





# Diabetic Retinopathy & Maculopathy

**Information for Patients** 

Ophthalmology Departments
Clinic 8, Lincoln County Hospital: 01522 307180
Royle Eye Department, Pilgrim Hospital: 01205 445626
www.ulh.nhs.uk

## References

If you require a full list of references for this leaflet please email patient.information@ulh.nhs.uk

The Trust endeavours to ensure that the information given here is accurate and impartial.



If you require this information in another language, large print, audio (CD or tape) or braille please email the Patient Information team at <a href="mailto:patient.information@ulh.nhs.uk">patient.information@ulh.nhs.uk</a>

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## **Summary**

Diabetic retinopathy and maculopathy are complications of diabetes, caused by high blood sugar levels damaging the small blood vessels at the back of the eye (retina). It can cause blindness if left undiagnosed and untreated.

Diabetic retinopathy and maculopathy progresses with time. It may not cause symptoms early on and usually takes several years to reach a stage where it could threaten your sight.

Looking after your diabetes can reduce the risk of you developing diabetic retinopathy and maculopathy and slow the rate at which it progresses.

To minimise the risk of threats to your sight, people with diabetes should:

- Ensure they control their blood sugar level, blood pressure and cholesterol.
- Attend diabetic eye screening appointments since 2003 annual screening has been offered to all people with diabetes, aged 12 and over, to pick up and treat any problems early on thereby reducing the risk of blindness.

Laser treatment for sight-threatening diabetic retinopathy and maculopathy can reduce the risk of you losing your sight. Laser treatment does not generally improve your sight, although in a few cases it might.

There are new treatment options of a course of

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#### **Feedback**

To provide feedback on this information leaflet or on any of our services, please contact the Patient Advice and Liaison Service (PALS).

PALS offer confidential advice, support and information on health-related matters.

PALS can be contacted via the following options:

Lincoln County Hospital, located near Main Reception. **01522 707071** 

Pilgrim Hospital Boston, located in Main Reception. **01205 446243** 

Grantham Hospital, located adjacent to Ward 6. **01476 464861** 

Email: pals@ulh.nhs.uk

Text message: PALS team 07815707746

Write to:

Patient Experience Team, Grantham & District Hospital, 101 Manthorpe Road, Grantham, NG31 8DG.

Online: <a href="https://www.ulh.nhs.uk/patients/patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patient-patie

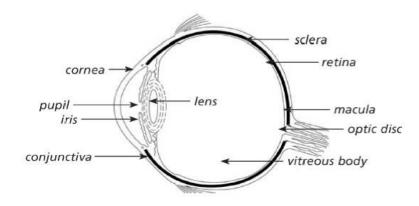
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### What is diabetic retinopathy and maculopathy?

When diabetes affects the small blood vessels in the part of your eye called the retina, this is known as diabetic retinopathy. The retina lines the inside of the eye and acts rather like the film in a camera.

The macula is the small central part of the retina that you use to read and see things clearly. You use the rest of your retina to see things around you and to see in the dark.

Blood vessels bring oxygen and nourishment to your retina. These blood vessels may be damaged in a number of ways if you have diabetes. Severe changes to the retinal blood vessels will affect the health of your retina and this can damage your sight.



# Why are diabetic retinopathy and maculopathy important?

Diabetic retinopathy can affect your sight and is still a significant cause of blindness in the working population.

Laser treatment for sight-threatening retinopathy and maculopathy reduces the risk of losing your sight but needs to be given at the appropriate stage and ideally before your vision has been affected.

# Who gets diabetic retinopathy and maculopathy?

All people with diabetes are at some risk of getting diabetic retinopathy. This is true whether your diabetes is controlled by diet, tablets or insulin.

