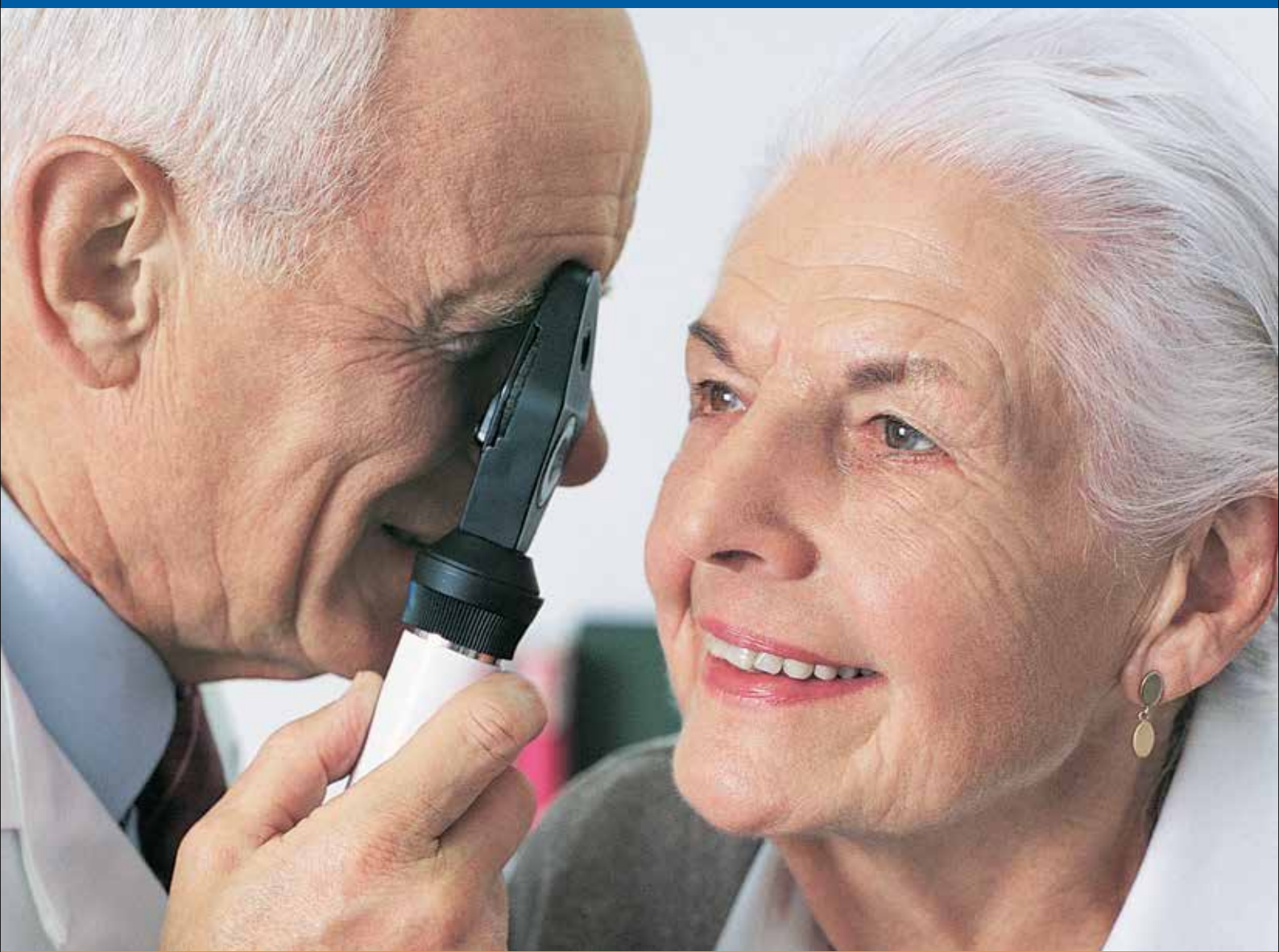


MACULAR DEGENERATION



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

Free information service provided by:



Our focus is your vision

Macular Disease Foundation Australia

Macular Disease Foundation Australia (formerly known as Macular Degeneration Foundation) is a charity with a mission to reduce the incidence and impact of macular disease in Australia. The Foundation is committed to working on behalf of the macular disease community through awareness, education, client services, research and representation.

