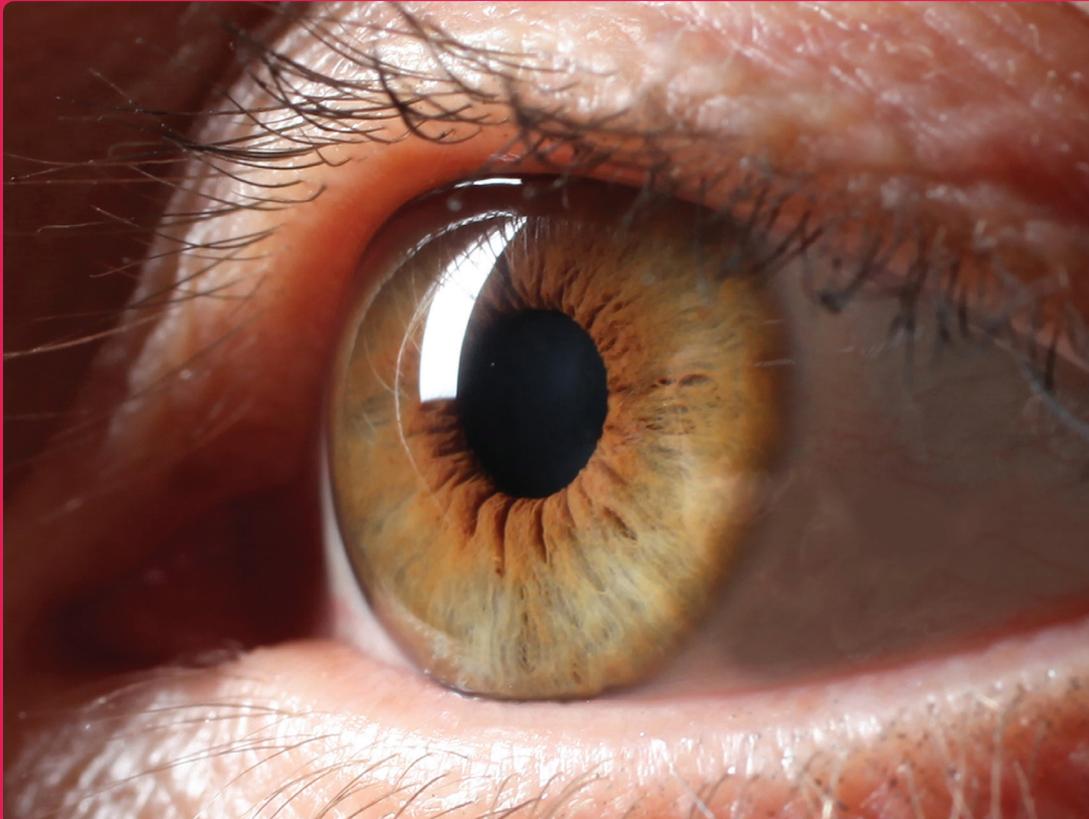


Macular Society

Beating Macular Disease

Your guide to
**diabetic
macular oedema**



Introduction

The Macular Society is the only charity dedicated to beating macular disease. This guide explains how diabetes can affect the eyes.

Being diagnosed with diabetic macular oedema can be distressing and worrying but, with the right information and support, people can cope very well. Macular oedema is painless and treatments are available. Macular oedema affects central vision, but peripheral vision is not affected. However, other forms of diabetic retinopathy may affect your wider vision.

How diabetes affects your eyes

People with diabetes are at risk of damage to their eyesight. To work properly, the eye needs a constant supply of blood. When control of blood sugar and insulin levels in the body is poor, the blood vessels of the eye become damaged. The blood vessels of the retina are particularly prone to leaking and a condition known as diabetic retinopathy can develop.

Diabetic macular oedema (DMO) is a form of diabetic retinopathy that occurs in the central part of the retina – the macula. DMO is a serious eye condition. Oedema is the medical term for fluid retention in the body.

