

See differently

#### Understanding

### Diabetes Related Eye Conditions

Including Diabetic Retinopathy



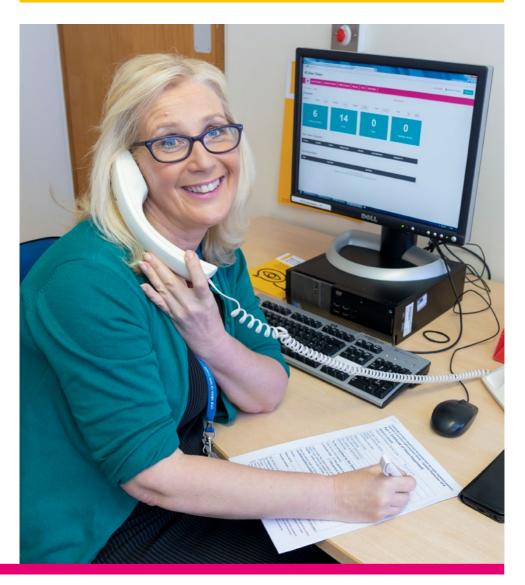


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#### **Sight Advice FAQs**

Ask the Sight Advice FAQ website your questions about sight loss, and get helpful answers: **sightadvicefaq.org.uk** 



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#### **RNIB's Understanding series**

The Understanding series is designed to help you, your friends and family understand a little bit more about your eye condition.

The series covers a range of eye conditions, and is available in audio, print and braille formats.

#### **Contact us**

We're here to answer any questions you have about your eye condition or treatment. If you need further information about how diabetes can affect your eyes or if you have questions about coping with changes in your vision, then our Helpline is there for you.

RNIB Helpline 0303 123 9999 helpline@rnib.org.uk Or say, "Alexa, call RNIB Helpline" to an Alexa-enabled device.

### What is diabetes?

Diabetes (diabetes mellitus) is a condition where your body is not able to use glucose properly, causing the glucose levels in your blood to become too high.

Glucose is a type of sugar that is produced by your body when you eat foods and have drinks containing carbohydrates. When your body breaks down these foods and drinks, glucose goes into your bloodstream, making your blood glucose (blood sugar) levels high. This high blood glucose level triggers your pancreas to make a hormone called insulin. The pancreas is an organ just behind your stomach. After you have eaten and your blood sugar level rises, insulin is released into your bloodstream. It moves the glucose from your blood into the cells of your body, where it is used to give you energy. When this process works well, your blood glucose levels are maintained and will return to a normal level.

If you have diabetes, your pancreas either doesn't make any insulin at all, it doesn't make enough, or your cells don't respond to insulin as well as they should. This means a high level of glucose stays in your bloodstream instead of being used to give your body the energy it needs. Diabetes is a lifelong condition, and it can lead to problems in various parts of the body. These other health problems are known as the complications of diabetes. Your eyes are one part of your body that diabetes can affect.

### Around one person in 15 is diagnosed with diabetes in the UK.



# What are the different types of diabetes?

Diabetes is a complex condition and there are many different types. The most common types of diabetes are type 1, type 2, and a type that occurs during pregnancy known as gestational diabetes.

There are also other forms of diabetes that can be caused by other factors. These include:

- type 3c, where there is an illness or a condition that affects the pancreas itself
- diabetes that is induced by taking certain medications, such as steroids
- diabetes that forms part of some rarer syndromes, such as Alström Syndrome, where other aspects of a person's general health are also affected.

#### Type 1 diabetes

If you have type 1 diabetes, your pancreas can't produce any insulin. This is because the body's immune system, which should fight infections, targets the cells that produce insulin in the pancreas by mistake. When the body's immune system attacks itself, it is called an auto-immune condition. It is not fully understood why this happens, but it is not because of anything that you have or haven't done. Although Type 1 diabetes can begin at any age, it normally develops at a younger age, before your 30s, and it is the most common type of diabetes to affect children. People with type 1 diabetes will need to use insulin to control the condition. Insulin can be given either via injection or an insulin pump, which is worn continuously on the body. To find out what delivery system is appropriate for you, speak to your diabetic medical team.

#### Type 2 diabetes

Type 2 diabetes is the most common type of diabetes. If your body doesn't make enough insulin or your body can't use insulin properly (insulin resistance), this is called type 2 diabetes. This type of diabetes normally develops later in life, typically over the age of 40 for most people, but it can happen at a younger age for some. The risk of developing type 2 diabetes increases with certain factors including:

• Your age: If you're Caucasian, your risk increases over the age of 40. If you're South Asian, (Indian, Pakistani or Bangladeshi), Black African or African-Caribbean, your risk can increase over the age of 25.

- Your ethnicity: your risk increases if you're of South Asian, Black African, African-Caribbean or Chinese descent.
- Your weight: if you're overweight or obese.
- Your waist measurement: greater amounts of fat around your waist can build up around the pancreas and liver and prevent the body's insulin from working properly.
- Your family history: where a parent or sibling has diabetes.
- Your general health: there can be an increased risk of diabetes if you have a history of high blood pressure, heart attack or stroke.

