Macular Degeneration

Macular Degeneration New Zealand

Macular Degeneration New Zealand (MDNZ) is a national charity that aims to reduce the incidence and impact of Macular Degeneration in New Zealand through awareness, education, client services and representation.

As a charity, MDNZ relies upon donations, bequests and fundraising to support its work. If you would like to donate to support MDNZ or arrange for a bequest please contact MDNZ.

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MACULAR
DEGENERATION
NEW ZEALAND

MDNZ acknowledges the extensive support, assistance and cooperation of the Macular Disease Foundation Australia.

Contents

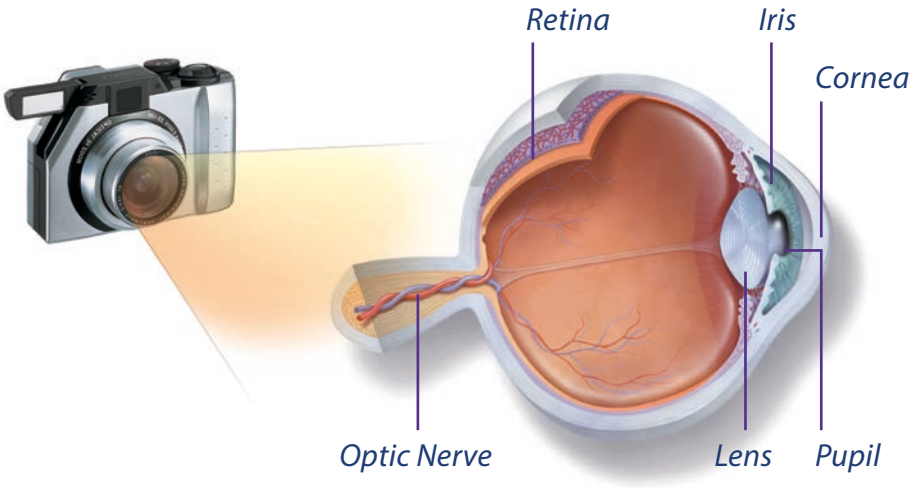
Introduction

Macular Degeneration (MD) is the leading cause of blindness and severe vision loss in New Zealand. This booklet provides information about MD. It explains MD and why the macula is important, describes how MD affects vision and how to reduce the risk of developing it. It also explains how to identify signs and symptoms of MD, treatments and support services available.

What is 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. MD is associated with ageing and usually affects people over 50 years of age. It is commonly referred to as Age-related Macular Degeneration or AMD. However, inherited forms of the disease can also affect young people.

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



What is the macula?

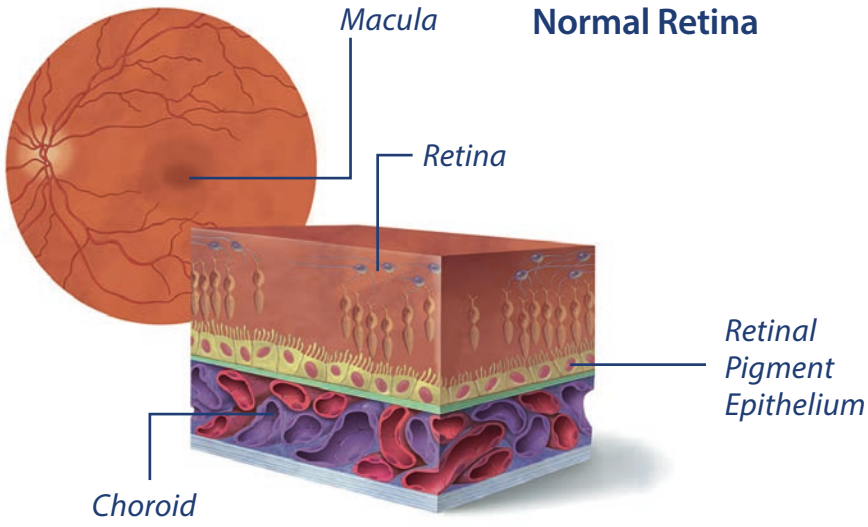
You are reading this using your macula.