Macular disease, including macular degeneration, is the leading cause of blindness* and severe vision loss in Australia. 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 or other events please contact the Foundation.

Macular Disease Foundation Australia

Helpline: 1800 111 709

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* legal blindness

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Introduction

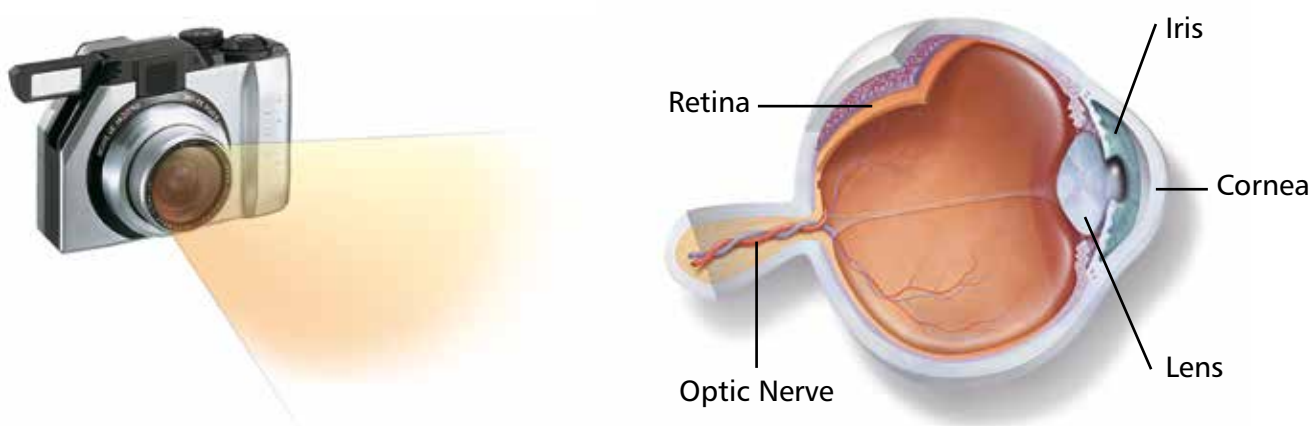
Sight is a precious sense. Vision is the way we access, appreciate and interpret the world. We need to look after and protect our eyes, especially as we grow older. It is therefore important to be aware of **macular degeneration**, the leading cause of blindness* and severe vision loss in Australia.

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 Macular Disease Foundation Australia as 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.

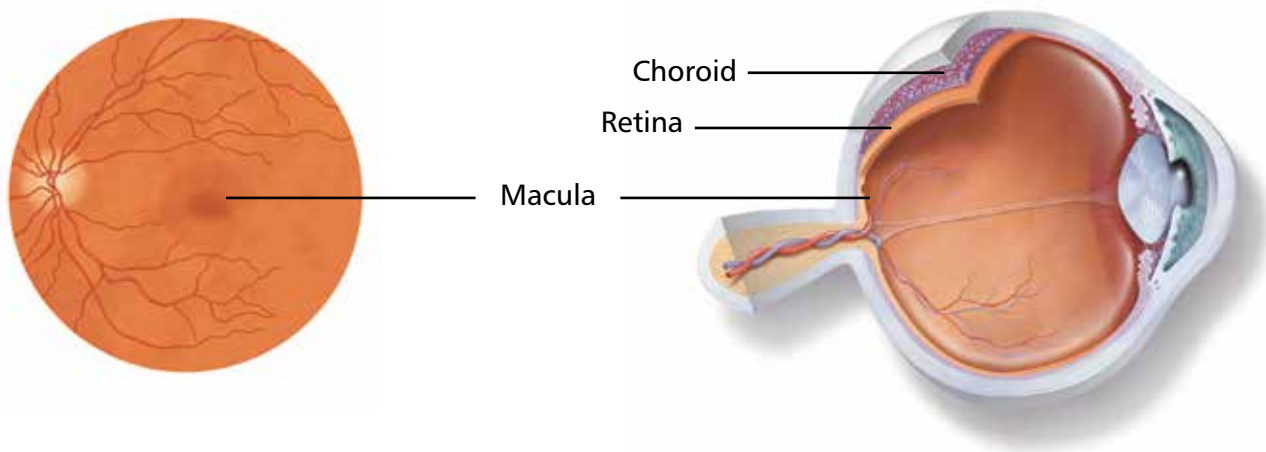


*legal blindness

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, 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 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.