Type 2 diabetes is often managed by eating a healthy diet, losing weight and exercising. For some people, these lifestyle changes can mean they don't need to take any medication to control their condition. However, some people still need to take tablets, and in some cases have insulin injections, to control their type 2 diabetes.

#### **Gestational diabetes**

Some women who are in their second or third trimester of pregnancy can develop a type of diabetes called gestational diabetes. In most cases, this diabetes goes away after pregnancy. However, having gestational diabetes increases your chances of developing type 2 diabetes later in life.

#### Type 3c

Type 3c diabetes only results from injury or illness of the pancreas, or when part or all the pancreas has been removed. This means the pancreas stops making enough insulin for the body. Not everyone whose pancreas is damaged in this way will develop type 3c diabetes, as the severity of the condition will depend on how much of their pancreas is affected and the health of the remaining tissue.

Further information about all types of diabetes can be found on the Diabetes UK website at **diabetes.org.uk**. Their contact details can also be found at the end of this booklet.

### How your eye works

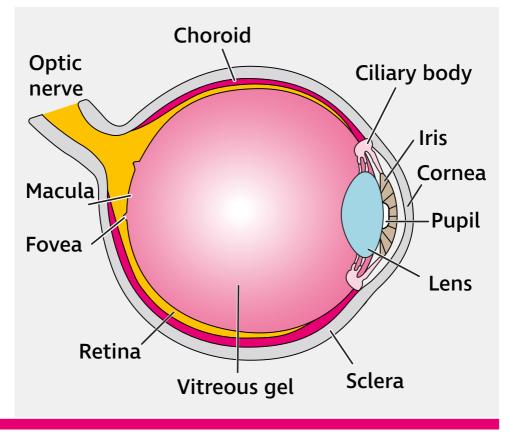
When light enters your eye, it's focused by the cornea and lens at the front of the eye onto your retina which lines the back of the eye. The retina is a delicate tissue that is sensitive to light. It converts light into electrical signals which then travel along the optic nerve to your brain. The brain interprets these signals to 'see' the world around you. When you look directly at something, the light entering your eye is focused onto a tiny area of your central retina called the macula. The macula is vital because it lets you recognise colours and see the fine detail needed to carry out activities such as reading and



writing. The rest of your retina gives you peripheral vision (also known as side vision) and the ability to see in dark conditions.

To keep the retina healthy, it is supplied with blood by a delicate network of blood vessels. These blood vessels can be damaged by diabetes.

The following diagram shows the cross-section of an eye. From the front to the back of the eye, it is labelled cornea, pupil, iris, lens, vitreous gel, optic nerve, macula, fovea and retina.



### How can diabetes affect my eyes?

Not everyone who has diabetes develops a related eye condition, so it's possible that your diabetes won't cause any changes to your vision. This is more likely when your blood glucose levels are more consistently within the target range recommended for you by your diabetic medical team. This is often referred to as having a good 'time in range'.

## However, when diabetes does affect the eyes, it can do so in other ways. These include:

#### An unstable glasses prescription

- The changes in blood sugar levels caused by diabetes can affect the natural lens inside your eye, especially when your blood glucose levels are not well controlled. Sometimes, these changes can be the first sign of diabetes and you may not yet be diagnosed.
- Your vision can become more blurred and can be variable throughout the day or from day to day, depending on the level of glucose in your blood. High levels of blood glucose can lead to high sugar levels in the fluid around the lens inside the eye. This causes the lens to swell with more water than usual. A swollen lens will focus light

differently on the retina at the back of the eye, leading to blurry vision. It can also mean that a glasses prescription will be variable and unreliable.

 As your blood glucose becomes better managed, this variation in your vision will settle down. However, this can take a month or two for some people. Your optometrist (optician) may be able to offer some advice as to how to manage with the change in your vision in the meantime. This may include using less expensive ready-made reading glasses in the short term, or possibly going back to an old pair of glasses you still have, if your vision is clearer with them during this period. It is advisable that you wait until your diabetes and your vision have become more stable before buying any new prescription glasses from an eye examination.

#### **Diabetic retinopathy**

 Over time, diabetes can affect the network of blood vessels supplying the retina at the back of the eye, and this damage changes how well the retina works. This is known as diabetic retinopathy. There are different stages of diabetic retinopathy, and how your vision is affected will depend on the severity of the changes to the retinal blood vessels and the area of the retina that is involved. Diabetic retinopathy is discussed in more detail in the next section of this information.

#### Cataract

Diabetes can cause the lens in your eye to become cloudy. This condition is known as a cataract. If you have diabetes, you're more likely to develop a cataract, and at an earlier age than might be expected in someone without diabetes. Cataracts can be removed with surgery.

More information about cataracts can be found on our website **rnib.org.uk/eyehealth** or by calling our Helpline.

