



My Personal Glaucoma Monitoring Record

*This booklet is for people who have glaucoma
or who might develop glaucoma in the future. Please bring
your booklet to every appointment.*



Name:

If found please contact:

Phone numbers

Hospital:

Eye clinic:

Glaucoma UK helpline: 01233 648170

(Open 9.30am – 5.00pm, Monday to Friday. Web address below.)

Details of local support groups:

Other sources of information and support

glaucoma.uk

The Glaucoma UK website contains lots of useful information about glaucoma. They also have a forum for patients and run a helpline that you can call to speak to someone in confidence about any questions or worries you have about glaucoma.



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This booklet has been developed for you in close collaboration with people with glaucoma and health professionals working in glaucoma clinics around the UK.



How this booklet can help you



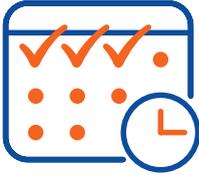
This booklet is for people who have glaucoma **or** who might develop glaucoma in the future. It provides **information** and tips to help you monitor and manage your condition.



Eye drops are the most common treatment for glaucoma. If you have been given eye drops it is very important that you use them as directed by your doctor. Using your drops properly will help to prevent sight loss in the future.



This '**orange book**' is designed for you to **make notes** about your appointments and eye test results so you can keep track of your condition.



It also features tips and advice to help you get into a **good routine** of using eye drops.



Remember to bring this **orange book** to all of your appointments. You can use it to note down questions or worries too.



If you're unsure about anything to do with your treatment **please talk** to your healthcare professional, they will be happy to help you.



We are here to help



Your healthcare professional team is here to help you and answer any questions you have at any stage of your condition. We want to help you start as you mean to continue. That way, you'll find it much easier to make your treatment part of your routine.



Your vision will be continually monitored by your healthcare professional team. These may include Visual Acuity tests, which assess your vision by how well you see the details of a letter or symbol from a specific distance. An eye examination may also include an assessment for intraocular pressure (IOP). Your healthcare professional team will answer any questions you may have on these tests.

If you have glaucoma in both eyes and are a driver, you must tell the DVLA.



Glaucoma is a lifelong condition with no cure, but together with your healthcare professional team, you can get your condition under control. You can discuss your ideas, questions, concerns and expectations with your health professional.



What may be expected in the first few visits to the eye clinic

Your healthcare team may:



- Give an explanation of what glaucoma is and what you can expect for the future
- Discuss your treatment plan and how it fits with your life



- Demonstrate how to use eye drops and ask you to practice in front of them (if/when you commence treatment with eye drops)
- Ask you to demonstrate how you are using eye drops while they observe (in future appointments, once your treatment has commenced)



- Provide details of local support groups
- Provide the name and details of a designated person you can contact if you have any problems, concerns or questions



- Give information about your condition
- Discuss whether your family members might develop glaucoma in the future and whether you may need to talk to them about this



Why am I being monitored?

Here is information on the different conditions and situations in which people need to be monitored in the glaucoma clinic – eye drops may play a role in managing all of these.

I have:

Ocular hypertension

Where eye pressure is consistently above the normal range, but this pressure isn't causing any damage to the optic nerve. You may be prescribed eye drops to help reduce your eye pressure and reduce your risk of developing glaucoma.

Glaucoma suspect

Glaucoma suspect describes a person with one or more risk factors that may lead to glaucoma. This person might have increased eye pressure but does not yet have definite optic nerve damage or vision loss due to glaucoma.

Primary open angle glaucoma / chronic open angle glaucoma

The most common type of glaucoma, where damage to the optic nerve usually occurs slowly over a long period of time due to increased pressure in the eye.

Chronic angle closure glaucoma / primary angle closure glaucoma

Damage to the optic nerve can be gradual, intermittent or happen quickly (an acute attack) due to a sudden rise in eye pressure caused by the angle between the iris and the cornea closing.



Pseudoexfoliative glaucoma

A condition where deposits of fibrillar material in the front of the eye can lead to raised eye pressure and damage to the optic nerve, sometimes more quickly than in open angle glaucoma.