The macula is the central area of the retina at the back of the eye. The macula is responsible for detailed central vision and most colour vision, the ability to read, recognise faces, drive a car, see colour clearly and other activities that require fine vision.

The rest of the retina is called the peripheral retina. It is used to see general shapes and provides get-about vision that is also called side or peripheral vision.

How does the eye work?

The eye works like an old style film camera. The front of the eye (cornea, pupil and lens) focuses an image on the retina that lines the back of the eye. The retina is light sensitive and acts like camera film in capturing the image. The image is then sent via the optic nerve to the brain where it is interpreted.



How common is Macular Degeneration?

One in seven New Zealanders (633,000) over the age of 50 has some evidence of MD. Approximately 17% of these people (108,000) experience vision impairment. MD is the leading cause of legal blindness in New Zealand and is responsible for nearly 50% of all cases of blindness.

What causes Macular Degeneration?

MD is caused by genetic and environmental factors. Risk factors include age, family history, smoking and diet and lifestyle factors.

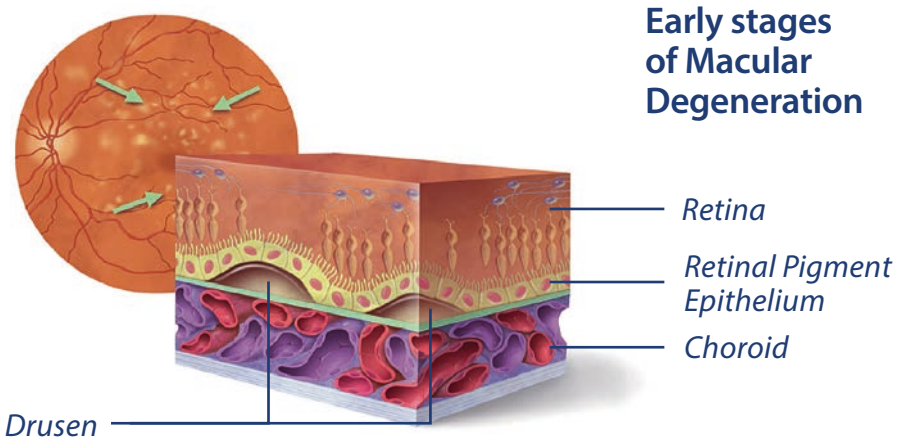
The incidence of MD increases with age.

MD can be hereditary, with a 50% chance of inheriting the genetic predisposition if there is a positive family history of the disease. Since at least 70% of cases of MD have a genetic link, it is crucial that people with MD inform their siblings and children and encourage them to have their eyes, including the macula, checked.

Smokers are 3 to 4 times more likely to develop MD, and smokers may develop the disease 5 to 10 years earlier than non-smokers. Those with a specific genetic predisposition who smoke have a significantly increased risk of developing MD.

What happens in Macular Degeneration?

MD is a disease that affects a special layer of cells in the eye called the retinal pigment epithelium (RPE). The RPE is like a barrier 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.



Early stages of Macular Degeneration

As MD progresses waste products from the retina build up underneath the RPE, forming yellow deposits called drusen. Drusen may be present without you knowing they are there. That is why it is important to have an eye test and the macula checked by an optometrist or eye specialist.

Early signs do not necessarily cause visual symptoms. Furthermore, not everyone with drusen will inevitably lose vision. However, the existence of drusen increases the chance of MD-associated vision loss.

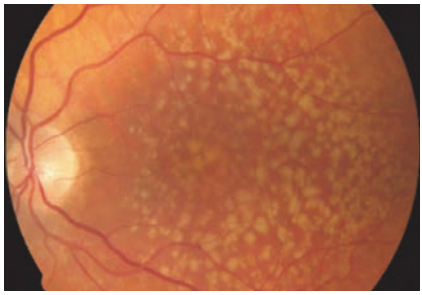
Advanced MD is characterised by vision loss because the RPE cells die or because they fail to keep blood vessels in the choroid from growing under the retina.