#### Glaucoma

Some people with diabetes may develop glaucoma, an eye condition where the pressure inside the eye damages the optic nerve at the back of the eye. Glaucoma can be treated with eye drops, laser treatment or surgery if necessary. More information about glaucoma can be found on our website or by calling our Helpline.

#### Other associated eye conditions

There may be an increased risk of other eye conditions when you have diabetes, including those that affect the cornea, eye muscle problems, or retinal vessel occlusion (a blocked retinal blood vessel). More information about retinal vessel occlusion can be found on our website or by calling our Helpline.



### What is diabetic retinopathy?

A healthy retina needs healthy blood vessels to deliver oxygen and nutrients and remove its waste products. The high blood glucose levels caused by diabetes can damage the blood vessels in the retina, so that they can become blocked, they leak, or they grow incorrectly. This can lead to complications in the eye known as diabetic retinopathy.

There are different types of retinopathy and the type you have relates to how much blood vessel damage has been caused by your diabetes. Retinopathy that affects the macula specifically is known as maculopathy. On medical reports, letters from the hospital or result letters from a diabetic eye screening test, these retinal changes may also be graded according to their severity from R0 to R3 (R0 to R4 in Scotland) for retinopathy, and from M0 to M1 (M0 to M2 in Scotland) for maculopathy. When no retinopathy is present, the grading given is R0 and where there is no maculopathy, the grading is M0.

#### **Background diabetic retinopathy**

Background retinopathy does not usually affect your sight and is graded R1 (R1 or R2 in Scotland, depending on the changes seen). Background retinopathy is present when the capillaries (the smallest blood vessels) in your retina become weakened, causing them to develop small areas of swellings in their walls. These swellings are known as microaneurysms. A microaneurysm may haemorrhage (bleed). It may also leak a fluid containing proteins and lipids (fats) called exudate. These changes don't cause sight problems immediately, but your eyes will need to be monitored to make sure your retinopathy doesn't progress and get worse.

#### Pre-proliferative diabetic retinopathy

If background retinopathy gets worse, many of the retinal blood vessels can become damaged or blocked. If these changes happen over a large area of your retina, it will have an insufficient blood supply, and this is known as ischaemia. When there is retinal ischaemia, the oxygen starved cells stop working properly and there will be signs that ischaemia is present when your retina is examined. This is known as pre-proliferative diabetic retinopathy, which is graded R2 (R3 in Scotland). Someone with pre-proliferative diabetic retinopathy will have their eyes examined more often to check that the retinal ischaemia does not get any worse.

#### **Proliferative diabetic retinopathy**

As retinal ischaemia increases, the body tries to make up for the lack of oxygen by growing new blood vessels on the retinal surface or into the clear vitreous gel just in front of the retina. This new blood vessel growth is known as neovascularisation. Unfortunately, these new vessels are weak, and they bleed (haemorrhage) very easily. The ischaemia can damage the retina, causing areas of sight loss where the retina cannot work properly. These changes are known as proliferative diabetic retinopathy, which is graded R3 (R4 in Scotland). Proliferative diabetic retinopathy is often treated with a laser treatment known as pan-retinal photocoagulation (PRP) laser.

The new vessels that form may also bleed into the vitreous gel. A vitreous haemorrhage can reduce or totally obscure your vision in the affected eye, as light entering your eye is blocked by the blood. With time, the blood may be reabsorbed into your body and your vision may improve. But there is a chance that these haemorrhages will keep happening, and the blood may not be completely reabsorbed. Your ophthalmologist may wish to monitor this over a few weeks or months, as for some people, a haemorrhage like this gradually goes away on its own over time. However, if you're

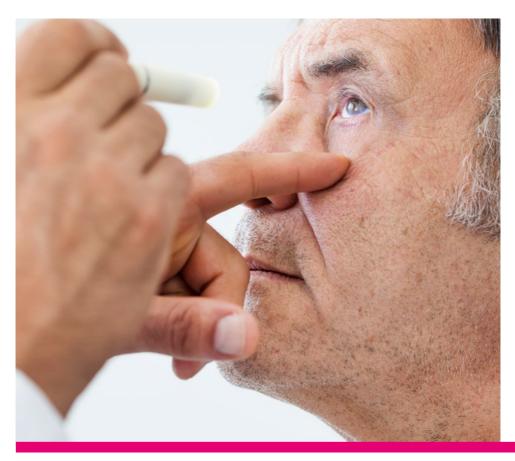
told that you need treatment to clear the blood from inside the eyeball, you'll be offered a surgical procedure known as vitrectomy. This treatment is discussed in more detail further on in this booklet.

If proliferative diabetic retinopathy worsens, scar tissue can develop on the retinal surface which can pull and distort the retina as it shrinks. This can sometimes cause the retina to detach from the back of the eye and can lead to more severe sight loss. Retinal detachment is also treated with vitrectomy surgery in some cases.