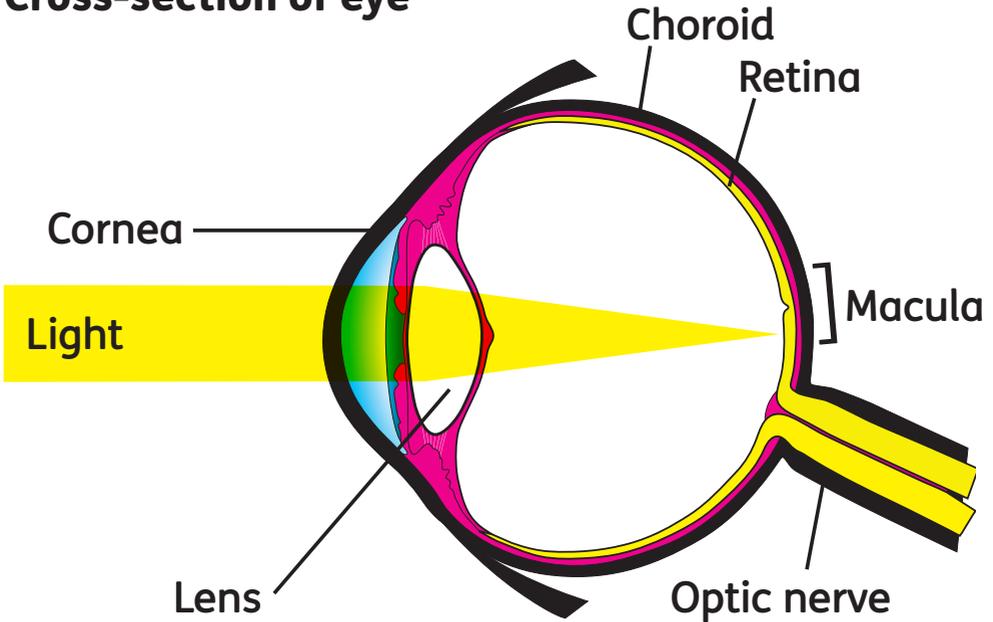
People with diabetes should reduce their risk of vision loss by attending their annual diabetic eye screening appointment.

What is the macula?

The macula is the central bit of the retina. The retina is the tissue at the back of the eye which senses light. The macula is about 5mm across. It is responsible for our central vision, our colour vision and the fine detail of what we see.

The macula has a very high concentration of photoreceptor cells that send signals to the brain which interprets them as images. The rest of the retina processes our peripheral, or side vision. Damage to the macula can mean losing the ability to read, watch TV or recognise faces.

Cross-section of eye



Symptoms

In the early stages of diabetes a person may not notice any effect on their vision. Damage to the retina occurs over many years in someone with diabetes. It may affect the entire retina but when the damage causes only small bulges in the

blood vessels of the retina, the eyesight remains good. However, when the blood vessels in or close to the macula become damaged, or there is sudden bleeding or fluid leak into the macula, then sight can worsen dramatically.

- Dark spots like a smudge on glasses or gaps may appear in your vision, especially first thing in the morning.
- Objects in front of you might change shape, size or colour or seem to move or disappear.
- Colours can fade.
- You may find bright light or glare difficult.
- You may experience difficulty reading.
- Straight lines such as door frames and lamp posts may appear distorted or bent.

Preventing high blood pressure by giving up smoking and cutting down on salt in your diet can help to reduce the risk of retina damage.

If you notice a sudden change in your vision, contact your optometrist or hospital eye specialist urgently.

Risk factors

The longer you have diabetes, the greater your chance of developing sight loss through DMO. About 90% of people with type 1 diabetes will have some degree of retinopathy after 10 years of having diabetes. For people with type 2 diabetes the chance of developing some degree of retinopathy after 10 years varies between 67–80%, depending on whether they need to take insulin.

More than a third of all diabetic patients will develop a level of severity of macular oedema which, without changes to the person's lifestyle and better control of blood sugar, will require treatment.

If your blood sugar level is high, you increase the risk of developing retinopathy. Small changes in

your levels can significantly affect your risk of developing retinopathy and if you have high blood pressure as well, you have a higher risk of developing advanced retinopathy. Overall, 7% of all people with diabetes develop DMO, which will result in a noticeable loss of vision.

Diagnosis

If DMO is suspected, you will be referred to the eye hospital for tests. Your hospital specialist (ophthalmologist) may use:

- eye drops to dilate the pupils to allow them to clearly see the back of the eye. The drops may make your vision blurred and sensitive to light for a short time so consider taking someone with you.
- Scans using optical coherence tomography (OCT) to produce a cross-sectional image of the retina.
- Fluorescein dye angiography. A dye is injected into a vein in the arm. It travels to the eye, highlighting the blood vessels in the retina

so they can be photographed. The dye will temporarily change the colour of your urine.