Macular degeneration 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.

Macular degeneration is progressive and painless and although it 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 macular degeneration. Approximately 17% of these people (170,000 Australians) experience vision impairment. It is the leading cause of legal blindness in Australia and is responsible for 50% of all cases of blindness.

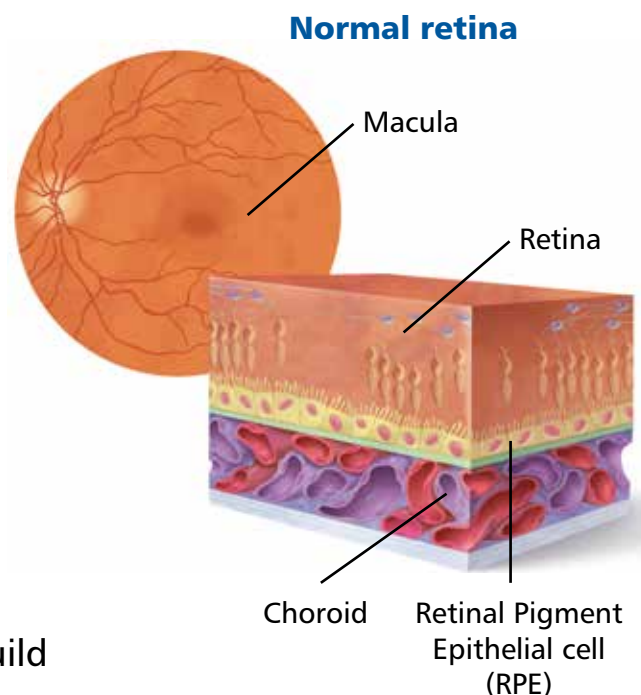
What happens in macular degeneration?

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.

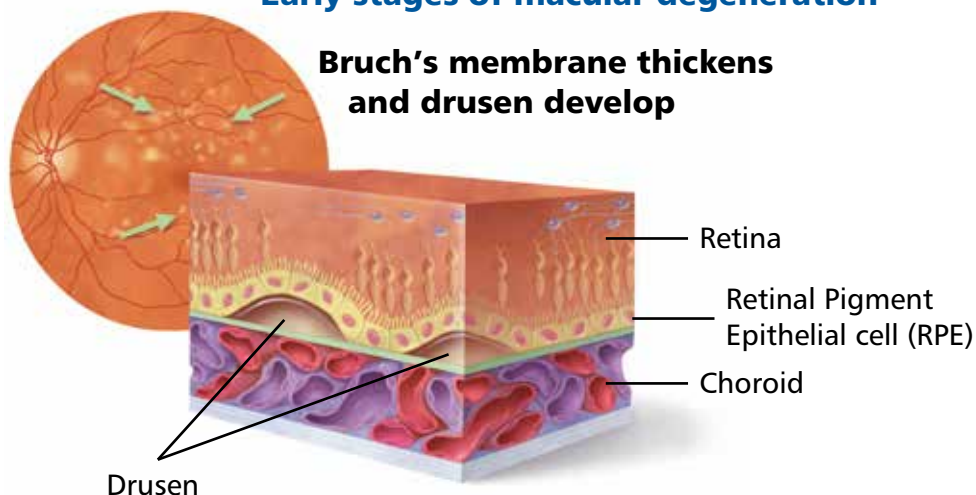
Early stage macular degeneration

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



Early stages of macular degeneration

Bruch's membrane thickens and drusen develop



It is possible to have these first signs of macular degeneration 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 developing late stage macular degeneration.

