Understanding eye conditions related to diabetes



supporting blind and partially sighted people



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.

Other titles in the series include: Understanding age-related macular degeneration Understanding cataracts Understanding Charles Bonnet syndrome Understanding dry eye Understanding glaucoma Understanding nystagmus Understanding posterior vitreous detachment Understanding retinal detachment Understanding retinitis pigmentosa

All these leaflets are available in audio, print and braille formats. To order please contact our Helpline on 0303 123 9999 (all calls charged at local rate), email helpline@rnib.org.uk or visit rnib.org.uk/shop

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About diabetes

Diabetes occurs when your body doesn't produce enough of the hormone "insulin" or because the insulin that is produced has a reduced effect. Insulin regulates the way your body uses the food you have eaten. If you have diabetes your body cannot cope in the usual way with sugar and other carbohydrates that you eat.

Nearly one person in 25 in the UK has diabetes mellitus.

Some children have diabetes but developing diabetes is much more common later in life. Diabetes can cause complications which affect different parts of your body, including your eye. The two main types of diabetes mellitus are known as Type 1 and Type 2 diabetes.

This leaflet explains how diabetes may affect your eyes. It gives information on how your eyes should be monitored, how eye conditions are treated and help for when your sight changes.

Type 1 diabetes

This type of diabetes commonly occurs before the age of 30 and is the result of the body producing little or no insulin. Type 1 diabetes is primarily controlled by insulin injections so it is sometimes called insulin dependent diabetes.

Type 2 diabetes

This type of diabetes commonly occurs after the age of 40. In this type of diabetes the body does produce some insulin, but the amount is either not sufficient or the body is not able to make proper use of it. Type 2 diabetes is generally controlled by diet, exercise and/or tablets. Although some people in this group will use insulin injections it is sometimes referred to as non-insulin dependant diabetes.

South Asian communities and diabetes

People from India, Pakistan, Bangladesh and Sri Lanka (South Asian communities) have a four or five times greater risk of developing diabetes than someone from a European community. Around 20–25 per cent of South Asian adults aged 50 or over in the UK develop type 2 diabetes. At the moment the reasons why people from these communities are more at risk of type 2 diabetes aren't fully understood. There are thought to be a number of factors involved. As well as genetic make up these include diet, being overweight and not doing enough exercise.

People from South Asian communities can also have problems using the insulin their bodies produce, making it more difficult for them to regulate the sugar in their blood. It also appears that they are more likely to put on weight around their middles, known as central obesity. This can put stress on the parts of the body that produce insulin meaning it isn't able to work properly.

If you are from a South Asian community it is important that you know about the risk of developing type 2 diabetes, the sight loss it can cause, and the steps you can take to reduce the risk of losing your sight. Diabetes UK provides lots of information on their website www.diabetes.org.uk

Gestational diabetes mellitus (GDM)

GDM is a type of diabetes that sometimes arises during the second or third trimester of pregnancy. For most women this diabetes goes away after pregnancy but it increases the chances of developing type 1 or type 2 diabetes in later life.

How your eye works



When you look at something, light passes through the front of your eye and is focused by the cornea and lens onto your retina. The retina is a delicate tissue that is sensitive to light. It converts the light into electrical signals that travel along the optic nerve to your brain. The brain interprets these signals to "see" the world around you.

The retina is supplied with blood by a delicate network of blood vessels. These blood vessels can be damaged by diabetes.

Light entering your eye is focused onto a tiny area of your central retina called the macula. This highly specialised area of the retina is about the size of a pinhead. It is vital because it allows you to see fine detail for activities such as reading and writing, and to recognise colours. The rest of your retina, called the peripheral retina, gives you side vision (or peripheral vision).

Your eye is filled with a clear jelly-like substance called the vitreous gel. Light passes through the gel to focus on the macula.

Diabetes and your eye

Diabetes can affect your eye in a number of ways:

- The most serious eye condition associated with diabetes involves the network of blood vessels supplying the retina. This condition is called diabetic retinopathy.
- The unusual changes in blood sugar levels resulting from diabetes can affect the lens inside your eye, especially when diabetes is uncontrolled. This can result in blurring of vision which comes and goes over the day, depending on your blood sugar levels.
- A longer-term effect of diabetes is that the lens of your eye can go cloudy, this is called a cataract.

