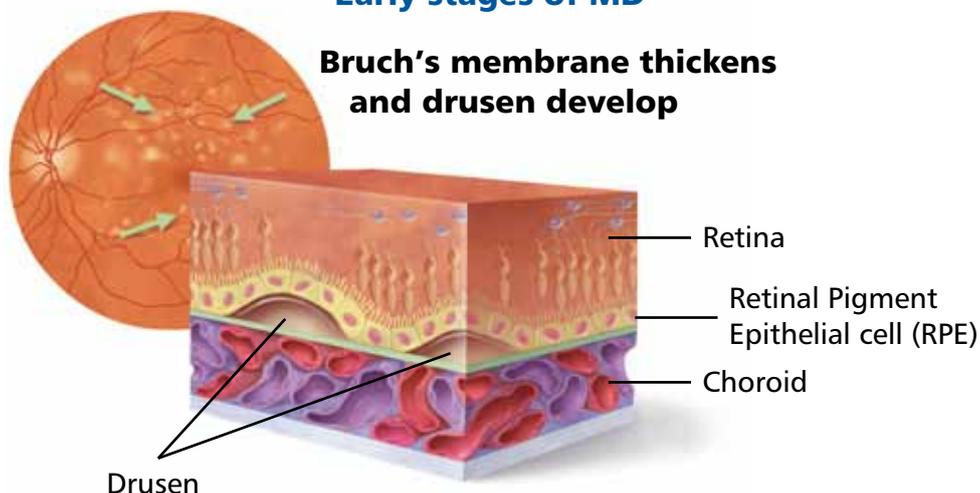
Early stage MD

As MD progresses, these waste products from the retina build up underneath the RPE forming yellow spots called drusen.



Early stages of MD

Bruch's membrane thickens and drusen develop



It is possible to have these first signs of MD called drusen without knowing and that is why it is so important to have an eye test and the macula checked. An optometrist or an eye specialist can examine the eyes for the early signs of the disease (drusen) by looking inside the back of the eye using special optometric equipment.

Small amounts of drusen do not necessarily cause visual symptoms. Also not everyone with drusen will inevitably lose vision. However, the existence of drusen does increase the chance of MD-associated vision loss developing later.

Late stage MD

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 from growing under the retina.

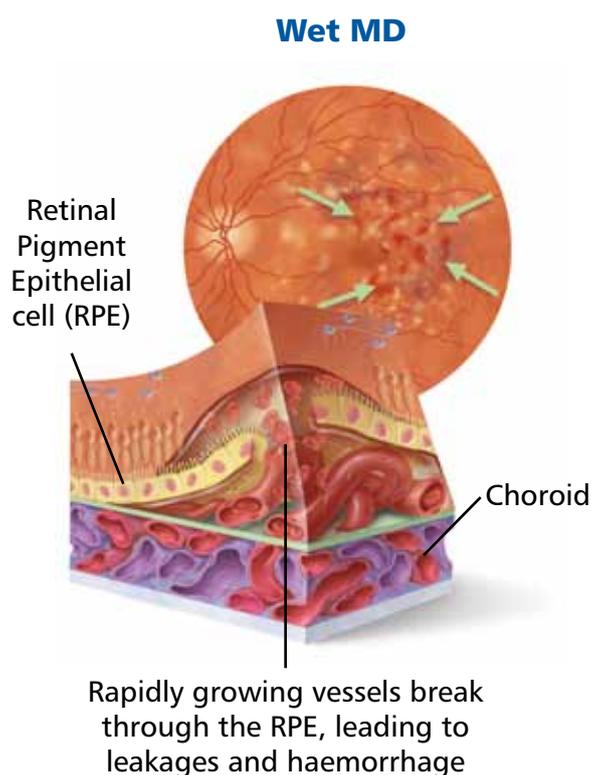
Dry MD

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 MD. Dry MD is a slow form of the disease causing a gradual loss of vision. It accounts for 33% of all cases of late-stage MD. Some people who have dry MD can later develop the more aggressive wet form. It is therefore important for any sudden changes in vision to be reported to the eye specialist as a matter of urgency. Any delay in treatment can risk vision loss.