You are at greater risk if:

- You have had diabetes for a long time
- Your diabetes is poorly controlled (high HbA1c)
- You have high blood pressure
- You are on insulin treatment
- You are overweight
- You smoke

# What does diabetic retinopathy and maculopathy look like?

The earliest changes are called **non-proliferative diabetic retinopathy**. Small changes develop on the blood vessels and look like tiny red dots. These are called micro aneurysms. Larger red dots are called retinal haemorrhages. They lie within the retina and are

#### Other useful contact details

Lincolnshire Eye Clinic Liaison Officer (ECLO) Service **01507 605604** 

Royal National Institute of Blind People (RNIB) 0303 123 9999

Macular Society **0300 3030 111** 

Diabetes UK **0345 123 2399** 

Royal College of Ophthalmologists **0207 935 0702** 

Driver and Vehicle Licensing Agency (DVLA) 0300 790 6801

#### **Contact details**

If you have any further queries please do not hesitate to contact us:

Eye Department (Clinic 8)
Lincoln County Hospital
Lincoln LN2 5QY

Tel: 01522 307180 or 01522 573566

Royle Eye Department Pilgrim Hospital Boston PE21 9QS

Tel: 01205 445626

Your call will be transferred to the hospital main switchboard outside normal working hours, Monday to Friday (9.00am to 5.00pm) and at weekends.

### How to find us

Clinic 8 is located in the Outpatients Department on Level 3 at Lincoln County Hospital.

Royle Eye Department is located near the outpatient department in the orange zone at Pilgrim Hospital, Boston.

Directions and hospital maps are located on United Lincolnshire Hospitals NHS Trust (ULHT) internet website <a href="https://www.ulh.nhs.uk/">https://www.ulh.nhs.uk/</a>

very like a bruise on your skin. Non-proliferative diabetic retinopathy does not usually affect your sight and does not need treatment. However, you will still need to be examined at least once a year.

As time goes by, your blood vessels may become constricted and the retina may become starved of oxygen and nutrition. Sometimes new blood vessels develop on the retina. This is called **proliferative diabetic retinopathy**. At this stage your sight is at risk as the new vessels may bleed or develop scar tissue. This can pull the retina away from the underlying layers of the eye, causing a **tractional retinal detachment**. If you develop proliferative retinopathy the eye doctor (ophthalmologist) will recommend laser treatment.

You may also suffer from the two different types of changes to the blood vessels in the macula. This is called **diabetic maculopathy**.

The commonest change is that the blood vessels become leaky. Fats and fluid that are normally carried along in the bloodstream may then leak into the macula. Fats that have leaked into the retina are called **exudates**. Fluid leakage causes water logging in the retina and is called **oedema**. Oedema at the centre of the macula will cause you to lose some sight and the ophthalmologist may recommend laser treatment, or if more appropriate, a course of injections of one of the anti-VEGF group of drugs (Avastin, Lucentis or Eylea) and less commonly steroid implants into the vitreous jelly of the eyeball.

You may already be aware that anti-VEGF group of drugs are also commonly used to treat wet Age-related Macular Degeneration.

Occasionally, the blood vessels in the macula become so constricted that the macula is starved of oxygen and nutrition causing your sight to get worse. This is called **ischaemic maculopathy** and does not usually respond to any type of treatment.

# How will I know if I have diabetic retinopathy and maculopathy?

Diabetic retinopathy does not usually cause a loss of sight until it has reached an advanced stage. Even sight -threatening retinopathy that is close to affecting your sight may not cause symptoms.

Your local NHS Diabetic Eye Screening Programme (NDESP) take regular photographs of the retina, usually once a year in the community, often in a van. NDESP will refer you to an eye doctor (ophthalmologist) in the hospital if they notice a hospital referable eye condition on your retina photograph.

An ophthalmologist can detect diabetic retinopathy and maculopathy by examining the back of your eyes to look at your retina. You must contact the eye department if you are currently under the care of the hospital (otherwise via your GP or optometrist) if you have a new problem with your sight such as:

- Your sight suddenly gets worse, distorted or you lose all or part of your vision.
- You get a sudden increase in floaters in your vision.

# Please contact us if you notice any of the following symptoms in the eye that received the injection:

- If you notice that your vision is deteriorating.
- If you find that you have increasing pain within that eye.
- If you notice increasing amounts of floating spots, blobs or webs.
- If you notice increasing swelling around the eye.
- If you notice increasing discharge from the eye. A minor amount of tearing or watering of the eye is to be expected.

# What are the risks of intravitreal injection treatment?

### Very common:

Blurred vision, floaters, eye irritation, conjunctival bleeding (bloodshot eye) and raised eye pressure; (usually temporary).