Dry Macular Degeneration

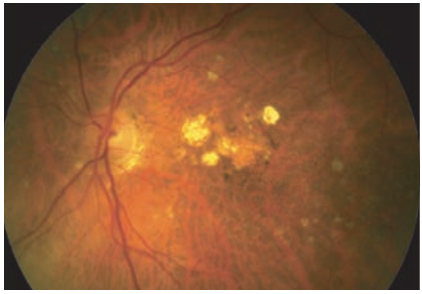
When RPE cells die, the retinal cells above them also die leading to patches of missing retina. This is commonly called geographic atrophy or dry MD. Dry MD is slowly progressive and causes gradual loss of vision over several years. It accounts for 33% of all cases of advanced MD. Five to 10% of people who have dry MD can develop the more aggressive wet form.

Wet Macular Degeneration

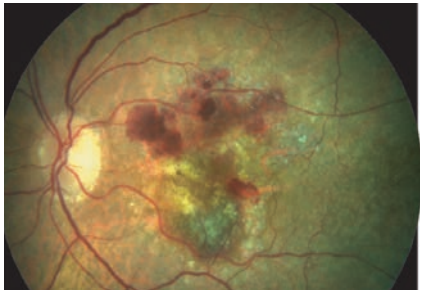
Wet MD occurs when the RPE cells fail to stop choroidal blood vessels growing under the retina. This growth is called choroidal neovascularisation (CNV). The rapidly growing vessels are fragile with leaky walls and they ooze fluid and blood under the retina, leading to scarring and vision loss.



This is what drusen looks like in the eye.



This shows dry MD with patches of missing retina, pigment changes and drusen.



This shows wet MD with bleeding and scarring under the retina.

How do I know if I have Macular Degeneration?

Symptoms include one or more of the following:

- **Distortion, where straight lines appear wavy or bent**
- **Difficulty reading or with any activity that requires fine vision**
- **Difficulty distinguishing faces**
- **Dark patches or empty spaces in the centre of the vision**

With macular degeneration, print may appear distorted, and parts of words may be missing.

Blurred vision

Loss of contrast

The need for increased illumination, sensitivity to glare, decreased night vision and poor colour sensitivity may also indicate something is wrong. These symptoms should not be dismissed as simply part of getting older.

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

Early detection and prompt treatment are crucial to saving sight.

Detecting changes in vision

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

What tests are used to diagnose MD?

Eye examination

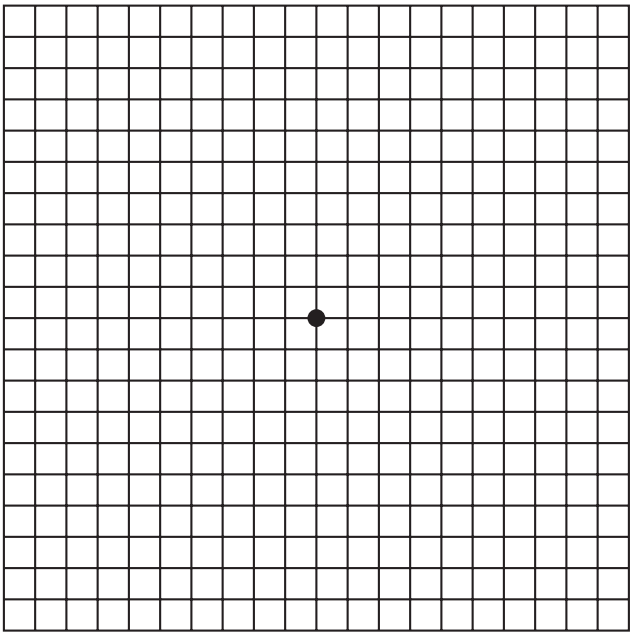
An eye care professional may use eye drops to dilate your pupils to allow a better view of the retina at the back of the eye. After dilation, the vision may be blurry for a few hours. You should not drive while the pupils are still dilated.

