

# Diabetic retinopathy: management and monitoring

Information for the public

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## Diabetic retinopathy: the care you should expect

Diabetic retinopathy is an eye disease. It is a very common complication of diabetes, most often affecting people who have had diabetes for a long time. You can get it if you have had high blood sugar levels or high blood pressure for a long time, because this can damage the back of the eye (the retina). If diabetic retinopathy is not treated, it can lead to sight loss.

There are different stages. Non-proliferative diabetic retinopathy is the early stage of the disease, with fewer symptoms. It's also known as pre-proliferative diabetic retinopathy. In some people, it may progress to proliferative diabetic retinopathy. Some people may develop a problem with the centre of the eye, called maculopathy. You can get this on its own or with retinopathy as well. Macular oedema and macular ischemia are types of maculopathy.

The care you are offered depends on the type or types of retinopathy you have. This may include observation, laser treatment, eye injections or an eye implant. We want this guideline to make a difference by making sure:

- You keep the best possible vision for the longest possible time.
- Your healthcare team helps you understand how closely managing your blood sugar level, blood pressure and blood lipids can help you keep your eyes in good health.
- Your eyes are checked regularly for any problems, to stop your eyesight getting worse and, if possible, improve it.
- Treatment options are discussed with you to agree the option that suits you best. If appropriate, observation (no treatment) is discussed with you too.
- Your healthcare team helps make it easier to get the treatment that is best for you, in the way that works best for you. This means they take into account things like your work or caring commitments, personal situation or disability.
- The different healthcare professionals involved in their care share information with each other about your eye health to reduce any risk to your sight (for example, you get the right medication after cataract surgery, or your blood glucose level is not being dropped so quickly that your eye health is put at risk).

## Making decisions together

Decisions about treatment and care are best when they are made together. Your health and care professionals should give you clear information, talk with you about your options and listen carefully to your views and concerns.

To help you make decisions, think about:

- What matters most to you – how can you and your healthcare team maintain or improve your eye health?
- What are you most worried about – are there risks or downsides from the disease or treatments that worry you more than others?
- How will the treatment and disease affect your day-to-day life?
- What happens if you do not want to have treatment?

If you need more support to understand the information you are given, tell your healthcare professional.

Read more about [making decisions about your care](#).

## Where can I find out more?

The [NHS website has more information about diabetic retinopathy](#).

The organisations below can give you more advice and support.

- [Diabetes UK](#), 0345 123 2399
- [Juvenile Diabetes Research Foundation \(JDRF\)](#), 020 7713 2030
- [Macular society](#), 0300 3030 111
- [Royal National Institute of Blind People \(RNIB\)](#), 0303 123 9999
- [Fight for sight](#), 020 7264 3900

You can also find information about people's experience of diabetic retinopathy on [healthtalk](#).

To share an experience of care you have received, contact your local [Healthwatch](#).

NICE is not responsible for the content of these websites.

We wrote this guideline with people who have been affected by diabetic retinopathy and staff who treat and support them. All the decisions are based on the best research available.

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