

# Patient standards for glaucoma

## A Patient Guide



The Charity for People with Glaucoma



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This document explains how patients who may or do have glaucoma should be cared for in a way that best involves and supports them. There are many standards and recommendations for patients in healthcare, such as those from NICE. This publication describes the standards for care which are very specific, or most important, to those with glaucoma-related conditions.

The standards have been developed by patients, patient charities and eye care professionals working together. They bring together key points from existing national guidelines in one document and cover the whole care pathway for those with glaucoma conditions. Those providing or commissioning care for these conditions should assess their services and, where the standards are not met, take action for improvement.

**These standards should be read in conjunction with the UKOA-RNIB Patient Standards for Ophthalmology, available from <https://bit.ly/2xudPxJ>**

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## Care pathways

### Referrals

- People with high eye pressure or possible glaucoma should be checked by a trained community optometrist with suitable equipment.
- After this the optometrist should be able to arrange an appointment directly with the hospital eye clinic.
- Urgent referrals should be sent directly to the hospital eye clinic without delay.
- People who do not need hospital eye care should not be referred:
  - Those who do not require treatment;
  - Those with a pressure not yet checked on the most accurate equipment;
  - Those previously checked at hospital whose condition has not changed.

### Discharge

- People who do not have glaucoma and do not need treatment should be discharged back to their optometrist.
- People who have been seen for possible glaucoma should see their optometrist every year.

### Stopping or avoiding unnecessary treatment

- People who are not at risk of loss of sight during their lifetime should not be offered treatment.
- People with glaucoma or high eye pressure (patients) should have a regular discussion of treatment choices including the risks and benefits of no treatment if appropriate.

### Monitoring

- Patients should be checked in the hospital or community by suitably trained staff, linked with a hospital glaucoma consultant.

- The timing of eye checks should be based on how likely their condition is to worsen, as recommended by NICE.
- Appointments should be booked as requested by the health care professional.

## **Information sharing between healthcare professionals**

- Every time a patient is seen, their healthcare professional should have all the required information on:
  - All previous relevant tests;
  - Medical and eye conditions which may affect glaucoma care;
  - Current general medicines and eye drops for glaucoma and other conditions;
  - Allergies and reactions to medicines.
- People who are being discharged:
  - Should be given a discharge information letter, with a copy sent to their GP;
  - Should have their discharge information sent to them and (with patient's consent) to their optometrist. This should contain enough relevant eye information to identify any change on subsequent checks.
  - Should be advised to take their discharge and eye information with them when attending future optometrist checks.

## **Understanding and supporting patients**

### **Adaptations**

- Services must be physically accessible, convenient for transport, and flexible for patients with different needs.
- Hard to reach and vulnerable groups should be specifically supported to receive screening and care.
- Communication, assessment, treatment and patient involvement methods should be adapted to factors such as disabilities, sight or hearing problems, cultural and language differences, as the patient needs.

- If using drops is difficult, professionals should discuss drop aids, laser or surgery with the patient.
- Patients with other eye conditions should receive care from professionals who can explain and deal with the combination of conditions.
- Where an appointment is missed or cancelled:
  - A glaucoma care professional should decide on further appointments based on the patient's eye situation;
  - Letters about the missed or changed appointment and plan for further appointment should be sent to the patient, GP and optometrist;
  - GPs and carers should be involved for vulnerable patients such as those with learning difficulties or dementia.

## **Information and support**

- Professionals should discuss, and offer written accessible information on, diagnosis, referral, outlook, treatment and discharge, at first visit and repeat as necessary at follow-up visits.
- Professionals should ensure the patient has understood any information.
- Professionals should keep track of what information has been provided previously, e.g. via a check list.
- Information given should include:
  - The name of their condition, its life-long implications and their outlook for keeping good vision;
  - Information on pressure, visual fields and findings of their eye check;
  - If the patient has only high pressure, what their long-term risk of glaucoma is;
  - Early glaucoma or high pressure has no symptoms;
  - Glaucoma usually gets worse over time and affects peripheral (outer edges of) vision first;
  - Most people treated for glaucoma will have good quality of life and not go blind;