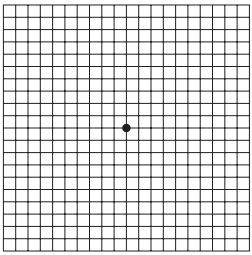
Amsler Grid

The Amsler Grid may be used to detect distortion in vision where straight lines appear wavy or bent and to see if there are dark spaces or empty patches in the vision.

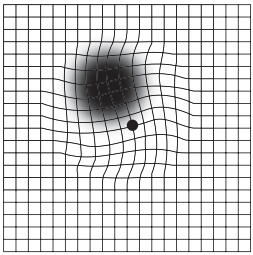
The Amsler Grid

The Amsler Grid is an essential self-monitoring tool used to detect changes in vision. It is not a substitute for regular eye examinations.





Normal vision



See an eye care professional

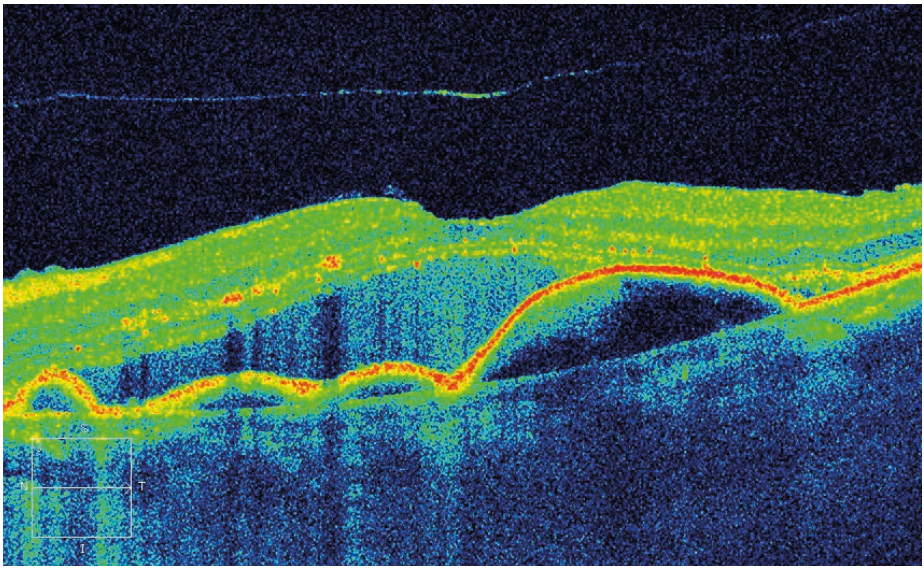
Instructions:

1. **Do not remove glasses or contact lenses normally used for reading.**
2. **Hold the grid at eye level about 35cm from your face.**
3. **Cover one eye with your hand and focus on the centre dot with the uncovered eye. Repeat with the other eye.**

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 doctor or optometrist immediately.

Optical Coherence Tomography (OCT)

An OCT scan is a standard investigation for the diagnosis and ongoing management of wet MD. It is a non-invasive imaging technique that uses light to produce very high resolution cross sectional images of the retinal layers.



This OCT image of a patient with wet MD shows elevation of the retina due to fluid leaking underneath it. This image was originally published in the ASRS Retina Image Bank. Author: James Soque. Photographer: James Soque. Title: OCT Cirrus 5 line HD scan EDI ARMD SRF RPED stage 3 PVD. Retina Image Bank. 2013; 5064. © The American Society of Retina Specialists.

Fluorescein Angiogram

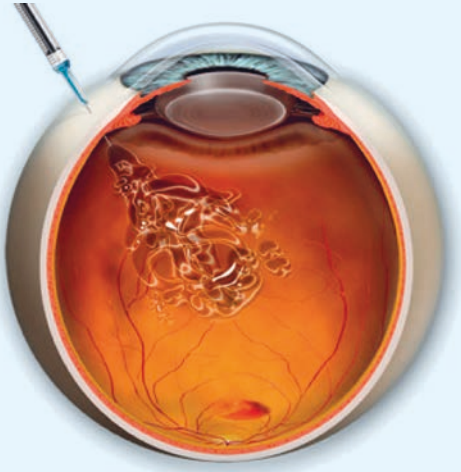
Fluorescein angiography is sometimes used to investigate wet MD. It involves injecting fluorescein dye into a vein in the arm to image the blood circulation at the back of the eye. As the dye circulates through the choroidal and retinal blood vessels, a camera with a special filter is used to take a series of photographs over about 10 minutes. The dye highlights any abnormalities or damage to the blood vessels.