Wet MD

Wet MD occurs when the RPE cells fail to stop choroidal blood vessels from growing under the retina. This growth is called choroidal neovascularisation (CNV). The rapidly growing vessels are fragile with leaky walls and they ooze fluid and blood under the retina, leading to scarring and vision loss.

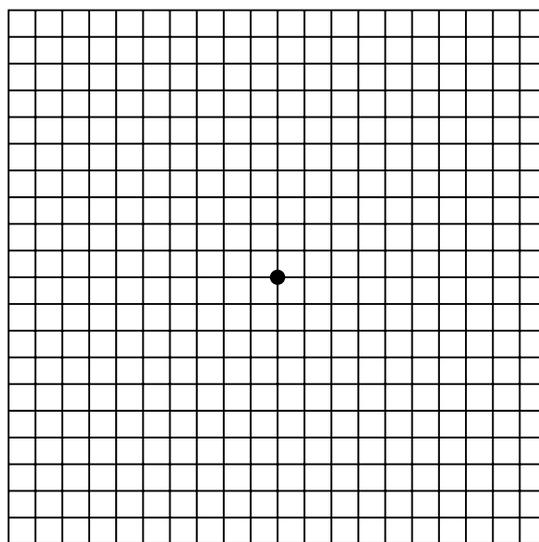
Wet MD is the most severe form of the disease with approximately 17,000 new cases diagnosed annually in Australia. Vision changes associated with wet MD are often sudden and severe.



Detecting changes in vision

Any sudden changes in vision or the development of symptoms should be reported to an eye specialist immediately as a matter of urgency. An appointment should be obtained within a week. Early detection of wet MD is crucial to saving sight. The earlier treatment is given, the more likely it is that vision can be saved. Delayed treatment increases the likelihood of losing sight.

The Amsler grid is an essential tool to self-monitor for possible symptoms or sudden changes in vision. It should be used daily. It does not however take the place of having a regular eye test and macula check. More information on the Amsler grid is on page 11.



What causes Macular Degeneration?

MD is caused by genetic and environmental factors. Risk factors include age, family history, smoking and diet and lifestyle factors. One in seven Australians over the age of 50 have some evidence of MD, and the incidence increases with age. MD can also be hereditary, with a 50% chance of developing MD if there is a direct family history of the disease. Since at least 70% of cases of MD have a genetic link, it is critical that people with MD inform their siblings and children, and encourage them to have their eyes tested and macula checked.

Studies have shown that those who smoke are three to four times more likely to develop MD, and smokers may also develop the disease five to ten years earlier than non-smokers. Those with a specific genetic predisposition who smoke have a significantly increased risk of developing wet MD.

Eye health checklist

Although family history and age cannot be changed, the following can help to reduce the risk of developing MD:

- Have an eye test and make sure the macula is checked
- Don't smoke
- Keep a healthy lifestyle, control weight and exercise regularly
- Eat a healthy, well-balanced diet
- Eat fish two to three times a week, dark green leafy vegetables and fresh fruit daily, and a handful of nuts a week. Limit the intake of fats and oils.
- Choose low glycemic index (GI) carbohydrates instead of high GI whenever possible
- In consultation with a doctor, consider a suitable supplement
- Provide adequate protection for your eyes from sunlight exposure, including for those who are very young



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

Nutrition for eye health

Studies show that diet is important in reducing the risk of Macular Degeneration and in slowing its progression. Eating a healthy, well-balanced diet high in antioxidants, vitamins and other nutrients can help keep our eyes healthy.



Important antioxidants for eye health include lutein and zeaxanthin. These are present in high concentrations in a healthy macula and help to protect the eye. They are found in dark green leafy vegetables such as spinach and silver beet as well as naturally yellow fruit and vegetables such as sweet corn and capsicum. In addition, vitamin C, vitamin E, zinc and selenium are important antioxidants for a healthy macula.

Omega-3 fatty acids are also very important to eye health. All fish and shellfish contain omega-3s but higher concentrations are found in oily varieties of fish such as salmon, mackerel, anchovies and trout.