Late stage macular degeneration

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 macular degeneration

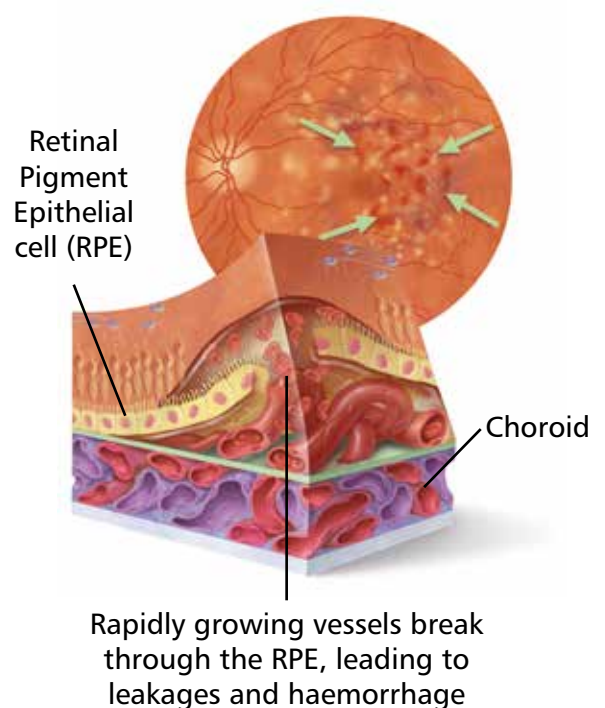
When RPE cells die, the retinal cells above them also die, leading to patches of 'missing' retina. This is commonly called geographic atrophy or 'dry' macular degeneration. This is a slow form of the disease causing a gradual loss of vision. It accounts for 33% of all cases of late-stage macular degeneration. Some people who have either the early or the dry form 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 macular degeneration

Wet macular degeneration 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.

This is the most severe form of the disease with approximately 21,000 new cases diagnosed annually in Australia. Vision changes are often sudden and severe.

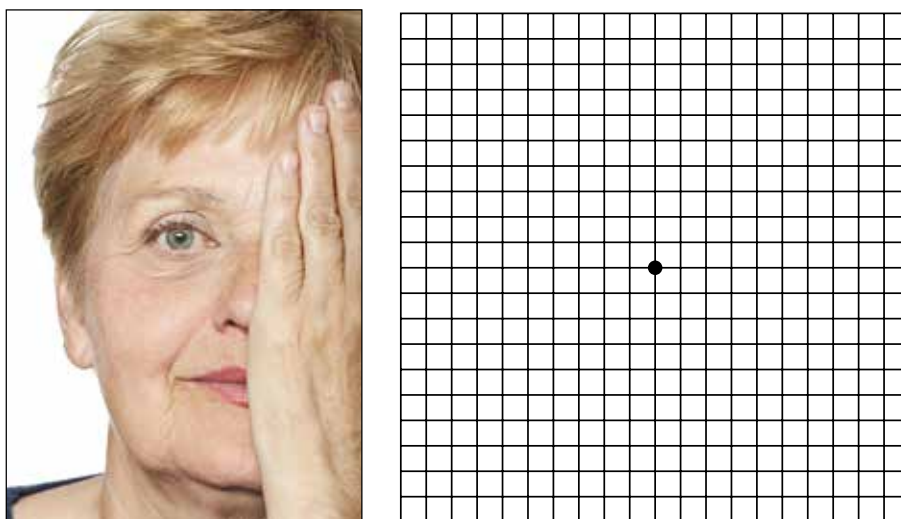
Wet macular degeneration



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 macular degeneration 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?

Macular degeneration is caused by genetic and environmental factors. Risk factors include age, family history, smoking, diet and lifestyle. One in seven Australians over the age of 50 has some evidence of the disease, and the incidence increases with age. It can also be hereditary, with a 50% chance of developing it if there is a direct family history. Since at least 70% of cases have a genetic link, it is critical that people with macular degeneration 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 macular degeneration, 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 macular degeneration.