Advanced ischaemia in the eye can lead to further new blood vessel growth on the iris, the tissue giving your eye colour, as well as over the drainage channels inside the eye which affects the eye pressure. This can cause your eye pressure to increase and lead to neovascular glaucoma. If there are new blood vessels growing on your iris, it's likely that you'll be offered laser treatment to the retina. More information on laser treatment can be found further on in this booklet.

When proliferative changes are active and unstable, there is an increased risk that over time, your sight could be permanently affected. At this stage, you'll be offered treatment such as laser treatment or surgery. When the condition is stabilised after successful treatment, your eyes will still be monitored closely, either within the eye clinic or the diabetic eye screening service. If your retinopathy becomes active again, further treatment will be needed.

Not everyone with diabetes will develop proliferative diabetic retinopathy, but it's more common in people with type 1 diabetes than in those with type 2.



## Diabetic maculopathy and diabetic macular oedema

When diabetic retinopathy affects your macula, it's known as diabetic maculopathy and is graded M1 (M1 or M2 in Scotland depending on severity). Diabetic maculopathy may cause your central vision to become blurred, and this affects seeing fine detail and colour. This makes detailed tasks like reading, writing and recognising faces more difficult.

If the blood vessels near the macula are leaky, fluid can build up and cause macular swelling. This is called diabetic macular oedema (DMO) and it can cause your central vision to be blurred and distorted, as well as making colours appear washed out. Over time, DMO may give you a blank patch in the middle of your vision.

DMO may be treated with laser in some cases if the leak is away from the centre of the macula. However, if it affects the central part of the macula, it may require treatment with injections into the eye. More information on the treatment of DMO can be found later in this information.

# Can I reduce the risk of developing retinopathy?

If your blood sugar levels are continually high, there's a greater chance the blood vessels in your eyes will become damaged and that more serious diabetic retinopathy will develop over time. There is also some evidence that for some people, a sudden and intensive reduction in a previously high blood sugar level can also cause problems, so speak to your diabetic medical team if you have any questions about how best to manage your condition. However, the more consistently your blood sugars stay within your target range, the lower your risk of developing serious problems with your eyes. Looking after other aspects of your health is also important, such as managing your blood pressure and cholesterol.

There are things you can do to help control your risk of developing retinopathy or stop it from getting worse. These include:

- Doing your best to keep your blood glucose level in your target range as consistently as you can.
- Controlling your blood pressure to keep it within your target range.
- Controlling your cholesterol levels.

- Keeping as fit as you can with regular exercise and a healthy diet to help maintain a healthy weight.
- Giving up smoking. Nerve damage (known as neuropathy), kidney disease and cardiovascular disease are more likely in smokers with diabetes. Smoking increases your blood pressure and raises your blood sugar level, which makes it harder to control your diabetes. Your GP can tell you about NHS stop smoking services in your area.
- Attending all your diabetic health checks at the GP surgery or diabetic clinic is important. Diabetes isn't always easy for some people to control, so do speak to your diabetic nurse or medical team if you need further support with this.
- Attending regular diabetic eye screening appointments as advised. Early detection and treatment will protect your sight.

## However, there are some risk factors that you cannot control:

- How long you've had diabetes: The longer you've had diabetes, the more likely you are to develop some form of retinopathy.
- Your age: You're more likely to develop diabetes as you get older.

- Your ethnicity: If you or your family are from India, Pakistan, Bangladesh or Sri Lanka (South Asian communities), or from an African-Caribbean background, you're more likely to get type 2 diabetes. The factors behind this aren't fully understood but are thought to involve insulin problems, genetics, diet and lifestyle.
- **Pregnancy:** This is a particular risk if you are already diabetic or have had gestational diabetes before.

Unfortunately, despite doing all they can to reduce their risk factors, some people still develop more serious diabetic retinopathy which affects their sight. However, by attending all diabetic eye screening and hospital eye clinic appointments as advised, will mean that these changes can be detected sooner rather than later, so that appropriate treatment can be given to try to protect your sight and stop your condition from getting worse.

For detailed information on how to reduce your risk of all diabetic complications, visit Diabetes UK's website at **diabetes.org.uk** 

# Why are regular eye examinations and screening tests so important?

Most of the eye problems caused by diabetes can be treated, but it is vital that these problems are picked up as soon as possible, as treatment is more effective when given early. Having your eyes checked regularly and attending diabetic eye screening can pick up any changes before they affect your sight.

#### **Diabetic eye screening**

It's rare for very young children with diabetes to be affected by diabetic retinopathy. Therefore, NHS diabetic eye screening is offered to people with diabetes who are aged 12 years or older. Depending on where you live, screening may take place every year or every two years. Screening may happen more frequently if there is evidence of retinopathy in your eye.

Your GP should arrange for you to have your initial diabetic eye screening, after which you'll be screened as often as is necessary. At your appointment, you'll have a detailed eye examination at a specialist screening clinic, which may take place at your GP surgery, your local hospital, optometrist's practice, or another nearby clinic. If you have diabetes and you're pregnant, you will have retinal screenings more often during your pregnancy and after your baby is born as you are at higher risk of progression of diabetic eye disease during pregnancy. However, if you have gestational diabetes, you do not have a higher risk of eye disease during your pregnancy and will not be called for diabetic eye screening.