People who eat a higher proportion of carbohydrates with a low glycemic index (GI) compared to high GI, have a lower risk of developing MD. Low GI carbohydrates include most fruit and vegetables, whole grain cereals and whole grain breads.

Supplements for eye health

People who are concerned about getting enough nutrients in the diet should consider an appropriate supplement.

Those who are unable to eat leafy green vegetables should consider a lutein supplement, and if unable to eat two to three serves of fish each week then consider a fish oil supplement.



People who have been diagnosed with MD should also consider a supplement made according to the Age-Related Eye Disease Study (AREDS). This was a major clinical trial conducted by the National Eye Institute in the USA. The study evaluated the effects of antioxidants and zinc on the progression of age-related MD and identified a specific formula that reduced the risk of progressing to the later stages of the disease.

For those in the intermediate stage of MD in one or both eyes or the late stage of MD in one eye, taking an AREDS supplement containing high levels of antioxidants and zinc significantly reduced the risk of progression of the disease by 20 to 25% and delayed vision loss. However, there is presently no evidence that the AREDS formula is of any benefit to people who do not already have MD, or who only have a few small drusen.

The specific **daily** amounts of antioxidants and minerals used in the AREDS study were:

Zinc	80 mg
Vitamin C	500 mg
Vitamin E	400 IU
Copper	2 mg
Beta-carotene	15 mg *

It is extremely difficult to obtain the required levels of some of these antioxidants from diet alone.

*** Note:** Beta-carotene has been omitted from most AREDS products because of concerns about it increasing the risk of cancer in smokers. This removal is strongly supported by the MD Foundation on the advice of the Foundation's Medical Committee. People who smoke, or have smoked, or have asbestosis should not take a supplement that contains beta-carotene.

Supplements are not a cure for MD. The AREDS study shows that taking the AREDS formula may reduce the risk of progression; it does not stop or reverse damage caused by the disease. The impact of taking a high dose antioxidant and zinc combination supplement for greater than six years is not known.

For more details, refer to the Macular Degeneration's Foundation's Nutrition & Supplements fact sheet.

How do you know if you have Macular Degeneration?

You can have the early signs of MD (drusen) without knowing and that is why it is so important to have an eye test and macula check. During the early stages of MD, symptoms will typically not be noticed.

As the disease progresses, symptoms can include one or more of the following:

- Difficulty in reading or any other activity which requires fine vision
- Distortion, where straight lines may appear wavy or bent
- 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.



Loss of
visual acuity



Metamorphosia
(distortion)



Loss of contrast
sensitivity



Scotoma
(central blind spot)

Any changes in vision should never be dismissed as just part of getting older. For both wet and dry MD the earlier a diagnosis is made, the earlier that steps can be taken to slow disease progression. With wet MD, the earlier the treatment is started, the greater the likelihood of saving sight.

It is essential to have an eye test and a macula check by an eye care professional with regular follow-up according to their recommendation. A rapid referral should be arranged from the optometrist or GP to an eye specialist if any sudden changes in your vision or any symptoms of MD are noticed. If you already have an eye specialist and therefore do not require a referral, you should explain your symptoms and ask for an appointment within one week.

Early detection and prompt intervention are crucial to saving sight.

What tests are used to diagnose Macular Degeneration?

Pupil dilation

The eye care professional may dilate (enlarge) the pupils using eye drops to help give a better view of the retina at the back of the eye. After a pupil dilation, the eyes may be blurry for a few hours. Driving should not be undertaken while the eyes are still dilated.

Fluorescein angiogram

If the eye specialist suspects wet MD, a fluorescein angiogram will generally be used. Fluorescein dye is injected into the blood via a vein in the arm. The dye rapidly reaches the eye, and circulates through the retina, highlighting any abnormalities or damage to blood vessels. A camera with a special filter then takes a series of photographs. This procedure only takes a few minutes.

Optical coherence tomography

An optical coherence tomography (OCT) scan is now a standard procedure in the diagnosis and ongoing management of wet MD. An OCT scan is a non-invasive imaging technique that uses light to produce very high-resolution cross-sectional images of the tissue layers within the retina. Using an OCT scan, eye specialists can detect and monitor wet MD.

Before any visit to the eye care professional, it is advisable to check if any special requirements for the visit are required. For example, will it be possible to drive home afterwards?