Eye health checklist

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

- 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
- Use an Amsler grid daily to check for symptoms of macular degeneration
- 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 macular degeneration. Low GI carbohydrates include most fruit and vegetables, whole grain cereals and whole grain breads.

Supplements for eye health

Supplements are vitamins, minerals or other substances taken in tablet form. The use of supplements for macular health are broadly divided into two areas:

- Supplementing the diet: if dietary intake of nutrients, particularly eye health nutrients, is inadequate a supplement may be considered. This can be appropriate whether or not you have been diagnosed with macular degeneration.
- AREDS2-based supplements: for those diagnosed with age-related macular degeneration, a supplement based on the Age-Related Eye Disease Study #2 may be considered.

It is important to speak to a health care professional about the most appropriate supplement for your individual needs.



Supplementing the diet:

Lutein: those who obtain insufficient lutein through a daily diet including dark green leafy vegetables should consider a lutein supplement.

Omega-3: those who are unable to eat 2-3 serves of fish each week may consider a fish oil (omega-3) supplement, however, there is currently a lack of good evidence confirming the benefits of supplementation versus eating actual fish.

AREDS2 supplements:

People who have been diagnosed with age-related macular degeneration (AMD) should consider taking a supplement based on the AREDS formula. The Age-Related Eye Disease Studies (AREDS) are the only studies for which there is good, long-term evidence for the benefits of high dose nutrients for people diagnosed with AMD. The original AREDS study showed that a supplement based on a specific formula of zinc and antioxidants slowed the progression of AMD: for people in the intermediate stage of AMD in one or both eyes, or in the late stage in one eye, the AREDS formula reduced the risk of progression of the disease by 20 to 25% and delayed vision loss.

The AREDS study showed that the formula had no effect on those with no AMD, or only very early signs of AMD (eg a few small drusen), or for those with advanced disease in both eyes.

In May 2013, the AREDS researchers announced the results of their follow-up study, AREDS2. Their recommendation was the continued use of the original AREDS formulation, but with beta-carotene removed, to be replaced by lutein/zeaxanthin.

The AREDS 2 Formula daily dose is:

Zinc (as zinc oxide)	80 mg
Vitamin C	500 mg
Vitamin E	400 IU
Copper (as cupric oxide)	2 mg
Lutein	10 mg
Zeaxanthin	2 mg

It is important to consult your doctor about taking supplements and to discuss the most appropriate one for your needs.

Supplements are not a cure for macular degeneration. 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.

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

How do you know if you have macular degeneration?

You can have the early signs of macular degeneration (drusen) without knowing and that is why it is so important to have an eye test and macula check. During the early stages, 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 macular degeneration the earlier a diagnosis is made, the earlier that steps can be taken to slow disease progression. With wet macular degeneration, 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. If any sudden changes in vision occur or any symptoms are noticed, see an eye specialist without delay (within a week).

Early detection and prompt intervention are crucial to saving sight.

Tests 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.

Retinal photographs

Retinal photographs are commonly used by optometrists and ophthalmologists. They provide a detailed image of the retina and a basis for comparison for future eye examinations.

Fluorescein angiogram

If the eye specialist suspects wet macular degeneration, 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 macular degeneration. 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.

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 vision due to macular degeneration. These changes may include distortion (straight lines appearing wavy) 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 macular degeneration, however studies have shown that diet and lifestyle changes, including the use of an appropriate supplement may slow down the progression of the disease. Any changes to diet or lifestyle should be undertaken in consultation with a doctor.

Is there a treatment for dry macular degeneration?

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

Is there a treatment for wet macular degeneration?

There are a number of medical treatments available for wet macular degeneration. 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 macular degeneration, 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 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 are typically 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 was the first anti-VEGF drug registered in Australia for the treatment of wet age-related macular degeneration (AMD). Lucentis is 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 macular degeneration. In Australia, Avastin is typically used for people who are not eligible to receive the approved drugs Lucentis or Eylea via 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 after the 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® (verteporfin)

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 macular degeneration called polypoidal choroidal vasculopathy as some of these cases do not settle completely with anti-VEGF drugs.