#### Common:

Cataract, bleeding into the vitreous jelly, retina tear, retina detachment.

#### **Uncommon:**

Infection (endophthalmitis), blindness.

#### Coincidental/rare:

Stroke and heart attack.

Eye drops will be put into your eyes to numb the surface and rarely you may also have an injection of anaesthetic into the white part of your eye (subconjunctival). Antiseptic iodine eye drops will be applied to cleanse your eye to prevent infection. A small clip will be used to help keep your eye open. You will be asked to look in the opposite direction to the site of injection and a very fine needle will be used to deliver the drug into the vitreous jelly of your eyeball through the white part of the eyeball.

The eye doctor and their team will check that you have not lost vision in your eye usually by making sure you can see a hand in front of your eye.

# What should I expect after intravitreal injection treatment?

Most people will experience floating spots, blobs or webs that last 2 to 3 days immediately after the injection and should not increase after 24 hours. These are bubbles in the injected drug.

It is NOT uncommon to have a bloodshot eye or bruising of the white part of the eye. This may increase over the first few days and can look very serious. If your eye is NOT painful and your vision is NOT worse this does not require you to be seen by the doctor. It usually resolves within 2 weeks. It is common to have some minor irritation or feeling of 'grit' or 'sand' in the eye, but this should not increase or be severe.

# How do I prevent diabetic retinopathy and maculopathy?

Diabetic retinopathy and maculopathy can get worse over time, but the following measures can help you to reduce your risk of developing diabetic retinopathy and maculopathy and to slow the progress of sight-threatening retinopathy and maculopathy.

- Eat a healthy balanced diet; try and cut down on salt, fat and sugar.
- Control your blood sugar level as effectively as possible. You should attend your GP surgery to have your average blood sugar level over the past few weeks done at least once every six months. This is called HbA1c test and for most people with diabetes it should be around 48mmol/mol or 6.5%. You should know this number as it is the most important measure of your diabetic control.
- Attend your GP surgery regularly to check that your blood pressure and cholesterol level are normal and if necessary to have treatment for these.
- Stop smoking.
- Lose weight (if overweight).
- Exercise regularly (e.g. walking).

#### What is the aim of laser treatment?

The aim of laser treatment is to stabilise the changes caused by diabetes in your eyes. The treatment does not generally improve your sight although in a few cases it might.

#### What does laser treatment involve?

A course of laser treatment may involve one or more sessions with an eye doctor before the changes are controlled.

You will usually receive the treatment as an outpatient. Your eyesight will be checked and eye drops will be used to dilate your pupil. Both pupils will be dilated if you are having bilateral treatment. For this reason, **you should not drive** - please arrange for someone else to drive you home after your visit.

After the eye doctor has examined your eyes and you have agreed on the treatment and signed the form giving your permission (consent form), you will be taken through to the laser room.

Eye drops will be put into your eyes to numb the surface and sometimes you may also have an injection of anaesthetic into the white part of your eye (subconjunctival). Then a special contact lens will be placed on the eye to hold your lids open and to focus the laser beam onto your retina. The lens will be removed after you have had the treatment.

The laser treatment involves focusing an intense beam of light onto your retina in small spots. The number of spots will vary according to the type of diabetic change you have and how severe the changes are. Treatment usually takes 20 to 25 minutes for each eye. Your eye will get used to the brightness during the treatment but at the end you will be dazzled and your sight will seem darkened for several minutes. You may want to bring a

Usually, this continues for up to two months and very occasionally, for up to six months after treatment.

Around one in 10 people report seeing a small but permanent blind spot close to the centre of their sight.

The chance of you completely losing your central vision after laser treatment for maculopathy is around one in 300 (0.3%).

### What does intravitreal injection treatment involve?

A course of intravitreal injection treatment will involve several regular sessions and visits to the hospital, usually on a monthly basis, with an eye doctor and their team until the changes are controlled.

There will be a minimum of three injections, once a month for the first three months, with further monthly injections depending on the progress of your eyesight and scans.

You will usually receive the treatment as an outpatient.

Your eyesight will be checked and eye drops will be used to dilate your pupils if a scan is also required. Both pupils will be dilated. **You should not drive** - please arrange for someone else to drive you home after your visit.