Amsler grid eye exam

An Amsler grid is an essential self-monitoring tool used to detect changes in your vision. These changes may include distortion (straight lines appearing wavy or bent) or dark or empty spaces. The Amsler grid should not be relied upon for medical diagnosis and is not a substitute for regular eye examinations. Any sudden changes in vision noticed while using an Amsler grid should be reported immediately to the eye specialist. The Amsler grid is used one eye at a time and this is important for isolating potential issues in individual eyes.

A magnetised Amsler grid has been attached to the inside back page for placement in a prominent place (eg on the fridge) for daily testing.

Treatment for Macular Degeneration

There is no cure for MD, however studies have shown zinc and antioxidants may slow down the progression of MD. For both dry and wet MD, diet and lifestyle changes may also slow down the progression of the disease.

Any changes to diet or lifestyle should be undertaken in consultation with the doctor.

Is there a treatment for dry MD?

Currently there are no medical treatments available for dry MD, however a substantial amount of research is being conducted to find a treatment.

Is there a treatment for Wet MD?

There are a number of medical treatments available for wet MD. These treatments do not cure the disease but aim to stabilise and maintain the best vision for as long as possible. In some people, treatment can improve vision.

In wet MD, an excessive growth of blood vessels causes bleeding, leakage and scarring under the retina. This process results in the rapid and severe loss of central vision which, if left untreated, becomes permanent. A protein called Vascular Endothelial Growth Factor (VEGF) is predominantly responsible for the leaking and growth of the new blood vessels. To slow or stop this process various drugs that block this protein (called anti-VEGFs) may be injected into the eye. Clinical trials have shown that the use of anti-VEGF drugs maintains vision in the vast majority of wet MD patients.

These anti-VEGF drugs are administered as injections into the eye. The usual treatment regimen begins with monthly injections for three months. Then to maintain control of the disease injections must usually be continued on an indefinite basis. The interval between these ongoing injections is determined on an individualised basis by the eye specialist in consultation with the patient.

Lucentis® (ranibizumab)

Lucentis is the first anti-VEGF drug registered in Australia for the treatment of wet Age-related MD (AMD). Lucentis has been approved by the Therapeutic Goods Administration and was listed on the Pharmaceutical Benefits Scheme in August 2007.

Eylea® (aflibercept)

Eylea is an anti-VEGF drug developed for the treatment of wet AMD and was registered by the Therapeutic Goods Administration in April 2012 and has Pharmaceutical Benefits Scheme listing.

Avastin® (bevacizumab)

Avastin is an anti-VEGF drug which was originally developed and registered for the treatment of certain cancers. It is not registered by the Therapeutic Goods Administration for use in the eye and therefore its use is called 'off-label' when treating patients with wet MD. In Australia, Avastin is typically used for people who are not eligible to receive the approved drugs Lucentis or Eylea that are on the Pharmaceutical Benefits Scheme.

Treatment with injections

The choice of the most appropriate drug should be discussed with the eye specialist. The following applies regardless of which drug is used:

- It is not a long procedure and usually occurs in the specialist's rooms, although some patients may be treated in a day stay unit.
- Appointments with the eye specialist should not be missed, even if there does not appear to be any problem with vision.
- Vision should continue to be monitored every day using an Amsler grid, one eye at a time. This monitoring is important for all injection schedules including if the duration between injections is being increased or even if injections have ceased.
- Any sudden changes in vision should be reported to the eye specialist immediately as matter of urgency, regardless of whether or not injections are being received. Do not wait for the next appointment.
- Even if vision has stabilised or improved, treatment may still need to be continued.
- Treatment should not cease unless on the advice of the eye specialist.
- Injections are often required for an indefinite period to maintain vision.
- If there are any concerns regarding coping with injections or any difficulties post injection it is important to raise these concerns with the eye specialist in the first instance, given the critical nature of the treatment.