Not everyone who has diabetes develops an eye complication. Of those that do, many people have a very mild form of retinopathy which may never progress to a sight-threatening condition.

Diabetic retinopathy

The most serious complication of diabetes for your eye is the development of diabetic retinopathy. Diabetes affects the tiny blood vessels of your eye and if they become blocked or leak then the retina, and possibly your vision, will be affected. The extent of these changes determines what type of diabetic retinopathy you have. Forty per cent of people with type 1 diabetes and 20 per cent with type 2 diabetes will develop some sort of diabetic retinopathy.

Background diabetic retinopathy

This is the most common type of diabetic retinopathy and many people who have had diabetes for some time will have this early type.

The blood vessels in the retina are only very mildly affected, they may bulge slightly (microaneurysm) and may leak blood (haemorrhages) or fluid (exudates). As long as the macula is not affected, vision is normal and you will not be aware that anything is wrong. Your retinal screening test will keep a close check on these early changes and ensure that any signs of progression to more serious stages of retinopathy are detected early.

Proliferative diabetic retinopathy

If diabetic retinopathy progresses, it can cause the blood vessels in the retina to become blocked. These blockages, when affecting a significant part of the retina, can result in areas of the retina becoming starved of oxygen. This is called ischaemia. If this happens your eye is stimulated into growing new vessels, a process called neo-vascularisation. This is the proliferative stage of diabetic retinopathy and is nature's way of trying to repair the damage by growing a new blood supply to the oxygen starved area of your retina.

Unfortunately, these new blood vessels are weak, and grow in the wrong place – on the surface of the retina and into your vitreous gel. As a result, these blood vessels can bleed very easily which may result in large haemorrhages over the surface of the retina or into the vitreous gel. These types of haemorrhages can totally obscure the vision in the affected eye as light is blocked by the bleed. For many people, with time, the blood can be reabsorbed and their vision can improve. But for others these haemorrhages may keep happening and the blood may not fully reabsorb. This can lead to more permanent loss of sight. Extensive haemorrhages can lead to scar tissue forming which pulls and distorts the retina. This type of advanced diabetic eye disease can result in the retina becoming detached with the risk of serious sight loss.

Only between 5 and 10 per cent of all people with diabetes develop proliferative retinopathy. It is more common in people with type 1 diabetes than type 2. Sixty per cent of type 1 diabetics show some signs of proliferative disease after having diabetes for 30 years.

Diabetic maculopathy

Diabetic maculopathy means that your macula is affected by your diabetes. This may occur either with background, or proliferative retinopathy. If this happens, your central vision will be affected and you may find it difficult to see detail such as recognising people's faces in the distance or seeing detail such as small print. The amount of central vision that is lost varies from person to person. However, the vision that allows you to get around at home and outside (peripheral vision) is not affected.

Some people develop a type of maculopathy called diabetic macular oedema. This causes fluid to collect in your macula which can cause further problems with your central vision. Most diabetic maculopathy can be treated with a laser, and more recently injections, with the aim of preserving as much vision as possible, although vision may improve in some treated eyes.

Reducing risk

Risk factors for developing diabetic retinopathy can be divided into those you are able to control and those you cannot. Good diabetic control significantly lowers your risk of retinopathy.

The following actions reduce your risk of developing retinopathy or help to stop it from getting worse:

- Controlling your blood sugar (glucose levels).
- Tightly controlling your blood pressure.
- Controlling your cholesterol levels.
- Keeping fit, maintaining a healthy weight and giving up smoking are all part of good diabetes control. Nerve damage, kidney 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. Diabetes UK can offer you information and support on living with diabetes.
- Regular retinal screening (there is more information about this in the following section). The most effective thing you can do to prevent sight loss due to diabetic

retinopathy is to attend your retinal screening appointments. Early detection and treatment prevents sight loss.

Risk factors that cannot be controlled:

- The length of time you have had diabetes. This is a major risk for developing diabetic retinopathy.
- Your age affects the progression of diabetic retinopathy.
- Your ethnicity. If you or your family are from India, Pakistan, Bangladesh or Sri Lanka you are more at risk of developing diabetes and the sight-threatening conditions diabetes can cause.