If you have any vision problems in between your appointments seek immediate advice from your diabetes care team or GP. Do not wait until your next hospital appointment.

Treating DMO

DMO can be treated if caught early. Drugs are injected into the eye to stop fluid leaking from the blood vessels. Following diagnosis, people will usually have a number of injection treatments in the first few months. Subsequent check-ups will then be required to assess when more injections are needed.

The injections are not as bad as they might sound. The eye is anaesthetised and the needle goes into the corner of the eye so the patient does not see it. These are called intravitreal injections. The treatment cannot restore sight if there is already significant damage to the macula.

There are two drugs in use for treating DMO: Lucentis® (ranibizumab) and Eylea® (aflibercept). They act on the blood vessels in the retina to reduce fluid leakage that leads to oedema in the eye.

The frequency and number of injections depends on how a patient responds to the drug. Ask your eye doctor about your treatment programme. Do not miss a treatment session – any sight loss cannot be recovered.

A third drug, Avastin® (bevacizumab), may be used. However, its routine use is to treat cancer and it is not licensed in the UK for treatment in the eye.

Some people who have had cataract surgery or who have a particular form of DMO may be offered an intravitreal injection of a steroid drug called Iluvien® (fluocinolone acetonide) or Ozurdex® (dexamethasone). They are slow-release drugs implanted in the eye.

Laser treatment

Some people may be offered laser treatment when the DMO does not involve the centre of the macula. This treatment aims to stabilise vision and does not generally improve sight. It usually involves one or more visits to an outpatient laser clinic for treatment by an ophthalmologist.

Before the procedure, local anaesthetic will be administered to the surface of your eye, as well as eye drops to widen your pupils. A special contact lens will be placed on your eye to hold your eyelids open and allow the laser beam to be focused onto your retina. Laser treatment is not usually painful, but you may feel a sharp pricking sensation.

Protecting your eyes

Diabetes is a lifelong condition, so maintaining a healthy lifestyle and monitoring your blood sugar, blood pressure and cholesterol levels is crucial to avoid damage to your eyes.

The following can help to protect your eyesight:

- Monitor your blood sugar levels regularly, aiming to keep within limits recommended by your doctor or nurse.
- Maintain a healthy weight and blood pressure.
- Eat plenty of fruit and green vegetables.
- Drink only a modest amount of alcohol.
- Take regular exercise.
- Do not smoke.

It is essential that you attend your diabetes clinic appointments. Your diabetes care team will maintain and monitor your diabetes care plan. Make sure that your eyes are screened at least once a year to spot any problems early.

If you wear glasses or contact lenses continue to visit your optician regularly and tell the optometrist that you are diabetic.

Managing daily living

Loss of central vision through DMO can be very frustrating and can greatly affect everyday life. You can make your remaining vision more comfortable by wearing lenses that block UV and blue light and that reduce glare, and by wearing a hat with a brim or visor to shade eyes from direct sunlight.

Even if you are having treatment for DMO, it is important to know what to do if you reach a stage where you begin to struggle with daily tasks:

- Improve the lighting at home and work. A person with normal sight needs three times as much light at 65 as they did when they were 21. A person with DMO will need even more. Control glare and keep general lighting levels bright and even.
- Use task lighting for reading and close-up tasks. Daylight bulbs can be helpful.
- Bright and contrasting colours can help

differentiate between objects.

- A wide variety of low vision equipment is available including magnifiers. You may be able to buy or borrow them from your local low vision service.
- Computers have options that can read text and emails as audio. Using technology, including the Kindle or iPad, means you can read books in large print format.
- Buy or borrow large-print books, audio books, newspapers and magazines.
- Use talking equipment such as watches, wall clocks, microwaves and kitchen scales.
- Audible liquid level indicators warn when a cup or jug is full.
- Tactile bumps help you find settings on appliances like washing machines.
- Use large face clocks and watches, large print stickers for keyboards and telephones with large numbers.

Your guide to diabetic macular oedema

- Ask your ophthalmologist whether you might be eligible to be registered as sight impaired. This can be useful to help you get more support from social services and it also alerts the government anonymously to how many people have problems with DMO.

For more information about how to manage daily tasks, visit macularsociety.org/daily-living-skills



Visual hallucinations

Some people with DMO experience visual hallucinations called Charles Bonnet syndrome. These images might be of people, animals, landscapes or patterns.

