

DIABETIC EYE DISEASE



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Our focus is your vision

Macular Disease Foundation Australia

Macular Disease Foundation Australia 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 and diabetic retinopathy, is the leading cause of blindness* and severe vision loss in Australia.

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

E: info@mdfoundation.com.au

W: www.mdfoundation.com.au

* legal blindness

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What is diabetes?

Diabetes is a complex, serious, chronic (long-lasting) condition which can have substantial effects on many parts of the body including the eyes, nerves, brain, kidneys, heart and limbs. These effects are largely the result of damage to blood vessels.

A critical aspect of diabetes is that, although it cannot be cured, the complications and related health problems can be significantly reduced or prevented in the vast majority of people with optimal management of blood glucose levels, careful attention to diet, weight management, and regular physical activity.

Diabetes is a very serious condition. It requires daily self management and personal responsibility including the management of blood glucose levels, blood pressure and blood lipids through the maintenance of a healthy weight, healthy diet and healthy activity. Access to a multidisciplinary health professional team will support diabetes care in an individualised manner.

There are three main types of diabetes:

- **Type 1 diabetes** is an autoimmune condition in which the immune system is activated to destroy the cells in the pancreas which produce insulin. It is not known what causes this autoimmune reaction. Type 1 diabetes is not linked to modifiable lifestyle factors and cannot be prevented. Type 1 diabetes can occur at any age though onset is commonly in children, adolescents and young adults. All people with type 1 diabetes need insulin therapy to survive.
- **Type 2 diabetes** is a chronic condition in which the body becomes resistant to the normal effects of insulin and/or gradually loses the capacity to produce enough insulin in the pancreas. It is not known what causes type 2 diabetes. Type 2 diabetes is associated with modifiable lifestyle risk factors (overweight/obesity, unhealthy diet, physical inactivity, stress). Type 2 diabetes also runs in families. Type 2 diabetes commonly develops in adults, although it is becoming more common among children and young adults.
- **Gestational diabetes** is a type of diabetes that occurs during pregnancy and affects 5-10% of pregnancies in Australia. This condition normally disappears after the baby is born, however both the mother and the baby have a higher chance of developing type 2 diabetes later in life.

Diabetes and eyes

Everyone with diabetes is at risk of developing diabetic eye disease. Most people consider sight to be their most precious sense so it is critical to be aware of the risk of diabetic eye disease and to understand how to prevent its onset. For those who already have diabetic eye disease, there are steps to take to reduce the risk of further vision loss.

The management of diabetes can be difficult. Living with diabetic retinopathy and the potential impact on vision can be challenging. However, most people with diabetic retinopathy should keep most, if not all vision, providing it is diagnosed early and all steps are taken to keep it under control.