After the eye doctor has examined your eyes and you have agreed on the treatment and signed the form giving your permission (consent form), you will be taken through to the treatment room.

### What is the treatment for maculopathy?

The eye doctor will apply gentle laser burns close to the central part of the retina - the part that you use to see clearly.

There are new treatment options approved by the National Institute for Health and Care Excellence (NICE). These consist of a course of injections of anti-VEGF drugs (Lucentis, Eylea) or steroid implants (Ozurdex, Iluvien) into the vitreous jelly of the eyeball.

These drugs stabilise macula swelling in diabetic maculopathy that is too close to the centre of the macula for laser treatment or has not responded to laser treatment.

Avastin, which is also an anti-VEGF, is commonly used off-label if your eye condition falls outside NICE approved guidance for treatment under the NHS. Off-label use means that the manufacturer of the medicine has not applied for a licence for it to be used to treat your condition. However, the medicine will have a licence to treat another condition, in this case colon cancer by it's anti-VEGF effect. This has the same effect as for the licenced drugs. Avastin has undergone several clinical trials for injection into the eyeball. We will always inform you it is off-label and discuss possible risks and benefits with you.

# What are the risks of laser treatment for maculopathy?

Some people can 'see' the laser pattern after treatment.

pair of dark glasses to wear home after the treatment.

## What should I expect after the laser treatment?

Your sight will normally return to its previous level over a few hours and you will be able to continue your work or normal activities the next day.

Rarely, your sight can take longer to return to normal.

If you have had a lot of treatment, your eyes may ache. You should find that mild painkillers, such as aspirin or paracetamol, ease the pain.

### Will I feel any discomfort?

Treatment is usually not painful but may in some cases be associated with pain or discomfort.

Sometimes the treatment will cause a sharp pricking feeling when certain areas of the retina are treated. This will happen where nerves run under the retina.

If you have had a number of laser sessions in the past, you are more likely to feel some discomfort during the treatment.

Pain may be prevented with the use of simple analgesia such as paracetamol but on occasion you may require the eye doctor to give an injection of anaesthetic under the white of your eye (subconjunctival), or less frequently general anaesthesia.

Please tell your eye doctor if you are experiencing intolerable pain.

You should contact the eye clinic if you have any new eye problems after your laser treatment.

### What is the treatment for proliferative retinopathy?

The eye doctor will apply a large number of laser burns to your peripheral retina. The peripheral retina is the part of the retina that allows you to see to the side and in the dark.

This treatment is called pan-retinal photocoagulation and you will usually have more than one session, two to three sessions are usually required at the start. The ophthalmologist may give you an injection of an anaesthetic under the white of the eye (subconjunctival) to make you more comfortable during the treatment.

# What are the risks of laser treatment for proliferative retinopathy?

At the end of a course of treatment for proliferative retinopathy, the following may apply.

You may notice a temporary worsening of your sight due to the macula (the small, highly sensitive central area of the retina) becoming waterlogged. This should resolve spontaneously but the ophthalmologist may need to advise treatment in a small number of cases. Occasionally, some people have a bleed into the jelly that fills the eye (the vitreous). If you notice a shower of floaters (specks that float across your vision) or your sight gets worse, you should contact the eye clinic.

There is a risk of causing a reduction of visual field (side vision) in around 40 to 50% of people after full panretinal laser photocoagulation. The risk of losing one's driving licence after full pan-retinal laser photocoagulation to both eyes is less than one in five (20%).

You must inform The Driver and Vehicle Licensing Agency (DVLA) if you have had pan-retinal laser photocoagulation in both eyes. They will arrange to have your side vision (visual field) tested at your local optometrist before making a decision on whether you can continue driving.

Other side effects include reduced night vision, dimness of vision, reduced colour vision and increased sensitivity to light (photophobia).

# The risk of vision loss from not receiving treatment at the right time is much higher than for laser therapy.

Sometimes laser therapy does not work and your vision can still get worse despite treatment. Your eye doctor may recommend a course of injections of anti-VEGF drug (off-label) into the vitreous jelly of your eyeball. Occasionally surgery may be required to remove persistent blood from the vitreous jelly or to repair a detached retina due to scar tissue.