- Once lost, sight cannot return;
  - That glaucoma can run in families and family can be tested by their optometrist;
  - The aims of treatment (lowering of pressure to keep vision), the different types of treatment (drops, laser, surgery), how they work, side effects, risks and benefits;
  - Drop treatment is usually long term and many do not need laser or surgery;
  - Using the eye drops properly is key to prevent worsening;
  - How to store and use eye drops (see below);
  - The importance of regular checks and coming to clinic appointments;
  - How long appointments take with realistic waiting times, and how often appointments will be;
  - How eye tests are done in clinics, that the patient cannot drive after dilating drops, and whether they need any help to come to appointments;
  - When the next appointment will be and how they will be told about this;
  - That they should get in touch if they do not receive their appointment in the expected time;
  - Information on delayed and cancelled appointments, how long are delays, why they happen and whether it is safe;
  - The DVLA (Driving Vehicle Licensing Agency) rules for driving and advice on their own driving situation.
  - On discharge, what this means and that the patient understands their need for future checks with their optometrist.
- Sources of information and support including patient support groups e.g. International Glaucoma Association (IGA), the Royal National Institute of Blind People (RNIB), SeeAbility, NHS Choices and local voluntary groups;
  - There should be easy access to an Eye Clinic Liaison Officer (ECLO) in the hospital which fits with the RNIB ECLO quality framework.

- Low vision information, registration and certification should be offered to all suitable people as soon as possible, even if still being treated.
- There should be access to low vision aid (LVA) services within 18 weeks.

## Shared decision making

- Patients should be involved as partners in decisions on care of their condition and asked what level of involvement in decisions they would like.
- Professionals should not make assumptions on what the patient wants and should talk to the patient to find out.
- When treatment options are discussed, professionals and patients should decide together on a practical and realistic plan taking into account all factors (age, general health, work and lifestyle, risk of eyes worsening, what the patient prefers etc).
- If the patient wishes, inform carers and engage them in support.
- The patient may decide not to take a medicine – the healthcare professional must advise on risk and benefits if this could be harmful and record the patient's decision.
- Professionals should discuss the risks and benefits of early surgery with people with glaucoma who are losing their sight despite treatment or have severe glaucoma, using shared decision making.

## Involvement in care

### Using drops properly

- Patients should be informed how to use eye drops, including shaking the bottle, method (getting the drop in, tear duct blocking), expiry dates and storage.
- Professionals should demonstrate method of putting in drops, and watch the patient or carer putting in drops and repeat education until they are successful. This should be rechecked from time to time.
- Professionals should discuss drop aids, provide them or advise where to get them (e.g. GP or pharmacist or via IGA) where required and teach how to use them.

- Professionals should explain how, where and when to obtain repeat prescriptions, and their importance.
- Patients should be helped to timetable their drop use or link this to activities of daily living.
- Treatment should be kept simple – as few bottles and as few times per day as safely possible, using combination drops to help.

## **Side effects**

- Information should be provided about side effects of treatment.
- At every visit there should be checks to see whether a patient has side effects and discussion about:
  - How the patient would like to deal with side effects;
  - Other treatment options so the patient can make an informed choice;
  - Adjusting the dose;
  - Switching to another medicine;
  - What else might help (e.g. timing of drops).

## **Are patients using treatment as advised?**

- Professionals should:
  - Check how treatment is used at every visit;
  - Check method of putting in drops if treatment not working;
  - Ask questions which make it easier for the patient to say honestly how they are using the treatment;
  - If not using drops as advised, explore why;
  - Agree a realistic plan (see “using drops properly”) based on the patient’s specific problems and preferences and a date to check how things are going.

- The hospital should work with pharmacists and optometrists to help check drop use and provide support.
- Carers/family/friends should be included to help support treatment.

## What to do if problems arise

- Patients should receive information about the name and contact details of a qualified professional for queries or drug side effects.
- Patients should be advised when to make contact e.g. side effects to drops, symptoms of worsening glaucoma, no appointment or delayed appointments.
- Patients should be advised what to do in an emergency and what are serious symptoms

## Glossary

NICE: National Institute for Health and Care Excellence provides national guidance and advice to improve health and social care.

Optometrist: Optometrists are trained to make a health assessment for the eyes, offer clinical advice, prescribe spectacles or contact lenses and refer patients for further treatment, when necessary.

Opticians: Opticians use prescriptions written by the optometrist to fit and sell glasses or contact lenses.

Urgent referral: Where a patient needs care provided sooner than would happen when following a routine path through the health system because delay could or will lead to harm.

Emergency referral: Where a patient needs care provided within 24 hours because delay could or will lead to harm.

Healthcare professional: A trained member of staff such as a doctor, nurse, optometrist or orthoptist, who looks after patients and health conditions.