Eye testing

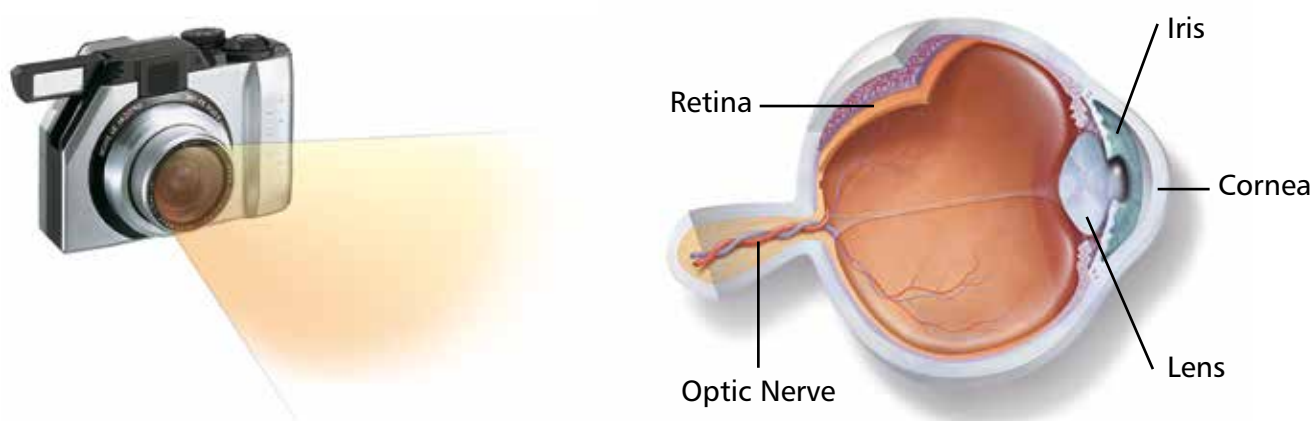
- Important! When you see your eye care professional, make sure you explain that you have diabetes and how long you have had it.
- If you have diabetes, visit an eye specialist (ophthalmologist) or an optometrist at least every two years for a comprehensive, dilated eye exam¹.
- People with diabetes with additional risk factors (eg high blood pressure, poor diabetes control), including indigenous people, need to have an eye check at least every 12 months, even if vision appears to be perfect¹.
- People with existing diabetic eye disease need to have an eye check every 12 months, even if vision appears to be perfect, or more frequently if disease is advanced¹.
- Be guided by the eye care professional, and do not cancel or delay appointments unless absolutely essential.
- The longer you have had diabetes, the more important it is to have regular eye tests, even if the tests have always been clear in the past. This is because the risk of eye disease is strongly related to the duration of diabetes.



Anthony Johnson / Fairfax Syndication

How does the eye work?

The eye is 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 thin 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. The retina is a very active, complex nerve tissue and is supplied with blood by a delicate network of specialised blood vessels.



Light entering the eye is focused onto an area of the retina called the macula, which is about the size of a pinhead. The macula is a highly specialised part of the retina and is responsible for seeing fine detail for activities such as reading and writing, and to recognise colours. The rest of the retina gives side (peripheral) vision.

How does diabetes affect the eye?

Diabetes can affect the eye in a number of ways:

- **Transient blurring of vision:** The unusual changes in blood glucose levels resulting from diabetes can affect the shape of the lens inside the eye, hence changing the focus, especially when blood glucose levels are high. This can result in blurring of vision, which comes and goes over the day, depending on blood glucose levels. This is generally a short term effect, but may impact some people for several months.
- **Diabetic retinopathy:** This is the most common and most serious diabetic eye disease. It is the leading cause of blindness in working-age Australians.

- **Cataract:** A longer-term effect of diabetes is that the lens of the eye can become cloudy. This is called cataract. Cataracts can form in anyone, but they are more frequent and occur earlier in life in people with diabetes.
- **Glaucoma:** Diabetes increases the risk of glaucoma which results in progressive damage to the optic nerve at the back of the eye. While this normally develops slowly, without symptoms in the early stages, it can lead to blindness if not detected early and treated effectively.

What happens in diabetic retinopathy?

Early stages

Over time, high blood glucose levels can lead to damage of the small, specialised blood vessels in the retina at the back of the eye. The vessels become weaker and may leak clear fluid and/or become blocked. This is called **non-proliferative diabetic retinopathy and normally does not affect vision.**

Vision-threatening stages

Leakage of fluid from damaged retinal blood vessels can result in swelling of the retina (edema) and disrupt its normal function. If this swelling is in the central macular area (causing **diabetic macular edema or DME**), it can cause progressive loss of detailed, central vision and even legal blindness, although it won't cause 'black' or total blindness. Diabetic macular edema is the most common cause of vision loss in people with diabetic retinopathy. It frequently affects both eyes at the same time.

Blockage of small retinal blood vessels can disrupt macular function but more importantly, can cause potentially blinding **proliferative diabetic retinopathy (PDR)**. If sufficient blockage occurs, there is a reduction in the supply of oxygen (ischaemia) to the retina. Nature tries to fix this by growing new blood vessels from the retina. Unfortunately, these new vessels are abnormal and are very fragile. They grow forward into the central gel cavity of the eye where they tend to break and bleed into the gel cavity obstructing vision.