This regular diabetic eye screening is essential in reducing the risks retinopathy can pose to your sight, as you may not be aware that anything has changed inside your eye until the damage has been done. Diabetic eye screening helps to prevent blindness in most people who are at risk, so if you've not had this type of test, ask your GP or diabetic clinic as soon as possible. "It's so important to have diabetic retinal screening. With diabetic eye problems, you're not aware that there's a problem until it's a lot further down the line. A lot of people only do something about their health when they feel something's wrong. But with your eyes, you will have retinopathy way before you notice that something's wrong yourself. The appointment's very short, there's no pain involved. They may notice something that you might not have noticed at all, and the quicker they can do something about that the better." – Berni Warren

## What happens at the diabetic eye screening appointment?

At this appointment, you'll have eye drops put into your eyes to dilate (widen) your pupils. This allows for a good view of your retina. You'll then have photographs taken of your retina using a digital retinal camera. You'll see a flash when the photos are taken but the camera won't touch your eye. You won't get the results immediately as the photographs need to be studied by someone who is trained in identifying and grading retinopathy.

#### What do the results mean?

If your results show no retinopathy (RO) or some background retinopathy (R1 or in Scotland R1 or R2), you'll normally continue with your regular screening.

If your results show signs of pre-proliferative retinopathy (R2 or in Scotland R3) that could affect your sight in the future, you will usually be invited back for repeat retinal screening sooner than usual. You may also be referred to be assessed by an ophthalmologist (hospital eye doctor) at the hospital eye clinic for further tests and possible treatment, particularly if you have proliferative retinopathy (R3 or in Scotland R4) or maculopathy (M1 or in Scotland M2) which can put your sight at greater risk.

"I've had retinal screening every year for 25 years. I used to have it done yearly and then it moved to every six months, when they detected that I had background retinopathy, and it was changing. In between me seeing a specialist and having a screening, I had a haemorrhage at the back of my eye, which meant that I got seen quicker. After that it was three monthly, as I was seeing the specialist and having treatment done." – Samantha Leftwich

#### Annual eye examinations with an optometrist

Your diabetic eye screening test doesn't replace your regular eye examination with your optometrist. This is because your diabetic eye screening test will only look for any diabetic changes at the back of your eyes. Your regular eye examination with your optometrist checks for other eye conditions so it's important to have both tests as regularly as you're advised. NHS eye tests are free for people with diabetes. Some optometrists will take a photograph of the back of your eyes as part of your regular eye examination, so that they can also monitor any retinal changes taking place. However, this photograph does not replace your diabetic eye screening appointment. By having both examinations, you're increasing the chances of picking up on any retinal changes early on, so that any treatment that might be necessary can be given sooner rather than later to protect your sight.

# How can diabetic retinopathy be treated?

#### Laser treatment (photocoagulation)

Proliferative diabetic retinopathy is treated with laser treatment to prevent further sight threatening complications. The laser used to treat proliferative diabetic retinopathy treats large areas of the edge of the retina (peripheral retina) and is known as pan-retinal photocoagulation (PRP).

If your maculopathy causes DMO which does not affect the centre of the macula, laser treatment (photocoagulation), can be given in some cases as a targeted treatment to a small, localised area of the macula.

Most sight-threatening diabetic problems can be managed by laser treatment if it is done early enough. Laser treatment doesn't make your sight better; its aim is to protect your vision from becoming a lot worse.

#### Macular laser or photocoagulation

Localised macular laser treatment may be used when only a small part of your macula is affected by diabetic maculopathy. The laser seals your blood vessels to stop them from bleeding and help to reduce swelling. The treatment normally only takes a few minutes. You don't usually notice worsening of your vision after this procedure because only a small patch of your retina is treated with the laser.

#### Pan-retinal photocoagulation (PRP)

When new abnormal blood vessels begin to grow more extensively (proliferative diabetic retinopathy), a larger area of your retina may need to be treated with laser. Treating more of your retina stops it from producing the growth factors



that make new blood vessels develop. When treatment is successful, the new blood vessels get smaller and disappear over a few months.

#### How is laser treatment carried out?

As laser treatment is performed at an outpatient clinic, you won't need to stay in hospital. You'll be given eye drops to dilate your pupils, so your ophthalmologist can get a better view of your retina when they look into your eyes.

Your eye is then numbed with anaesthetic drops and a small contact lens is put on the surface of your eye to keep it open and to focus the laser to the retina at the back of the eye. During the treatment, you'll be asked to move your eyes in certain directions so the correct part of your retina can be treated. You'll be able to do this easily with the contact lens in place. Ask your ophthalmologist how long each session of laser surgery is likely to last. The laser treatment itself doesn't usually take longer than 15 to 30 minutes. Some people need more than one treatment session, particularly when a greater area of retina needs to be treated.