If you have diabetes and plan to have a child, your GP will discuss with you how to manage the pregnancy. Retinal screening is carried out more often during pregnancy and for a while after you have had your baby. Similarly if you develop gestational diabetes during pregnancy, you will also have more regular retinal screening during pregnancy and after your baby is born.

Annual diabetic eye screening

If you have diabetes this does not necessarily mean that your sight will be affected. If your diabetes is well controlled you are less likely to have problems, or they may be less serious. However, if there are complications that affect your eyes, this can sometimes result in serious loss of sight.

Most of the complications that diabetes causes in the eye can be treated, but it is vital that they are diagnosed early. They can only be detected by a detailed examination of your eye carried out at a specialist screening centre. If you have diabetes your GP or hospital clinic should arrange for you to have annual retinal screening. At this appointment you will have eye drops put into your eyes which dilate the pupil and allow the specialist a good view of the retina. A picture is taken using a digital retinal camera and this is looked at in detail to see if there are any changes caused by diabetes.

As you may not be aware that there is anything wrong with your eyes until it is too late, having this regular test is essential. Research shows that if retinopathy is identified early, through retinal screening, and treated appropriately, blindness can be prevented in 90 per cent of those at risk. If you have not had this type of test, ask your GP or diabetic clinic as soon as possible. You should also go for an annual eye test with the optometrist (optician) as the retinal screening test does not replace the regular eye examination.

Some optometrists will take a photograph of the back of your eye as part of your regular eye examination. This photograph does not replace your retinal screening appointment. It is very important to attend both your retinal screening appointment and your regular eye test with the optician.

Treatment for diabetic retinopathy

Most sight-threatening problems caused by diabetic retinopathy can be managed by laser treatment if detected early enough. The aim of laser treatment is to prevent bleeding or to prevent the growth of new blood vessels. The laser can be used in two ways:

Localised laser treatment

When individual vessels or small groups of vessels are leaking, the laser can seal them. This stops the bleeding and helps reduce the swelling of the retina. This type of treatment is quick, sometimes taking only a few minutes. Localised laser treatment is used when maculopathy has been detected. Vision is not usually affected by this type of treatment because only a very localised area of the retina is treated.

Pan-retinal laser treatment

If new vessel growth (neo-vascularisation) has been detected you may need more extensive laser treatment. The aim is to treat large areas of the peripheral retina with the laser. This treatment stops the retina from producing the growth factors that stimulate new blood vessels to grow. If the treatment is successful, the new vessels shrink and disappear over a few months. Because large areas of the peripheral retina are lasered, the effects on your vision may be significant. It is quite common to permanently lose some vision to the sides (peripheral vision) and this may affect your ability to drive safely. Night and colour vision may also be affected.

When new vessels are first detected your vision may be very good and you may not have noticed any changes to the way you see. This is because, in the initial stages, new vessels have very little effect on the vision. After the treatment your vision may be very different, for example your peripheral vision may be quite poor. You may feel that the laser has made your sight much worse. The difficult issue is, that if left untreated, the new vessels will soon bleed and cause serious loss of vision. The laser treatment is the best option for preventing this.

It is important to remember that laser treatment aims to prevent your vision from getting worse. It cannot make your vision better.

How is treatment carried out?

You can usually be treated in an outpatient clinic and do not normally need to stay in hospital. Eye drops enlarge your pupils so that your eye specialist can look into your eye. Your eye is then numbed with drops and a small contact lens is put onto your eye to stop it blinking. During the treatment you will be asked to move your eyes in certain directions and you will be able to do this easily with the contact lens in place. When treatment is first suggested, ask how long each session is likely to last. Some people need more than one treatment session.

Is it painful?

Local treatment for sealing blood vessels does not usually cause discomfort. Pan retinal treatment can be uncomfortable, so you may need a pain-relieving tablet at the same time as your eye drops. Further pain relief is available so remember:

- don't be afraid to tell your eye specialist if the treatment is hurting
- don't be afraid to tell your eye specialist if you have found a previous session of laser treatment distressing.

Does laser treatment have any side effects?