PDT is a two-step process combining a light-activated drug (Visudyne) with the light from a cool 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. 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 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 Disease Foundation Australia Resources

Macular Disease Foundation Australia has developed a comprehensive range of publications and resources on macular degeneration and low vision. Call the Foundation for a free information kit or to register to receive newsletters and invitations to attend education sessions and events.

Low Vision - A Guide

This booklet provides 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 provides information to help create a “fall free” environment.

Nutrition & Supplements for Macular Degeneration

This fact sheet provides information on nutrition and supplements for maximising macular health. This is a valuable guide both for those with macular degeneration 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 macular degeneration and low vision. Contact the Foundation to register to receive the newsletter.

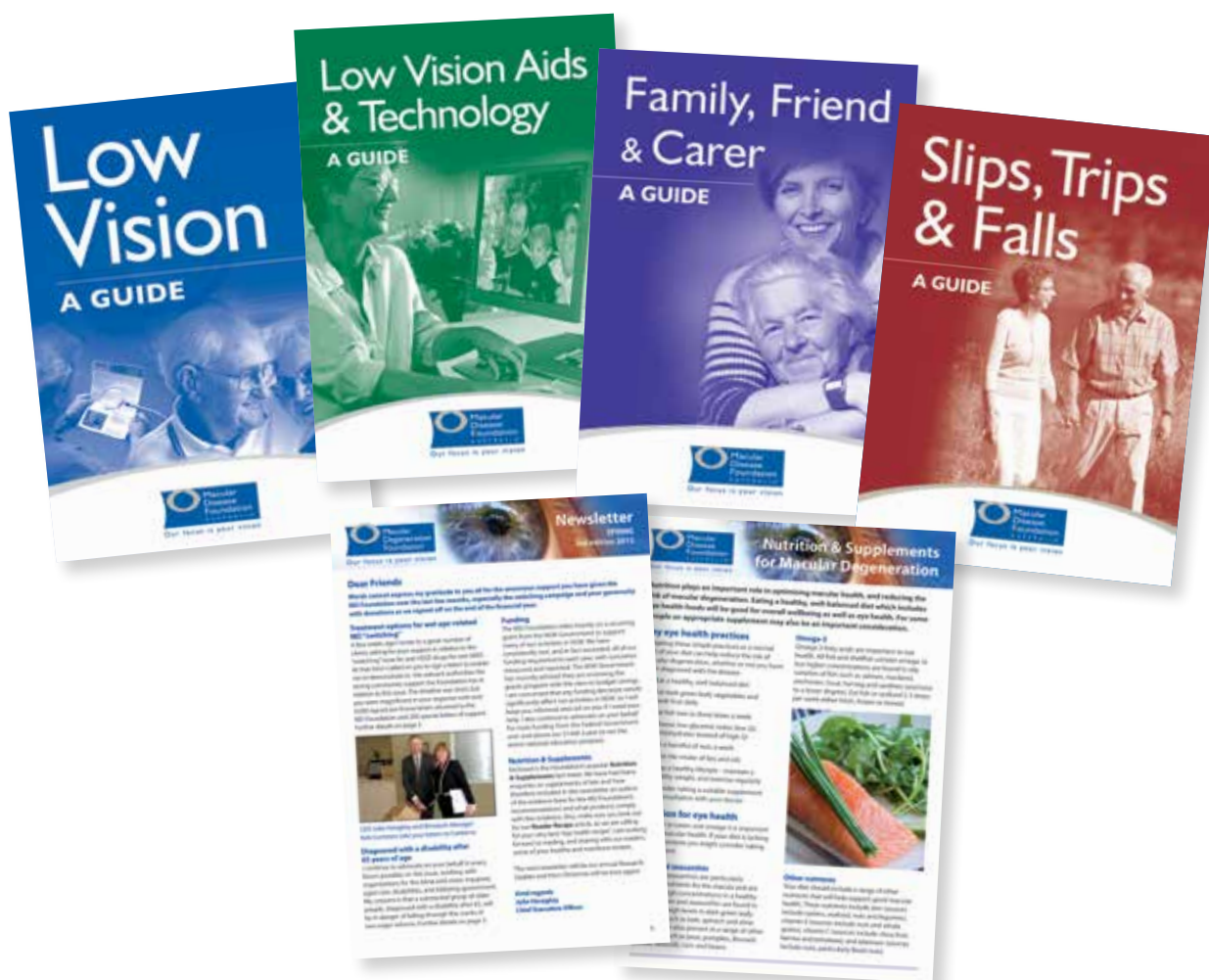
Information in other languages

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

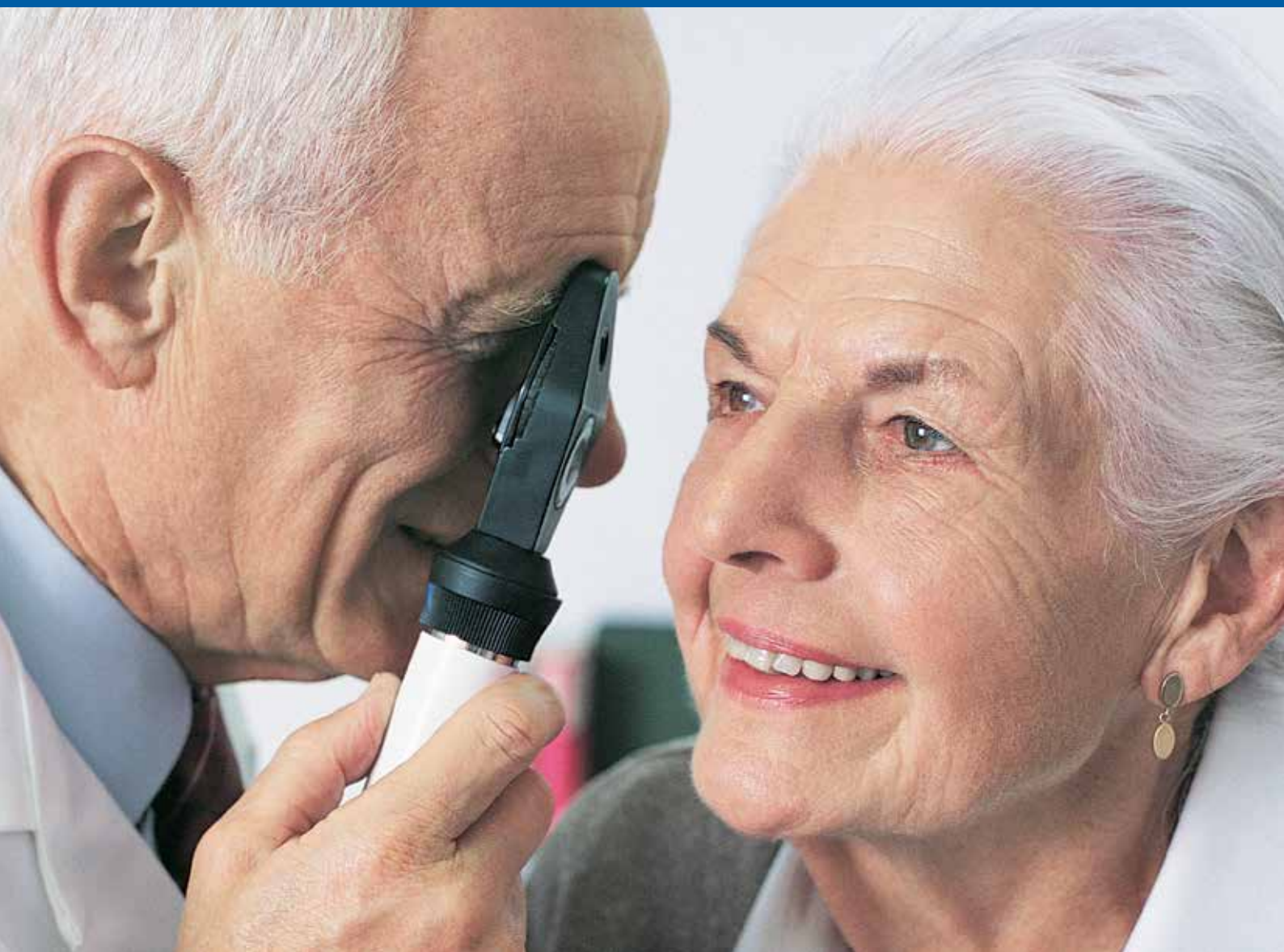
What to ask your eye care professional: a helpful resource to help ensure you ask the right questions of your eye health care professional in order to best understand your condition.