#### Is laser treatment painful?

Localised macular laser treatment does not usually cause too much discomfort because it doesn't take long and only treats a small area of your retina. Pan-retinal (PRP) laser treatment can be more uncomfortable because a larger area of your retina is being treated. You may be given painkillers before the treatment. Don't be afraid to tell your ophthalmologist if the treatment hurts or if you found a previous session of laser treatment painful.

#### **Does laser treatment have any side effects?**

All treatments have the potential to cause some side effects. However, you will put your vision at greater risk in the longer term by not having the laser treatment.

In the short-term, both localised macular and pan-retinal laser treatment can temporarily affect your sight because of the brightness of the laser beam. It can reduce your vision for an hour or two after the treatment. You may feel "dazzled" or feel like your vision has become darker for some time after your treatment. You may also temporarily lose a little of your central vision or see small black spots, all of which should get better with time.

As localised macular laser treatment only treats a very small area of your retina, it doesn't affect your vision as much in the long term. In some cases, it may not affect it at all.

#### However, pan retinal (PRP) laser can have more lasting effects on your vision because a larger area of your retina is being treated. This may mean:

- your peripheral vision may become quite poor
- your colour perception and your night vision may be affected
- occasionally, your central vision may not be as good as before, so reading may be more difficult.

When you're told you have new blood vessels on your retina, your vision may still be very good, and you may not notice any changes in the way you see. You may not understand why you've been told you need laser treatment at all, as initially, these new blood vessels can have very little effect on your sight. However, because they are fragile and can bleed very easily, leaving them untreated puts you at a greater risk of more serious sight loss over time.

It's important to remember that while laser treatment cannot make your vision better, it does aim to prevent your vision from getting worse. The side effects of pan retinal laser treatment may make you feel that it has made your sight much worse than it was before treatment and this can be frustrating. However, it's important to remember that if left untreated, the new vessels will soon bleed and cause a more serious loss of vision. This means that without laser treatment, you may end up losing a lot more of your sight in the long run.

Ask your ophthalmologist to talk you through your treatment plan; the advantages and disadvantages of the treatment as well as the possible side effects to your sight, and whether these are temporary or permanent.

If you drive and have had laser treatment in both eyes (or if you're sighted in only one eye and have had laser treatment in this eye), you must inform the Driver and Vehicle Licensing Agency (DVLA). They may ask that you have further tests to make sure your peripheral and central vision is good enough for safe driving.

# What if my eye becomes painful after treatment, or if my vision gets worse?

After a long laser treatment session, you may have a headache. You can take over-the-counter painkillers, which should help.

However, if the pain is severe, or if your eyesight gets worse, you should contact your ophthalmologist or eye clinic immediately. If this is not possible, go straight to the Accident and Emergency (A&E) department at your nearest hospital.

# How is diabetic macular oedema (DMO) treated?

If fluid leaks out of the retinal blood vessels near the macula, it can cause swelling in the macular tissue. This swelling is known as diabetic macular oedema (DMO).

The very centre of your macula is called the fovea, and if your DMO doesn't affect this tiny area of the retina, laser treatment can be used to reduce the macular swelling that is present to try to prevent any further blurring of your central vision.

However, as the fovea is a very delicate part of the macula, it cannot be treated directly with the laser. If you have DMO that does affect the fovea, your eye may benefit from treatment with an injection instead. There are a range of different drugs which can be used to treat central DMO.

#### **Anti-VEGF injections**

Anti-VEGF injections are a common treatment for central DMO. Anti-VEGF stands for anti-vascular endothelial growth factor, and it is given as an injection into the eye.

Anti-VEGF drugs work by reducing leakiness of blood vessels and stopping new leaky blood

vessels from growing. They can also help the fluid to be reabsorbed, reducing your macular oedema, and this can improve vision for some people.

The anti-VEGF drug is injected through the white of your eye into the vitreous gel inside your eye. You will need a course of injections over several months. Anti-VEGF treatment is given on the NHS when your central macula has swollen to a certain size. This means your treatment may depend on how swollen your macula is. Your ophthalmologist will be able to tell you if your macular oedema can be treated by anti-VEGF injections on the NHS.

"I think the treatment has kept my right eye going. So, it's definitely worth it. Having injections sounds horrible, but it's not nearly as bad as it sounds. It's done very quickly, and you have a drape put over your eye, there's a clamp to hold your eye open, you have lots of numbing drops, iodine in your eye, and then the injection's done." – Berni Warren

You can find out more about anti-VEGF treatment from our website or by calling our Helpline.

#### **Steroid implants**

Sometimes, you may be given a treatment which involves the injection of a steroid implant into your eye. The implant slowly releases small amounts of steroid into your eye to help control the swelling. You may be treated using an implant every 6 months or with one that can stay in your eye for up to three years.

Steroid implants can be offered to you if your DMO hasn't responded to the anti-VEGF injections or if anti-VEGF treatment wasn't appropriate for you in the first place. Your ophthalmologist will be able to tell you whether this treatment would be suitable for you and how often your implant treatment would be needed.