This angiogram of a patient with wet MD shows new blood vessels that have formed and are leaking under the retina. This image was originally published in Retina Gallery. Author: Steven Cohen. Title: Classic subfoveal choroidal neovascular membrane – 6/120 vision. Retina Gallery. 2010.

What treatment is available?

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

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



Anti-VEGF drugs

In wet MD, blood vessels are prompted to grow under the retina by a protein called vascular endothelial growth factor (VEGF). These vessels can bleed, leak fluid and cause scarring under the retina leading to rapid vision loss that becomes permanent if left untreated. To slow or stop this process, various drugs that block VEGF (called anti-VEGFs) can be used.

These drugs consist of an antibody directed at VEGF. They are injected into the eye, spread to the retina and block VEGF induced blood vessel growth. Anti-VEGF drugs have been proven effective in many clinical trials and maintain vision in the vast majority of patients with wet MD.

Treatment usually begins with monthly injections for 3 months. In order to maintain control of the disease, injections may be required indefinitely. However, the interval between injections is determined on an individualised basis by the eye specialist in consultation with the patient.

Avastin (bevacizumab)

Avastin was primarily developed, tested and approved to decrease new blood vessel growth associated with cancer. It is highly effective and used worldwide for treating wet MD. It is funded by PHARMAC, the New Zealand government agency that decides which medicines are subsidised for use in the community and public hospitals. However, it is not registered for the treatment of MD as it was not designed for use in the eye. Avastin is typically used as the initial treatment of wet MD in New Zealand.

Eylea (aflibercept)

Eylea is similar to Avastin and Lucentis but works slightly differently to them. It binds to VEGF significantly more strongly than both Avastin and Lucentis, and also binds placental growth factor (another factor involved in the development of abnormal blood vessels). It is longer acting and only needs to be injected every 2 to 3 months rather than monthly. It is registered for use in the eye and its availability in the New Zealand public health service is restricted by PHARMAC.

Lucentis (ranibizumab)

Lucentis is very similar to Avastin. It is derived from the same parent molecule but is much smaller and has been pharmacologically altered to provide stronger binding to VEGF than Avastin. Lucentis was specifically formulated and registered for use in the eye. It costs significantly more than Avastin and is only available through the private health sector.

Treatment with injections

The choice of the most appropriate drug should be discussed with an eye specialist. Irrespective of which drug is used, the following is a general guide to treatment with eye injections.

- The eye is numbed with eye drops or local anaesthetic. The procedure is quick, relatively painless and usually carried out in the specialist's rooms, although some patients may be treated in a day stay unit.
- Appointments with an 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. This is important for all injection schedules, including when the interval between injections is being increased or injections have ceased.
- Any sudden changes in vision should be reported to an eye specialist immediately, 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 stop unless on the advice of an eye specialist.
- Injections may be required indefinitely to maintain vision.
- If there are any concerns regarding coping with injections, or any difficulties following injection, it is important to raise these with the eye specialist.

Photodynamic Therapy (PDT)

This is a 2-step process combining a light-activated drug called Visudyne (verteporfin) with light from a cold laser directed onto the abnormal area of the retina. Once activated, the drug causes the abnormal vessels to close off. PDT does not cause direct damage to the

surrounding retina. Therefore, it can be used to treat new vessels that are under the centre of the macula (fovea).