The process is progressive and without any symptoms until the vessels bleed. These vessels then scar and may pull on the retina, possibly causing the retina to detach. If proliferative diabetic retinopathy is not treated early, it can result in total ('black') blindness.

With time, the majority of people with diabetes will develop retinopathy, however the severity of disease is greatly influenced by how well diabetes is controlled.

How common is diabetic retinopathy?

Diabetic retinopathy is the leading cause of preventable blindness in working age people in Australia and is considered to be a significant health threat worldwide¹. Almost 1.1 million Australians have diagnosed (known) diabetes². Of these, over 300,000 have some degree of diabetic retinopathy, and about 65,000 have progressed to sight-threatening eye disease¹.



***1.1 million
Australians
have diagnosed
diabetes and
are at risk.***

Risk factors for diabetic retinopathy

Uncontrollable risk factors

- **Duration of diabetes:** The duration of diabetes is the strongest risk factor for developing retinopathy¹. This means that it is very important to keep getting regular eye checks, even if all previous checks have been clear.
- **Ethnicity:** Aboriginal and Torres Strait Islander Australians are two to four times more likely than the general population to develop diabetes and are therefore at a much higher risk of developing vision problems related to diabetes¹. Other groups including some Middle Eastern and Asian populations and Pacific Islanders are also at higher risk.
- **Genetics:** Studies have found that many genetic factors can influence the onset of complications in diabetes, including the severity and speed of onset of diabetic retinopathy¹.
- **Medical history:** Women who have previously been diagnosed with gestational diabetes (or a condition known as polycystic ovary syndrome) are at increased risk of developing type 2 diabetes¹, and hence retinopathy, later in life.

Controllable risk factors

- **High blood glucose:** People who have persistently high blood glucose levels are at risk of serious vision loss and blindness.

Action:

- ✓ Regular follow-ups with healthcare professionals are essential to help preserve vision. People with diabetes whose blood glucose is not at target levels are almost eight times more likely to develop diabetic retinopathy.
- ✓ It is important to speak to the GP or diabetes specialist about personal target blood glucose range, which can depend on age, medical condition and other risk factors.
- ✓ If there is already some degree of diabetic retinopathy, the goal is to get glycated haemoglobin (HbA1c) level to 7% or less (53 mmol/mol)¹. (HbA1c is a measure of the blood glucose control over the preceding few months. Note that the HbA1c target is different to the target for blood glucose at any particular time). A periodic test of HbA1c is therefore recommended.
- ✓ For some people, continuous blood glucose monitoring may be recommended. Guidance should be sought from a diabetes specialist.

- **High blood pressure:** People with diabetes and high blood pressure are not only more likely to develop diabetic retinopathy but it will also progress more rapidly. It will also aggravate any macular edema (fluid leakage)

Action:

- ✓ If there is already some degree of diabetic retinopathy, the aim should be to get systolic blood pressure (the bigger number) to 130 mm Hg or less¹.

- **Blood lipids:** People with abnormal blood lipids are at greater risk of developing diabetic retinopathy.

Action:

- ✓ Get blood lipids to normal levels.
- ✓ Guidance should be sought from a GP or diabetes specialist.



- **Weight and exercise:** People who carry excess weight, especially around the waist, are at substantially increased risk of their diabetes progressing. Regular exercise helps insulin to work better, lowers blood pressure, helps reduce weight and reduces stress. A relatively small weight loss of even 5 to 10% of current weight can result in a significant reduction of risk.

Action:

- ✓ Incorporate exercise into a daily routine.
- ✓ Discuss any planned changes in diet or exercise program with a GP or diabetes specialist.
- ✓ A Credentialed Diabetes Educator® diabetes educator can support the increase of exercise into daily routine.