Normal-tension glaucoma

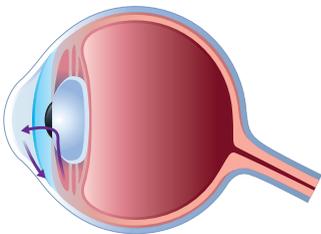
This type of glaucoma occurs when your eye pressure is within normal range, but there is damage to your optic nerve. It is treated in the same way as open angle glaucoma – by lowering eye pressure to a level that will keep your sight safe.



Other

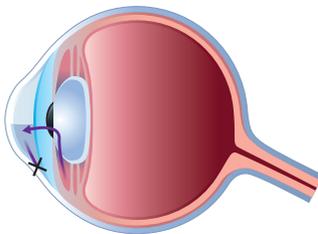
If you have another type of glaucoma not listed here, your healthcare professional may give you some specific advice about this.

Development of glaucoma



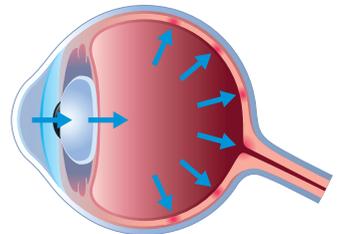
Healthy Eye

Flow of aqueous humour through the drainage canal.



Glaucoma

1. Drainage canal blocked; build up of fluid.



Glaucoma

2. Increased pressure damages the optic nerve.

Attending all your appointments is very important so any changes can be monitored.



My appointment today

Before your appointment write down any questions, concerns or things you want to talk about. For example, do you have a question about your eye drops? Are you experiencing any side effects? Is there anything coming up that might affect your normal routine with your eye drops, such as going on holiday, changing job, or a family event?

Write your notes here



Date

Who I saw today

My treatment plan

**What we discussed
during the appointment**

**Expected follow-up
appointment**

We are always here to help you so get in touch if you want to talk to someone in between appointments. You can find a list of useful contacts on page 2.



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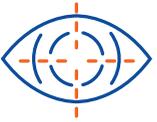
Example treatment journeys

Everyone's journey is different, whatever kind of glaucoma they may have. However, there are three things everyone has in common.



Diagnosis

- Usually an optometrist carries out several tests before referring a person to hospital for further investigations
- A specialist based in the hospital carries out further tests/investigations to make a diagnosis



Treatment options

- If needed, eye drops may be prescribed once a diagnosis has been made
- Some people may be offered laser treatment or surgery, perhaps alongside other medication
- Advice about laser surgery is available from Glaucoma UK



Ongoing monitoring and support

- The condition and treatment will be monitored on an ongoing basis. Treatment may be changed, for example if it isn't working well or if the person is troubled by side effects – it is a lifelong process
- It's important to attend all appointments as many people don't notice gradual sight loss so monitoring the condition is really important

It is important to attend all of your appointments so your condition can be monitored properly

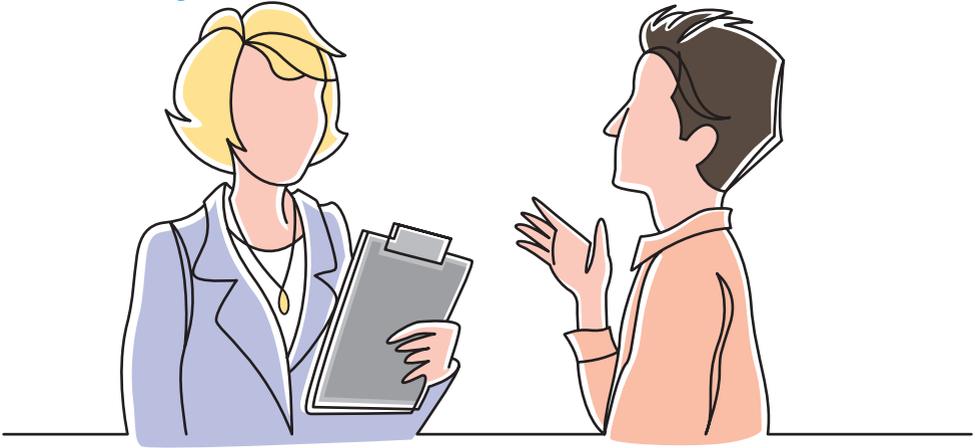
- There is no cure but you can really help with getting the condition under control by using your eye drops

Most people require ongoing treatment – it is important you continue with this unless told otherwise

- There are lots of ways to help make eye drops part of your normal routine



Jeff's story



As part of his routine eye test, Jeff was screened for glaucoma and was recommended to have further tests.