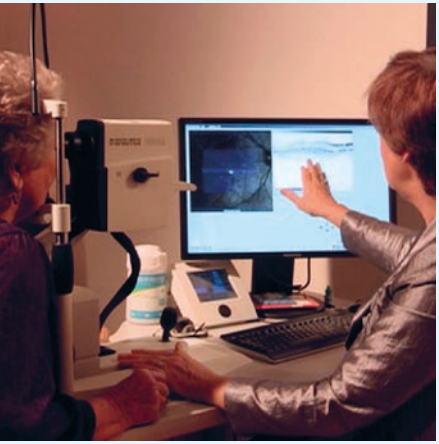
Several treatments are needed to keep the leaking blood vessels closed and stop the progression of wet MD. Close follow up and monitoring is needed to determine if further treatment is required.

Unlike treatment with anti-VEGF drugs that usually maintain vision, patients undergoing PDT continue to lose vision in the first 6 months before vision stabilises.

PDT is now rarely used to treat ordinary wet MD. It is sometimes used in conjunction with an anti-VEGF drug to treat a type of MD called polypoidal choroidal vasculopathy (PCV), as some of these cases do not settle completely with anti-VEGF treatment.

Laser photocoagulation

This treatment consists of a concentrated light beam of high-energy thermal light that is directed onto the retina to destroy and seal leaking blood vessels. It is not painful. The laser not only destroys the abnormal vessels but also destroys adjacent retina. Therefore, it may only be used for treating new vessels that are not under the central part of the macula.



Laser photocoagulation is only used for a small percentage of patients with wet MD. Close follow up is required as there is a 50% recurrence rate.

Treatment options for wet MD should be discussed with an eye specialist.

If you have private health insurance, please check your policy or with your insurer as treatment cover differs between companies.

Coping with vision loss

The challenge

It takes time to adjust to vision loss. People experience different feelings from acceptance to disbelief. Some people experiencing vision loss for the first time may find daily activities challenging. However, with support, assistance and the right advice these challenges can be overcome to maintain quality of life and independence. The more a person knows about their condition, its effects and options for dealing with the challenges presented by low vision, the more confidence they will feel.

The low vision pathway

Moving forward with vision loss begins with taking control. A low vision assessment is the best way to get started. This enables people to find the best strategies and support options for their individual needs. Low vision support utilises advice on appropriate lighting, visual aids and technology to provide solutions for managing daily tasks.

A positive attitude, perseverance and the ability to seek help and support has enabled many people with low vision to fulfil their aspirations and maintain their quality of life and independence in work, home and social settings.

Charles Bonnet syndrome

Charles Bonnet syndrome is a term used to describe the phenomenon of visually impaired people seeing things that they know are not real. Visual hallucinations or phantom images can be extremely vivid and realistic and range from simple, repetitive patterns to detailed images of people, animals or buildings. About 30% of people who experience major vision loss experience this. The images are a consequence of losing sight whereby the brain attempts to compensate for the gaps in vision.

What can I do?

Although age and family history cannot be changed, the following can help reduce the risk of MD and slow its progression.

- Don't smoke
- Eat a healthy, well-balanced diet
- Eat green leafy vegetables and fresh fruit daily
- Eat fish 2 to 3 times a week
- Choose low glycemic index (GI) carbohydrates instead of high GI
- Eat a handful of nuts a week
- Limit your intake of fats and oils
- Maintain a healthy lifestyle, control weight and exercise regularly
- Consider taking a supplement in consultation with your doctor

The Age Related Eye Disease Studies (AREDS 1 and 2) are two major clinical trials conducted by the National Eye Institute in the USA. The studies identified a specific formula of antioxidants including high dose zinc that significantly reduced the relative risk of progression of MD and delayed vision loss.

The daily amounts of these are:

Zinc	**80 mg**
Copper	**2 mg**
Vitamin E	**400 IU**
Vitamin C	**500 mg**
Lutein	**10 mg**
Zeaxanthin	**2 mg**

Any changes in diet or lifestyle should be undertaken in consultation with your doctor. More information is contained in MDNZ's Nutrition and Supplements fact sheet.

MDNZ resources

MDNZ has a range of publications and resources on MD and low vision.

These may be ordered online www.mdnz.org.nz, or by calling MDNZ on 0800 MACULA (622 852)

Call us for a free information kit.