- **Smoking:** Smoking significantly increases the risk of diabetes and its related conditions. It also increases blood pressure and blood sugar levels, making it harder to control diabetes.

Action:

- ✓ Seek help to quit smoking. The GP can advise on the many support options available.



Preventing diabetic retinopathy

Early detection is critical

Early diabetic retinopathy does not have any symptoms, and progressive damage occurs before any change to vision. Sometimes disease progression can be rapid.

Thirty years ago, the chances of going blind within five years of being diagnosed with severe diabetic retinopathy were no better than 50%. Today, early diagnosis, management and treatment of diabetic retinopathy gives a highly likely chance of saving sight.

Blood glucose levels (sometimes called “sugar” levels)

Strict control of blood glucose will significantly reduce the long-term risk of vision loss. Diet and exercise, along with prescribed medications, are key to achieving control of blood glucose. A Credentialed Diabetes Educator® diabetes educator will often work with the GP and provide detailed self management education.

Blood glucose levels can be monitored at home with a device (blood glucose meter) available from diabetes educators, your state/territory diabetes organisation and most pharmacies. A diabetes educator or pharmacist can help to choose a meter and provide proper training. Talking blood glucose meters are also available for people with vision impairment. A periodic blood test of HbA1c is also recommended as this gives an indication of blood glucose control over several months.

The National Diabetes Services Scheme (NDSS) which is an Australian Government scheme administered by Diabetes Australia provides subsidised access to diabetes self management products and supports.

*For suppliers of talking aids, including blood glucose meters, refer to the Macular Disease Foundation’s publication, **Low Vision Aids & Technology – A Guide** or call the Foundation on 1800 111 709.*

To find a Credentialed Diabetes Educator® diabetes educator go to www.adea.com.au

Contact Diabetes Australia, your state/territory diabetes organisation and the NDSS by visiting www.diabetesaustralia.com.au or 1300 136 588.

Diet

Diet is critical to manage blood glucose levels. Healthy eating for diabetes includes selecting high fibre, lower glycemic index (GI) carbohydrate foods and reducing fat, especially saturated fat. Food intake should be balanced with exercise to maintain a healthy body weight. Always talk to the GP before embarking on or changing a diet.

Ask the GP for a referral to an Accredited Practising Dietitian and diabetes education program for support on healthy eating, including a healthy meal plan tailored to individual needs. Further information on diet is available from Diabetes Australia and State Diabetes Associations. See contacts details at the back of this booklet.

Physical activity

Regular physical activity, including aerobic exercise and resistance training, is an important part of optimal diabetes management. Aerobic exercise can include brisk walking, running, cycling, swimming and dancing. Resistance exercises like modest weight training improve muscle strength and complement the benefits of aerobic exercise.

Physical activity can also be an effective way to manage stress levels and release tension, both of which are important for managing blood glucose levels. Always talk to your GP or diabetes health professional before embarking on a new exercise plan.



How do you know if you have diabetic retinopathy?

The early (non-proliferative) stages of diabetic retinopathy usually have no symptoms. However, once the disease reaches the proliferative stage, vision loss can occur rapidly and can be permanent.

This makes it essential for all those living with diabetes to have a comprehensive dilated eye examination at least every two years, or more often if recommended, and to follow professional advice to reduce the risks of diabetic retinopathy.

Once diagnosed with diabetic retinopathy, there is a need to be checked at least every 12 months, and possibly as often as 3-monthly, depending on the level of disease.

Regardless of whether or not a diagnosis of diabetic retinopathy has been made, it is important to visit an eye specialist or an optometrist as soon as possible if there are any sudden changes in vision.

The following symptoms may not necessarily be signs of diabetic retinopathy, but should always be checked:

- dark spots or holes in the visual field
- blurred, distorted, dim or double vision
- difficulty seeing at night, or increased sensitivity to lights and glare
- frequent changes in glasses prescription
- bright haloes around lights
- flashes and large “floaters” (floaters are specks in the form of dots, circles, lines or cobwebs that move across the field of vision. These will be most noticeable when looking at a white wall or clear sky).