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 research that is underway globally.



Disclaimer: Information contained in this booklet is considered by Macular Disease Foundation Australia 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. Macular Disease Foundation Australia 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 Macular Disease Foundation Australia



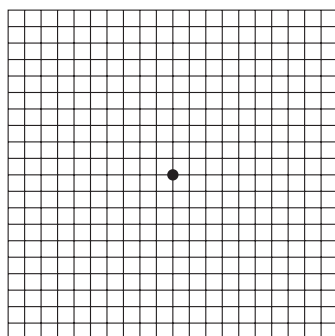
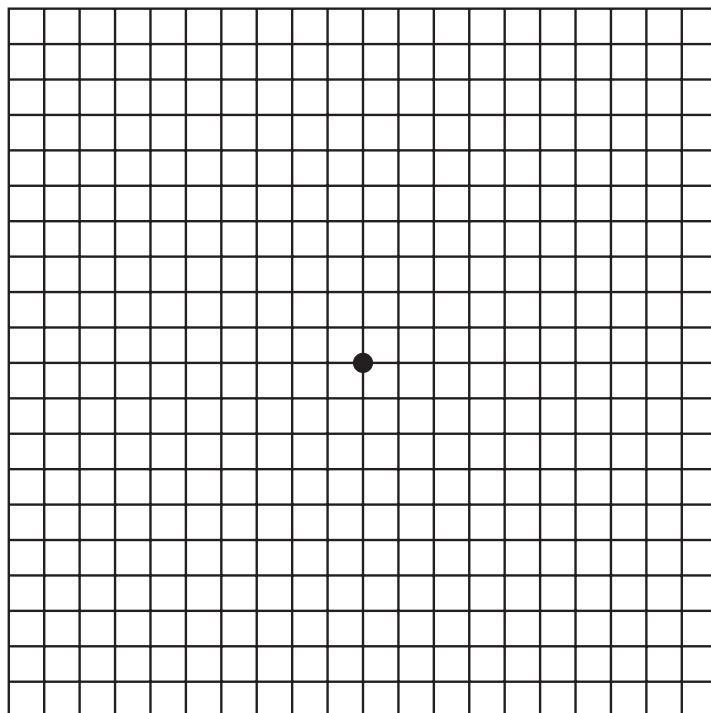
Our focus is your vision

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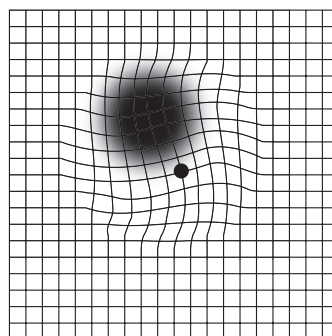
Helpline: 1800 111 709
www.mdfoundation.com.au

AMSLER GRID

The Amsler grid is used to test for symptoms of macular degeneration



Normal vision



Consult your eye care professional immediately

If any grid lines appear wavy, broken or distorted, or if there are blurred or missing patches, this may be a symptom of macular degeneration.

Sudden changes in vision? See your eye care professional without delay.

EARLY DETECTION IS CRITICAL IN ORDER TO SAVE SIGHT

For more information phone the
Macular Disease Foundation Australia

1800 111 709

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

See reverse for instructions

AMSLER GRID

Instructions:

- 1.** Do not remove glasses or contact lenses normally used for reading
- 2.** Hold grid at eye level at your normal reading distance in a well lit room
- 3.** Cover one eye and focus on the centre dot with the uncovered eye (make sure the eye is fully covered)
- 4.** Repeat with the other eye

Key symptoms of macular degeneration may include:

- Difficulty in reading or doing any other activity which requires fine vision
- Distortion, where straight lines 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.