Photodynamic Therapy (PDT) with Visudyne®

Unlike with anti-VEGF drugs, with which the vision is usually maintained, patients having PDT normally continue to lose vision in the first six months. Their vision then generally stabilises so that the eye does not progress to severe vision loss. PDT therefore is now rarely used to treat ordinary AMD. It is sometimes used in conjunction with an anti-VEGF drug in people with a type of MD called polypoidal choroidal vasculopathy as some of these cases do not settle completely with anti-VEGFs.

PDT is a two-step process combining a light-activated drug (Visudyne) with the light from a cold laser. The laser is directed on to the abnormal retinal area to seal and halt or slow down the progression of abnormal retinal blood vessels. It is necessary to avoid sunlight for 24 to 48 hours after the drug has been infused.

Laser photocoagulation

This treatment consists of a concentrated beam of high energy thermal light which is directed on to the retina to destroy and seal the leaky blood vessels.

The laser not only destroys the new leaking blood vessel but also destroys the retina adjacent to the new vessel. Therefore it is primarily used for treating new vessels that are not under the central vision. This represents only a small percentage of patients who have wet MD. Close follow up and monitoring with the eye specialist is needed to determine if further treatment is required, as there is a 50% recurrence rate.

Treatment options for wet Macular Degeneration should be discussed with the eye specialist.



Coping with vision loss

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 experiencing vision loss for the first time may find daily activities challenging. However with support and the right advice these challenges can be overcome in order to maintain quality of life and independence.

The low vision plan

Moving ahead with vision loss begins with taking control of the situation. It is important to have a plan in order to maintain quality of life and independence. A good plan will include the following:

- ✓ **Assessment:** a low vision assessment is the best way to get started in order to find the best strategies and support options for individual needs.
- ✓ **Guidance, advice and support:** Low vision services can provide solutions for managing everyday tasks, including aids and technology, to help maintain quality of life and independence.

Hallucinations - Charles Bonnet Syndrome

Charles Bonnet Syndrome (CBS) is a term used to describe the phenomenon of visually impaired people seeing things which they know are not real. Sometimes called 'visual hallucinations' or 'phantom images', the images can range from simple, repetitive patterns to detailed pictures of people, animals or buildings. About 30% of people who experience major vision loss report seeing these phantom images which can be extremely vivid and realistic. These images are a consequence of losing sight where the brain attempts to make up the gaps in the images.

It is very important to advise the eye specialist of any experience with phantom images. A fact sheet on Charles Bonnet Syndrome is available from the Macular Degeneration Foundation and this can be used to explain the condition to the GP, to inform other healthcare professionals and to explain to family and friends.

Macular Degeneration Foundation resources

The Macular Degeneration Foundation has developed a comprehensive range of publications and resources on MD and low vision. Call the Foundation for a free information kit or to register to receive newsletters and invitations to attend MD and low vision education sessions.

Low Vision - A Guide

This booklet 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 low vision service providers.

Low Vision Aids & Technology - A Guide

This booklet provides information on aids and technologies for those with low vision and explains how these aids can help maintain independence and improve quality of life.

Family, Friend & Carer - A Guide

This booklet provides information on support and assistance for carers and those who have a friend or family member with vision impairment.

Slips, Trips & Falls - A Guide

This booklet is primarily written for people with low vision, along with their family, friends and carers, so that all can be part of creating a "fall free" environment.

Nutrition & Supplements fact sheet

This fact sheet provides information on nutrition and supplements for maximising macula health. This is a valuable guide both for those with MD as well as those seeking to reduce their risk of developing the disease.

Newsletters

The Foundation produces a free quarterly newsletter that provides the latest news on matters related to MD and low vision. Contact the Foundation to register to receive the newsletter.

Information in other languages

The Foundation produces information in Arabic, Chinese, Greek, Italian and Vietnamese.