People who haven't heard of Charles Bonnet syndrome often worry they are developing a mental health problem. However, it is actually a normal response of the brain to sight loss. As fewer messages reach the brain, the cells that normally process vision can create images of things that are not there.

They may occur once or twice, or continue for several years and can be distressing.

For further information about visual hallucinations, see our 'Visual hallucinations' leaflet, call the Advice and Information Service on 0300 3030 111 or visit [macularsociety.org/visual-hallucinations](https://www.macularsociety.org/visual-hallucinations)

Amsler grid

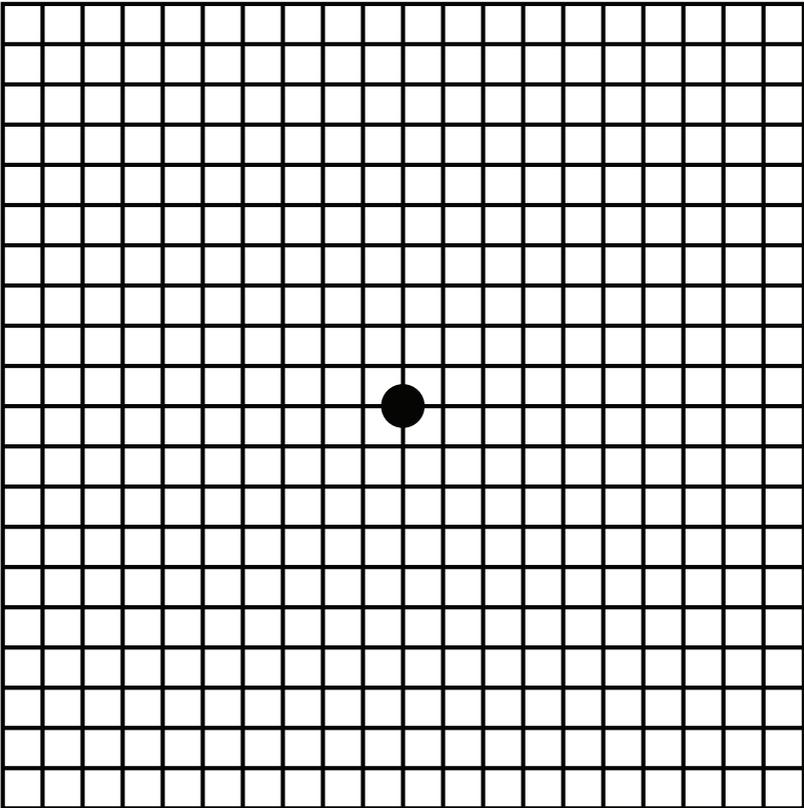
Use an Amsler grid to monitor your vision in case it changes.

Wear any reading glasses you normally use (but not varifocals). Hold the grid about 12 inches (30 cm) from you, where it is best in focus.

Cover each eye in turn and look at the central dot.

If you have DMO the lines of the grid may appear wavy or broken. Parts of the grid may be blurred or missing.

If you see any changes to your vision, contact your ophthalmologist immediately. Do this weekly or as often as your optometrist or ophthalmologist recommends.



How we help

Macular disease is the biggest cause of sight loss in the UK, with around 300 people diagnosed every day.

The Macular Society is the only charity determined to beat the fear and isolation of macular disease with world class research, and the best advice and support.

Our research programme is focused on finding new treatments and a cure to Beat Macular Disease forever. To support people affected by macular disease now, the Macular Society provides a range of support, information and services:

The Advice and Information Service (0300 3030 111) is available Monday to Friday, 9am to 5pm. Alternatively, you can email help@macularsociety.org



Our **website** provides a wide range of information and resources for people affected by macular disease. You can also find out more about the services we offer. Visit it at **macularsociety.org**

Our network of over 400 **Macular Support Groups** stretches across the UK. Each one offers practical and emotional support for people with macular disease, from those living with it today.

We provide a confidential **Counselling Service** over the phone. Call the Advice and Information Service for more information.

For more information on diabetes:

Diabetes UK 0345 123 2399

info@diabetes.org.uk. diabetes.org.uk.

Beating Macular Disease:

- Providing the best advice and information on living with macular disease.
- Local Support Groups helping you to beat the isolation of macular disease – with support and companionship.
- Research focused on finding a cure to Beat Macular Disease forever.

We rely on donations to fund support services and research to find a cure. To donate please go to macularsociety.org/donate or call **01264 350 551**.

Macular Society

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Patient Information Forum