No treatment is possible without some side effects, but the risks to your vision of laser treatment are far fewer than the risks of not having laser treatment. The short-term effects of the laser treatment are due to the brightness of the laser used. It can cause a temporary reduction of sight which may last an hour or two after the treatment. You may also lose a little central vision which may improve with time or notice the after effects of the laser as small black spots in your vision.

The local treatment has little long-term effect, as it only treats a very small area of your retina.

The more extensive pan-retinal treatment can have more lasting effects on your vision:

- It is quite common to lose some vision to the sides (peripheral vision) and this may affect your ability to drive safely.
- Night and colour vision may also be affected.
- Occasionally your central vision may not be as good as before so that, for example, print is not as easy to see.

The possible side effects of treatment depend on your eye condition and the type of treatment that your specialist suggests. Ask the specialist to talk you through what they plan to do, the advantages and disadvantages of the treatment and the possible side effects, temporary or permanent, for your vision. If you drive and have had laser treatment in both eyes or your one remaining eye you must inform the Driver and Vehicle Licensing Agency (DVLA). They may ask that you have a detailed eye examination to make sure your central and peripheral vision are good enough for safe driving.

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

After lengthy treatment, most people develop a headache so a headache tablet can be taken for this.

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

The importance of early treatment

Although your vision may be good, changes can be taking place in your retina that need treatment. Most sight loss due to diabetes is preventable if treatment is given early. The earlier the treatment is given the more effective it is. Remember:

- early diagnosis of diabetic retinopathy is vital
- attend your annual retinal screening appointment
- have an annual eye examination with the optician (optometrist). Eye examinations are free for people with diabetes.

The importance of early treatment of diabetic retinopathy cannot be stressed enough.

Remember, however, that if your vision is getting worse, this does not necessarily mean you have diabetic retinopathy. It may simply be a problem that can be corrected with glasses. So check it out.

Treatment for diabetic macular oedema

Diabetes can cause macular oedema. The macula is a tiny part of the retina at the back of your eye. Diabetes can cause a build up of fluid to collect on or under your macula which leads to macular swelling, medically known as "oedema". Diabetic macular oedema may make your central vision distorted or blurry and, over a period of time, it may cause a blank patch in the centre of your vision. When the macular oedema does not involve the centre of the macula (called fovea), laser treatment can reduce the leakage and prevent any more blurring. However, when the oedema affects the centre, then laser treatment offers no benefit.

Treatment is now available for this type of diabetic macular oedema on the NHS. Lucentis, an anti-vascular endothelial growth factor (anti-VEGF) treatment, is licensed for use to help control the swelling. Research has shown that Lucentis can reduce the swelling and macular thickness caused by diabetic macular oedema, and reduces the blurred central vision.

Anti-VEGF medications work by blocking the effects of a growth factor (VEGF) that blood vessels need in order to form and keep leaking. The anti-VEGF drugs stop the

growth of new blood vessels and can help to reduce macula oedema.

Lucentis is given by an injection into the white of your eye and you may have to have more than one injection over a period of months to get the best effect. There are restrictions on the use of Lucentis for diabetic macular oedema, and depend on how badly your macula is affected by swelling. Your ophthalmologist will be able to tell you whether your macular oedema can be treated this way on the NHS.

Treatment for advanced diabetic retinopathy

If your eye condition becomes more severe and the gel inside your eye becomes cloudy due to haemorrhages, or if scar tissue forms causing retinal detachment, it may be possible for you to have an operation called a vitrectomy. This procedure involves the vitreous gel being removed and replaced with a clear solution that light can pass through more easily.

When you have a vitreous or retinal haemorrhage the reduction in your vision can happen quickly and be dramatic. It can then seem frustrating that the specialist can advise waiting for up to six months before carrying out a vitrectomy. The waiting period enables your specialist to monitor how the bleed changes, to see if there are any new bleeds and more positively to see whether the bleed begins to be reabsorbed and if this results in your vision improving. The specialist will carry out the vitrectomy at the time most likely to give the best result.

A vitrectomy is a specialised and complicated operation and you need to discuss with your specialist the advantages and disadvantages of the procedure for your vision.