## Is there any surgery that can treat diabetic retinopathy?

Inside your eye, there is a clear gel called the vitreous gel. If you have a bleed from your retina into the vitreous gel, your vision will become cloudy. Often, this blood is reabsorbed by your body and your vision gets better on its own over a few months.

However, if your vision doesn't improve you may need to have surgery known as vitrectomy. In this surgery, the cloudy vitreous gel is removed and replaced with a clear liquid, which usually helps to improve your vision.

Vitrectomy is also carried out if retinal scarring causes your retina to detach. If this happens, reattaching your retina with vitrectomy surgery is essential to help prevent more serious sight loss.

If you have a large retinal and/or vitreous bleed, it can affect your vision quickly and severely which can come as a shock. Your ophthalmologist may advise you to wait for several weeks or months before carrying out a vitrectomy, to allow time for the bleed to resolve on its own first. This can be frustrating. However, during this time, your ophthalmologist will monitor how the bleeding changes, to see if there are any new bleeds, and whether the bleeding has begun to be reabsorbed. A vitrectomy is a specialised and complicated operation which does carry some level of risk, so your ophthalmologist would only carry out this surgery when it is needed, and when the benefits of this treatment outweigh the risks involved. They should discuss the advantages and disadvantages of the procedure with you before scheduling the surgery.

Don't be afraid to ask questions or say that you're worried about any aspect of your treatment.

- Remember:
- Don't wait until your vision has become worse to have an eye examination. Changes can develop inside your eye before you'll notice them. Therefore, you should always go to your diabetic eye screening appointments and as often as you're advised to attend.
- Have regular eye examinations with your optometrist as well as your diabetic screening, as these are invaluable. If you have diabetes, you'll receive free eye examinations funded by the NHS. An optometrist can examine your eyes and check for other eye conditions, such as glaucoma.

- Speak to someone at your diabetic eye clinic or to your optometrist if you notice changes to your vision. It may not mean you have diabetic retinopathy; it could simply be a problem that can be corrected with glasses. Having an eye examination will make sure important eye health changes are not missed.
- Early diagnosis of diabetic retinopathy is vital. Although your vision can seem good to you, there may be changes in your eyes that need treating. Most sight loss from diabetes is preventable if treatment is given early. The earlier the treatment, the more effective it is.



## Coping

It's completely understandable to be upset when you're diagnosed with an eye condition that's related to your diabetes, and it's normal to find yourself worrying about the future and how you will cope. You may find yourself wondering how this will affect your education or employment options and how you will be able to provide for yourself and your family moving forward.

#### **Support from RNIB**

It can sometimes be helpful to talk about these feelings with someone outside your circle of friends or family. By calling our RNIB Helpline, you are no longer alone. We can support you at every step, putting you in touch with the advisors you need from any of our supportive teams. From support with your education to advice on your employment, from using assistive technology to understanding more about your eye condition, we are here to help. Our Counselling and Well-being team is also available to provide the emotional support you may need. Your GP or social worker may also find a counsellor for you if you feel this might help.

#### The Eye Care Liaison Officer (ECLO)

You may think of further questions about your diabetic eye condition on your way home from hospital or in the days and weeks following your appointment. There is someone to turn to with these questions. Your eye clinic may have a sight loss advisor working alongside the doctors and nursing staff.

This advisor may be known as either the Eye Care Liaison Officer (ECLO), the Vision Support Officer or the Early Intervention Support Officer and they are on hand within your hospital to provide you with further practical and emotional support about your eye health.

To find out if your hospital eye clinic has an ECLO, you can search within the RNIB Sightline Directory by visiting **rnib.org.uk/sightline-directory**. Alternatively, you can call our Helpline to speak to our advisors within our Eye Health Information Service as they would be happy to discuss any questions you may have.

## Further help and support

#### Making the most of your sight

If you have a diabetic eye condition that is picked up early, you may not experience much of a change to your vision, meaning you can carry on with everyday activities such as reading, watching television and using the computer without any difficulty. However, if your diabetes has affected your sight, there are things that you can do to make the most of your remaining vision. This may mean making things bigger if your central vision is affected. In addition, using brighter lighting or using contrasting colours can make things easier to see.

We have a series of booklets with helpful information on living with sight loss, including Making the Most of Your Sight. You can find out more about our range of titles by calling our Helpline.

#### The low vision assessment

If your vision has got worse due to your diabetes, you may benefit from having a low vision assessment. Ask your ophthalmologist, optometrist or GP about low vision aids and having a low vision assessment. During this assessment with an optometrist, you'll be able to discuss the use of magnifiers and aids to help you to see things more clearly.

#### Assistive technology

There is also technology available that can help with low vision. Many smartphones and tablets are already equipped with in-built software that can enable people with low vision to access information. There are also specific apps and low vision devices that may help too, as well as computer software programmes that can be installed.