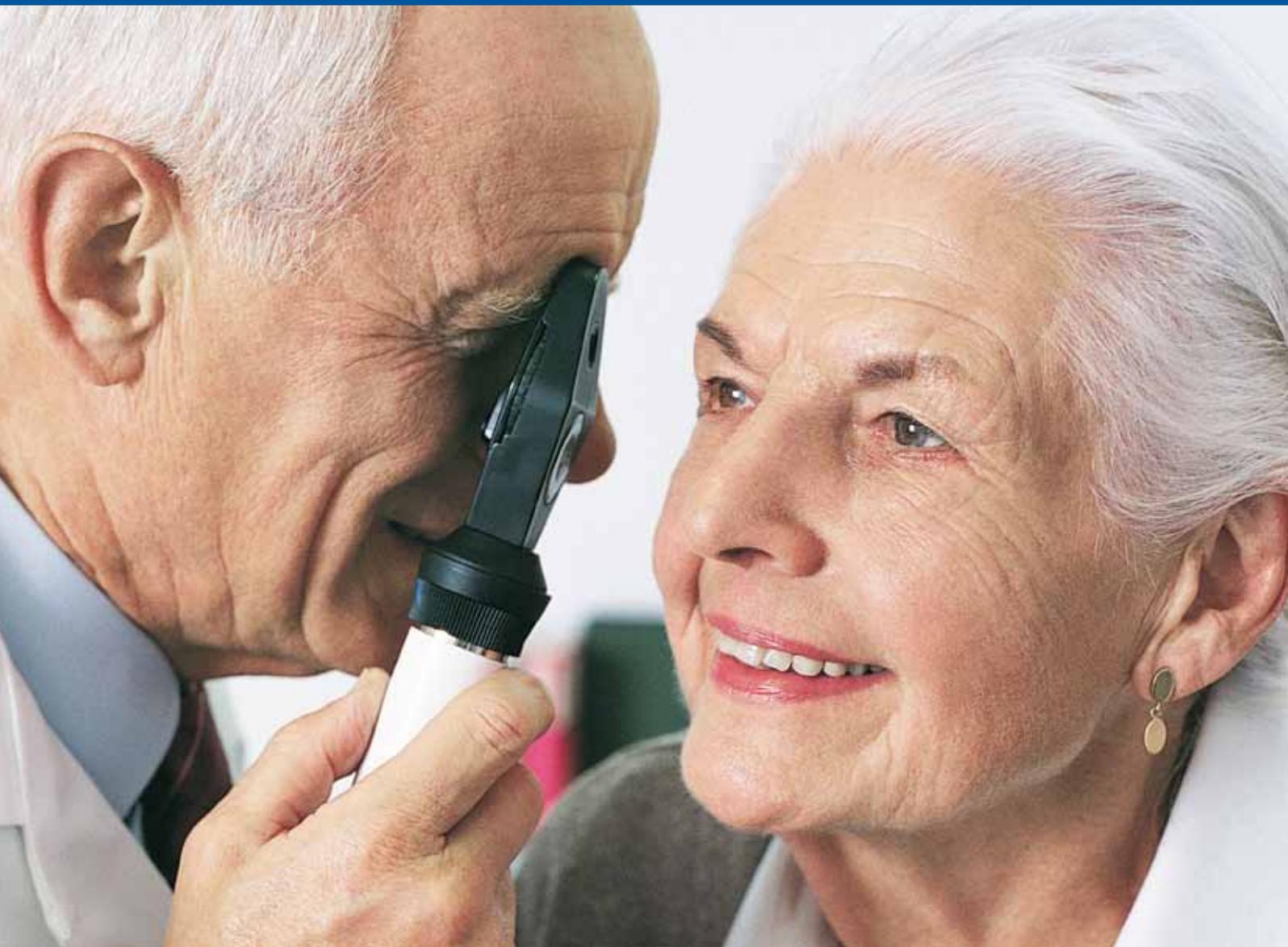
What to ask your eye care professional: a helpful resource to help ensure you ask the right questions of your eye health care professional in order to best understand your condition.

Charles Bonnet Syndrome: to help better understand the phantom images experienced by many people with vision loss.

Research Updates: each year the Foundation produces a Research Update publication that provides an overview of the key MD research that is underway globally.



Disclaimer: Information contained in this booklet is considered by the Macular Degeneration Foundation to be accurate at the time of publication. While every care has been taken in its preparation, medical advice should always be sought from a doctor. The Macular Degeneration Foundation cannot be liable for any error or omission in this publication or for damages arising from its supply, performance or use, and makes no warranty of any kind, either expressed or implied in relation to this publication.



Contact the Macular Degeneration Foundation



Our focus is your vision

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