Other ways diabetes can affect your eyes

Temporary blurring

The changes in blood sugar levels resulting from diabetes can affect the lens inside your eye, especially when diabetes is uncontrolled. This can result in blurring of vision which comes and goes across the day. This blurring may be one of the first symptoms of diabetes although it may also occur at any time when your diabetes is not well controlled. Once your diabetes is controlled most people find this variable blurring goes away.

Cataracts

A cataract is a clouding of the lens of your eye, which causes the vision to become blurred or dim because light cannot pass easily to the back of your eye. This is a very common eye condition that often develops as we get older, but people with diabetes sometimes develop cataracts at an earlier age. An operation can remove the cloudy lens, which is usually replaced by a plastic lens, helping your eye to focus properly again. Your eye clinic will monitor a cataract if it is forming as part of your regular check up. We have a guide on "Understanding cataracts" if you would like more information.

Important points to remember

- Early diagnosis of diabetic retinopathy is vital.
- Attend your annual diabetic eye screening appointment.
- Don't wait until your vision has deteriorated to have an eye test.
- Speak to your diabetic eye clinic if you notice changes to your vision.
- Most sight-threatening diabetic problems can be managed by laser treatment if it is done early enough.
- Don't be afraid to ask questions or express fears about your treatment.
- Good control of sugar, blood pressure and cholesterol reduces the risk of diabetes-related sight loss.
- Attend your diabetic clinic or GP surgery for regular diabetes health checks, including blood pressure and cholesterol monitoring.
- Smoking increases your risk of diabetes-related sight loss. Your GP can tell you about NHS stop smoking services in your area.

Monitoring blood sugar levels

Home testing your blood sugar levels is a very effective way of making sure you are controlling your blood glucose. You prick the side of a finger and place a drop of blood on a testing strip. You put the strip in a glucose meter which displays your blood glucose level on a screen.

If you have a sight problem you might find some meters difficult to read. However, you can now get easy-to-see meters and talking meters. Up-to-date details of meters are on the Diabetes UK website at www.diabetes.org.uk or you can call the Diabetes UK Careline on 0845 120 2960, Monday–Friday, 9am-5pm.

If you are having difficulties reading your meter at home tell someone involved with your diabetic care. You need to be able to carry out testing at home accurately and your diabetic nurse needs to work with you to ensure that you can use the meter you have chosen effectively.

What if my sight is permanently affected?

Much can be done to help you use your remaining vision. You should ask your eye specialist or optometrist about low vision aids. Alternatively, you can contact our Helpline on 0303 123 9999 or visit our website at www.rnib.org.uk/livingwithsightloss for more information about low vision.

If your vision is impaired, it is also worth asking your specialist to help you register as "sight impaired" (partially sighted) or "severely sight impaired" (blind). This opens the door to expert help and some financial concessions.

Being diagnosed with an eye condition can be very upsetting. You may find that you are worried about the future and how you will manage with a change in your vision. All these feelings are natural. Some people may want to talk over some of these feelings with someone outside their circle of friends or family. RNIB can help with our telephone Helpline and emotional support service. Your GP or social worker may also be able to find a counsellor for you, if you think this would help.

Useful contacts

Royal National Institute of Blind People

105 Judd Street, London WC1H 9NE t: 0303 123 9999 helpline@rnib.org.uk www.rnib.org.uk

Royal College of Ophthalmologists

17 Cornwall Terrace, London NW1 4QW t: 020 7935 0702 www.rcophth.ac.uk

Diabetes UK

Macleod House, 10 Parkway, London NW1 7AA t: 020 7424 1000 Diabetes UK Careline: 0845 120 2960 www.diabetes.org.uk

Driver and Vehicle Licensing Agency (DVLA)

Drivers Customer Services (DCS) Correspondence Team DVLA Swansea SA6 7JL t: 0300 790 6801 www.dvla.gov.uk

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Information sources

We 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.

The information used in RNIB's Understanding series of leaflets uses:

- Royal College of Ophthalmologists guidelines for treatment
- clinical research and studies obtained through literature reviews
- information published by specific support groups for individual conditions
- information from text books
- information from RNIB publications and research.

For a full list of references and information sources used in the compilation of this leaflet email publishing@rnib.org.uk

RNIB Helpline 0303 123 9999 helpline@rnib.org.uk

If you, or someone you know, is living with sight loss, we're here to help.

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