After undergoing additional tests, Jeff's healthcare professionals suspected he may have ocular hypertension – where the pressure in one of his eyes was higher than the normal range.

Jeff was prescribed drops and for the first few days, he had no trouble using them as directed. However, after a week or so, Jeff began to forget to use the drops.

As a shift-worker, it was hard to build them into his regularly changing shift patterns, but he knew he had to find a way to build them into his routine.

Like many people, Jeff was used to doing a lot of everyday tasks on his smartphone and so decided to look up apps for glaucoma. He found MyGlaucoma, an app to help him use the drops and set reminders so it soon became a habit.

On his last visit, Jeff's healthcare professional said he was doing really well and the eye drops are working well.

If you have trouble remembering to use your drops, try and find ways to help you remember until they become part of your daily routine. Find out more about MyGlaucoma on page 27.



Beryl's story



Beryl had recently become worried about her eyesight. She had become nervous about driving at night but wanted to maintain her independence to see family nearby.

At first, she thought her vision was deteriorating due to her age, but after routine tests, Beryl was diagnosed with open-angle glaucoma.

When Beryl started using eye drops, she found her eyes got

quite red and sore. She kept using the drops but after a while she wanted to stop. She called her eye clinic and spoke to a nurse about the problems she was having with the drops.

She was asked to come into the clinic for an appointment. Beryl explained that she had been suffering from side effects and the doctor prescribed a different eye drop. Beryl is now using her eye drops regularly and hasn't had any further problems.

If you experience side effects when using eye drops, remember the solution can be as simple as trying a different kind of eye drop. Talk to your healthcare professional and find a solution so you feel happy about using your eye drops every day.



Sanjay's story



Sanjay found out at an appointment with his healthcare professional that he may be at risk of developing glaucoma because his mother had the condition. His mum had already experienced some sight loss before she was prescribed eye drops and so he was keen to get checked out as soon as possible.

After further tests Sanjay was diagnosed with glaucoma and laser treatment was recommended. He was prescribed eye drops and told to use them after undergoing the procedure.

The laser procedure went to plan, and Sanjay began using his eye drops. He started to use the orange book to record his test results and make notes about his condition.

Sanjay also kept a diary to monitor his condition and to help him keep track of things. He finds it helps to write down questions or concerns right away so he can remember to discuss them at his next appointment.

Note down any questions or worries you have and discuss them at your next appointment.



Tips for using your eye drops

It's important to get used to your drops from the start. Once you get into the habit of using them at the same time every day, it's as easy as combing your hair or brushing your teeth! Here are some tips to help you build eye drops into your routine...

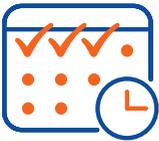


- Try placing your eye drops next to your toothpaste or where you keep breakfast items, so you are reminded to use them at the same time as other things in your daily routine



- Set your alarm clock for the first few days of using your eye drops so you get into the routine of using them, or use the MyGlaucoma app to set reminders on your phone

Find out more about this app on page 27



- Note down on a calendar when you have started a new bottle of eye drops so you know when to replace them
- Note that drops only last a month and bottles should be disposed of after 4 weeks even if there are some drops left in



- Travelling can be a challenge as the routine is different or it can be hard to stop to put drops in. Plan ahead and if you are driving then think about when you might need to stop to put drops in



- Help and support from another person can really help – if you are finding it difficult to use your drops then talk to someone about it



- Some people can feel self-conscious about using drops in social situations. Try to be open with friends and family about this so they can support you



- If you need to keep your eye drops in the fridge, keep them in an obvious, visible place – don't leave them forgotten in a hidden compartment or behind jars! You could even put a reminder note next to them



- For every day you take your eye drops properly, maybe you could reward yourself in some way. Whether it's a small piece of chocolate or a pound in a jar, rewards can be motivating!