The longer you have had diabetes, the higher the chance that you will get retinopathy. Even if your eye test results have always been clear, do not stop having regular eye checks.

What tests are used to diagnose diabetic retinopathy?

An optometrist or eye specialist will use several tests when diagnosing diabetic retinopathy.

Visual acuity testing

The visual acuity chart measures sight at various distances. From a specified distance, the eye specialist or the optometrist will ask that progressively smaller rows of capital letters be read aloud.

Ophthalmoscopy and slit-lamp examination

Microscope-like viewing instruments will be used to view the retina for the following signs of diabetic retinopathy:

- Leaking blood vessels with small haemorrhages on the retina
- Swelling and inflammation (edema)
- Fatty yellow deposits (exudates)
- Fuzzy white 'cotton-wool spots' that indicate areas where tissue has died and become opaque

Before this examination, the eye care professional should dilate (enlarge) the pupils using eye drops. This gives a better view of the retina at the back of the eye but may cause vision to be blurry for a few hours. It is unwise to drive while the vision is blurry, so arrange how to get home before the appointment. In some patients a photograph of the retina may be taken without pupil dilation.

Tonometry

After the use of some anaesthetic drops, the eye care professional may use a tonometer to measure intraocular pressure which is the pressure of fluids inside the eye.

Supplemental Testing

Additional testing may be undertaken, if appropriate, including:

- **Optical coherence tomography (OCT) scan:** a non-invasive procedure that produces high-resolution images of cross-sections of the retina, allowing its thickness to be measured. This test can also show abnormal fluid build-up in and under the retina.

- **Fluorescein angiogram:** for people with leaking blood vessels or macular edema, an eye specialist may perform a fluorescein angiogram. Fluorescein dye is injected into a vein in the arm and is taken up by vessels of the eye. This identifies any leaking vessels in the retina.

Treatment for early diabetic retinopathy

To attempt to slow, halt or sometimes even reverse the progression of diabetic retinopathy, every effort should be made to correct the modifiable risk factors as discussed previously. Most people with retinopathy will need regular follow-up exams to monitor the level of disease.

Fenofibrate

Typically, during the earlier (non-proliferative) stages of diabetic retinopathy, a person's vision will be monitored carefully. In the past, treatment may not have been recommended unless vision had been affected. The drug fenofibrate which is normally used for treating people with high or unbalanced blood lipid levels, has recently been shown to reduce the risk of diabetic retinopathy progressing by about 30%. It appears to provide benefit even for people who have normal lipid levels³. If you are not already taking this drug, and have any degree of diabetic retinopathy, you should discuss with your eye specialist whether this treatment may be suitable for you.

Treatment for more advanced vision-threatening diabetic retinopathy

Several treatment options are available depending on the stage and location of the disease.

Diabetic macular edema (DME)

The treatment for DME has changed significantly in recent years. Previously, focal or grid laser was the preferred treatment approach. Nowadays, for most people with DME, the usual treatment is a series of injections into the eye using an anti-VEGF drug or in some cases (particularly in people who have had cataract surgery) a steroid. In most people, this effectively reduces the swelling, and for many, some improvement in vision will occur. Some people may also require additional focal or grid laser.

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:

- An anaesthetic is given before the injection. Very little, if any pain should be experienced during the procedure.
- It is a quick procedure and usually occurs in the eye specialist's rooms, although some patients may be treated by the eye specialist in a day-stay unit.
- For those being treated with an anti-VEGF drug, injections are typically given every month for a few months, but may then be given less frequently once the swelling is controlled. For some people, the eye specialist may decide to cease the injections after a period, however others may need to continue to receive injections on an ongoing basis. Even if vision has stabilised or improved, treatment may still need to be continued. This is dependent on each person's individual medical circumstance and discussion between the eye specialist and patient.
- For those being treated with a steroid, the eye specialist will recommend the frequency of injections.
- The treatment schedule should always be followed, and cease only when advised by the eye specialist.
- Appointments with the eye specialist should not be missed, even if there does not appear to be any problem with vision.
- Any sudden changes in vision should be reported to the eye specialist immediately, regardless of whether or not injections are being received. Do not wait for the next appointment.
- Any difficulties experienced after an injection, including significant pain or changes in vision, should be advised to the eye specialist immediately.
- If there are any other concerns you have regarding coping with treatment, discuss them with the eye specialist.
- If injections are given in the doctor's rooms, it is important to register for the Medicare Safety Net as additional reimbursement of costs may apply once a threshold is reached each year. Contact the Foundation for more information on this if necessary.

Proliferative diabetic retinopathy

Potentially blinding proliferative diabetic retinopathy requires laser treatment to a large area of the retina. This is called PRP (pan-retinal photocoagulation) or scatter laser. A large number of laser spots are made in the peripheral retina. This helps to reduce the amount of oxygen needed by the retina and hence reduces the stimulus for the abnormal, fragile, new blood vessels to form. With sufficient treatment, the vessels shrink completely and often permanently. Because of the large number of laser spots needed, more than one treatment session is nearly always required. Although anaesthetic drops and possibly an anaesthetic injection are normally used, some discomfort may be experienced during laser treatment.

As vision is normally quite blurry for several hours afterwards, another person may be needed to take you home.

Some patients with proliferative disease may also receive injections of an anti-VEGF agent (see previous section).

Vitreous bleeding (haemorrhage)

In proliferative diabetic retinopathy (PDR), the abnormal new blood vessels eventually break and bleed into the clear gel (vitreous) that occupies the central cavity of the eye, resulting in partial or complete blockage of vision. The blood will often slowly clear over months but further bleeds usually occur as the PDR gets progressively worse. If left untreated, the scar tissue that forms may result in complete and permanent loss of all vision. Early, extensive laser treatment (PRP) must be undertaken.

In some severe cases of PDR, laser treatment is unable to penetrate the blood in the vitreous cavity. An advanced, delicate surgical operation called a vitrectomy may be necessary. During the operation, the vitreous gel and blood is removed, and any pulling on the retina is relieved. Some laser treatment is also usually given at the end of the procedure.

The procedure is done in an eye operating theatre under anaesthesia, usually on a day case basis.

Managing vision loss

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 will 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 maintain quality of life and independence.

Macular Disease Foundation Australia resources

Macular Disease Foundation Australia has developed a comprehensive range of publications and resources on 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 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 a “fall free” environment can be created.



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For information, guidance and support contact:

Macular Disease Foundation Australia

P: 1800 111 709

W: www.mdfoundation.com.au

E: info@mdfoundation.com.au



Diabetes Organisations

State	Organisation	Phone	Website
ALL	Diabetes Australia	1300 136 588	www.diabetesaustralia.com.au
NSW, ACT	Diabetes NSW & ACT	1300 136 588	www.diabetesnsw.com.au
VIC	Diabetes VIC	1300 136 588	www.diabetesvic.org.au
QLD	Diabetes QLD	1300 136 588	www.diabetesqld.org.au
SA	Diabetes SA	1300 136 588	www.diabetessa.com.au
WA	Diabetes WA	1300 136 588	www.diabeteswa.com.au
TAS	Diabetes TAS	1300 136 588	www.diabetestas.org.au
NT	Healthy Living NT	1300 136 588	www.healthylivingnt.org.au

References:

¹ Guidelines for the management of diabetic retinopathy, NHMRC, 2008

² <http://www.diabetesaustralia.com.au/Understanding-Diabetes/>

³ Keech A et al, Lancet 2007;370:1687

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Contact Macular Disease Foundation Australia



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**Macular Disease Foundation Australia
Suite 902, Level 9, 447 Kent Street
Sydney NSW 2000**

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

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