Brochures are also available in Chinese and Korean.

Amsler Grid

This is an essential tool for self-monitoring of sudden changes in vision and possible symptoms of MD.

Nutrition and Supplements fact sheet

This fact sheet provides information on maximising macular health for those with MD as well as those seeking to reduce their risk of developing it.

Eye Map

A quick guide to saving sight. Eight top tips to care for your eyes.

What to ask your eye care professional brochure

This is a helpful resource to ensure you ask the right questions of an eye care professional in order to best understand your condition.

Viewpoint Newsletter

The latest edition bringing you up-to-date information.

In order to ensure continued supply of brochures for the public please consider making a donation ***www.mdnz.org.nz***

Videos to watch online

www.mdnz.org.nz/videos-to-watch-online

- MDNZ Low Vision Services
- MD seminar by Tracey Wong
- Pic Picot opens up about his macular degeneratione
- Awareness and Education Seminar – Dr Andrew Thompson
- What is Macular Degeneration
- MDNZ One News video (Dianne Sharp)
- MDNZ Ambassador Story (Viv Jones)
- TV3 News interview with Dr Dianne Sharp
- A Patients Story – Ross Legh
- News that could save you sight – Philip Sherry
- Professor Bird – The Treatment Revolution
- Dr Dianne Sharp – The Treatment Revolution
- Hook, Line and Sinker – a full length feature film

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Other Low Vision Services

Blind Low Vision NZ

BLVNZ is a registered charity providing practical and emotional support for Kiwis who are blind or have low vision, helping them face the future with confidence and live a life without limits.

Phone **0800 24 33 33**
Web **www.blindlowvisionnz.org.nz**
Email **generalenquiries@blindlowvisionnz.org.nz**

Sight Support Trust

Contact for peer support and information about interventions for the prevention and management of all age related eye disorders.

Phone **0800 55 55 77**
Web **www.sightsupport.org.nz**

Glaucoma NZ

Glaucoma NZ is a registered charity aiming to save sight and eliminate blindness from glaucoma in New Zealand.

Phone **0800 453 826**
Web **www.glaucoma.org.nz**
Email **info@glaucoma.org.nz**

Humanware

Humanware provide a range of advanced electronic magnifiers, Braille products, and digital talking book players that help people with blindness and low vision achieve independence.

Phone **0508 22 55 73**
Web **www.humanware.com/en-new_zealand**
Email **sales@vahumanware.co.nz**

Low Vision Services

Low Vision Consultant Optometrist specialises in helping people with low vision to manage their visual problems.

- Phone **0800 555 546**
- Web **www.sightloss-services.com**
- Email **info@sightloss-services.com**

Retina NZ

Retina NZ is a charitable organisation offering support and education to people with retinal degenerative diseases.

- Phone **0800 569 849**
- Web **www.retina.org.nz**
- Email **admin@retina.org.nz**

Vision Impairment Charitable Trust Aotearoa NZ, VICTA

Low vision rehabilitation. To facilitate the independence, integration and wellbeing of people disabled by visual impairment in NZ.

- Phone **0800 206 620**
- Web **www.visualimpairment.org.nz**
- Email **enquiries@visualimpairment.org.nz**

Macular Disease Foundation of Australia

- Web **www.mdfoundation.com.au**

Macular Disease Society of UK

- Web **www.macularsociety.org**

Eight top tips to care for your eyes...

1. Healthy diet: green leafy veges, fresh fruit & oily fish

2. Take Supplements (AREDS 2 formula) as advised by your doctor

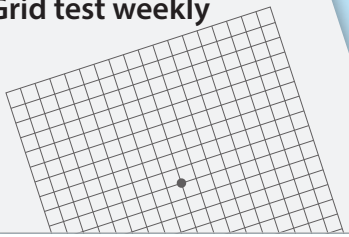
3. Healthy lifestyle: exercise regularly

4. Keep having your injections for wet macular degeneration

5. Stop Smoking

6. Wear Sunglasses

7. Take the Amsler Grid test weekly



8. Have an eye check with an optometrist every 2 years