Common questions about glaucoma treatment

When should I use my drops?

The number of times a day depends on the medicine you have been given. What is important is that you always use them at about the same time every day. If you need to use them twice a day then make sure this is at a regular interval, i.e. 12 hours apart. Work out a time that fits with your life and routine. This might help you to remember to use them.

Do I need to store my eye drops in the fridge?

Some glaucoma drops need to be stored in the fridge and some do not. Check the label on the drops to find out if yours need to be kept in the fridge or ask the pharmacist. However, some people find that keeping them in the door of the fridge is a good place as it keeps them cool so you can feel the drops going in. You might find it reassuring to know you have put them in correctly. Always check with your pharmacist if you can safely store your drops in the fridge as sometimes this can affect your medicine inside the bottle.

What should I do when I am on holiday?

You still need to use your eye drops at a regular time. It can be hard to remember when you are out of your normal routine so try setting an alarm on your phone or leaving the eye drops somewhere where you will see them and remember to use them. If the weather is hot you will need to keep your eye drops cool. Cool wallets can prevent your drops from becoming warm for up to 45 hours. They contain gel crystals which only require soaking in water (no refrigeration) to reactivate.



What should I do if I miss a drop?

If you miss a drop then carry on and take your next one when you are supposed to. Don't double up and take two drops. If you find that you are regularly missing drops then talk to your healthcare professional about this so they can help you to find a good way to remember to use them.

The eye drops the pharmacist gave me this time look different from the ones I've had before. Should I still use them?

Sometimes eye drops can come in different packaging, even though the medicine inside is the same. As long as it is the same kind of eye drop, usually indicated by the name, that is fine. If you are not sure then ask your pharmacist. It is really important that you keep using your drops.

I was given a special device to help me put my drops in but it doesn't fit onto the new bottle I have been given. What should I do?

Speak to your pharmacist and show them the difficulty you are having. You can also call your contact person at the eye clinic who can help you. Don't struggle on with it – ask for some help so you can make sure you continue to use your drops correctly.

I have been getting some side effects from the drops. Should I stop using them?

Speak to your contact person at the eye clinic if you are worried about side effects. Don't stop using your drops unless your healthcare team tells you to.

Why do I need to use the eye drops if I don't have any symptoms?

You can't feel glaucoma but it is really important you use your eye drops. They help to lower the pressure in your eye which can help protect your eyes from damage. If it is not treated then glaucoma can cause blindness.



How to use your drops

There are different techniques you can try for using your drops. If you are not sure you are doing it correctly or would like someone to demonstrate for you then please ask your health professional to show you.

Information and videos from the Moorfields Know Your Drops campaign are also available at:

moorfields.nhs.uk/knowyourdrops

Glaucoma UK is the only UK charity specialising in glaucoma support. Visit their website **glaucoma.uk** for useful information about glaucoma.



MyGlaucoma App

This app has been designed for people who have glaucoma. It provides information and tips to help you monitor and manage your condition.

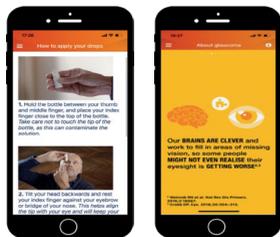
You may find that the app is helpful to get you into a good routine of using your eye drops and making them part of your daily life. You can also keep track of your appointments and test results.

The app can be used on its own or alongside this **orange book**. The choice is yours!

Here are some of the features of the app that you may find helpful:



- ✓ Customised reminders on when to use eye drops and alerts to keep on top of repeat prescriptions and appointments
- ✓ Allows you to track your eye pressure measurements



- ✓ Allows you to upload photos and notes for reference
- ✓ Tips and tricks for using eye drops
- ✓ Provides information about glaucoma and advice for managing glaucoma

The app also includes information about Glaucoma UK and the ways that they can support you and your family.

If this app sounds like something that you'd like to try, you can download it for free from the App Store for iPhone users and via Google Play for those with Android devices.





Santen has initiated, supported and funded the development of this booklet.



Supported by Glaucoma UK.