If you would like to find out more about the assistive technology that is available and how it can help you, our Technology for Life team advisors would be happy to chat to you. You can get in touch with this team by calling our Helpline.

"I use lots of the apps Be My Eyes, Seeing AI, other than that I use Supervision and a magnifier. I used to get frustrated that I had to eat the same meals every day. With the apps and voiceover, I feel a lot more independent as I can do a lot more things by myself." – Samantha Leftwich

#### Registration

You should also ask your ophthalmologist whether you're eligible to register as sight impaired (partially sighted) or severely sight impaired (blind). Registration can act as your passport to expert help and sometimes to financial concessions. Even if you aren't registered, a lot of this support is still available to you.

#### Social services support

Local social services should be able to give you information on staying safe in your home and getting out and about safely. They should also be able to offer you some practical mobility training to give you more confidence when you are out.

If you have questions about anything you've read in this information, please get in touch with us.

## **Further information**

If you need someone who understands sight loss, call our Helpline on **0303 123 9999**, say **"Alexa, call RNIB Helpline"** to an Alexa-enabled device, or email **helpline@rnib.org.uk**. Our opening hours are weekdays from 8am-8pm and Saturdays from 9am – 1pm.

You can also get in touch by post or by visiting our website:

#### **RNIB**

The Grimaldi Building 154A Pentonville Road London N1 9JE **rnib.org.uk** 

#### **Connect with others**

Meet or connect with others who are blind or partially sighted online, by phone or in your community to share interests, experiences and support for each other. From book clubs and social groups to sport and volunteering, our friendly, helpful and knowledgeable team can link you up with opportunities to suit you. Visit **rnib.org.uk/ connect** or call **0303 123 9999**.

#### Other useful contacts

#### **Diabetes UK**

Diabetes UK Helpline: **0345 123 2399** Email: **helpline@diabetes.org.uk** Web: **diabetes.org.uk** 

#### Juvenile Diabetes Research Foundation (JDRF)

A registered charity in England, Wales and Scotland that funds research to cure, treat and prevent type 1 diabetes.

London office: Helpline 020 7713 2030 Email: info@jdrf.org.uk

Scotland office: Helpline: 01224 248 677 Email: scotland@jdrf.org.uk Web: jdrf.org.uk

#### Driver and Vehicle Licensing Authority (DVLA)

Drivers' Medical Enquiries Swansea SA99 1TU Telephone: **0300 790 6806** Web: **gov.uk** 

## **RNIB Booklet Series**

### About the Starting Out series

Essential information about living with sight loss. Titles include:

- Benefits, Concessions and Registration
- Emotional Support
- Help from Social Services
- Making the Most of Your Sight

#### **About the Confident Living Series**

Information to build confidence and independence. Titles include:

- Reading
- Shopping
- Technology
- Travel

#### About the Understanding Series

More about your eye condition. Titles include:

- Age Related Macular Degeneration
- Cataracts
- Visual Hallucinations: Charles Bonnet Syndrome
- Dry Eye
- Diabetes Related Eye Conditions including Diabetic Retinopathy
- Glaucoma
- Nystagmus
- Retinal Detachment
- Inherited Retinal Dystrophies including Retinitis Pigmentosa
- Posterior Vitreous Detachment

For audio, print or braille versions of these booklets please contact our Helpline or visit **shop.rnib.org.uk** 

For a list of information sources used in these titles and to provide feedback on the Starting Out and Confident Living Series, email **ckit@rnib.org.uk**.

#### We value your feedback

You can help us improve our information by letting us know what you think about it. Is this booklet useful, easy to read and understand? Is it detailed enough or is there anything missing?

We would also like your views on the pictures and diagrams, are they appropriate, helpful and are there places where a diagram might have helped? How could we improve it?

Send your comments to us by emailing eyehealth@rnib.org.uk or by writing to:

Eye Health Information Service RNIB The Grimaldi Building 154A Pentonville Road London N1 9JE

#### **Information sources**

RNIB and The Royal College of Ophthalmologists do all we can to ensure that the information we supply is accurate, up to date and in line with the latest research and expertise. This publication uses information from:

- The Royal College of Ophthalmologists' guidelines for treatment
- clinical research and studies obtained through literature reviews
- specific support groups for individual conditions
- medical textbooks
- RNIB publications and research.

For a full list of references and information sources used in the compilation of this publication, email **eyehealth@rnib.org.uk** 

#### About The Royal College of Ophthalmologists

The Royal College of Ophthalmologists champions excellence in the practice of ophthalmology and is the only professional membership body for medically qualified ophthalmologists.

The College is unable to offer direct advice to patients. If you're concerned about the health of your eyes, you should seek medical advice from your GP or ophthalmologist.

#### rcophth.ac.uk



## rnib.org.uk

## **RNIB** Helpline

- Call: 0303 123 9999
- Email: helpline@rnib.org.uk
- Or say, **"Alexa, call RNIB Helpline"** to an Alexa enabled device.
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