

Patient standards for glaucoma – Patient friendly language

Care pathways

Referrals

- People with high eye pressure or possible glaucoma should be able to be checked by a trained community optician with suitable equipment
- After this the optician 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 checked on the most accurate equipment
 - Those previously checked at hospital whose condition has not changed.

Discharge

- Discharge people back to their optician if they do not have glaucoma and do not need treatment.
- People who have been seen for possible glaucoma should see their optician every year.

Stopping or avoiding unnecessary treatment

- Do not offer treatment to people who will not develop loss of sight during their lifetime.
- People with glaucoma or high 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 by suitably trained staff in the hospital or community who are 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 health care professional should have all the required information on:
 - all previous relevant tests
 - medical and eye conditions which may affect glaucoma care
 - current general and glaucoma medicines and eye drops
 - allergies and reactions to medicines.
- For people who are being discharged to their optician and GP:
 - Given a discharge information letter and send a copy to the GP.
 - With patient consent, send the discharge information and enough relevant eye information to identify change on further checks, to the patient and the patient's optician.
 - Advise people to take their discharge and eye information with them when attending future optician checks.

Understanding and supporting patients

Adaptations

- Services must be 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.
- Adapt communication, assessment, treatment and patient involvement methods to factors such as disabilities, sight or hearing problems, cultural and language differences, as the patient needs.
- If using drops is difficult, consider drop aids, laser or surgery.

- Patients with other eye conditions need 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 optician.
 - For vulnerable patients such as those with learning difficulties or dementia, involve the GP and carers.

Information and support

- Discuss, and offer written accessible information on, diagnosis, referral, outlook, treatment and discharge, at first visit and repeat as necessary at follow-up visits.
- Check the patient has understood
- 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, and visual fields and findings of their eye check
 - If only high pressure, their long-term risk of glaucoma
 - Early glaucoma or high pressure has no symptoms
 - Glaucoma usually gets worse over time and affects side 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 optician
 - 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 most 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, patient cannot drive after dilating drops, any help required to come to appointments
 - When the next appointment will be and how they will be told about this
 - To 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.
 - On discharge, explain what this means and check the patient understands their need for future checks with their optician. Ensure patients have a copy of their discharge letter format and clinical information for their optician;
 - Sources of information and support including patient support groups e.g. International Glaucoma Association (IGA), the Royal National Institute of Blind People (RNIB), See ability, NHS Choices and local voluntary groups

The DVLA (Driving Vehicle Licensing Agency) rules for driving and advice on their own driving situation.

- Patients should have 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
- Help explain the condition to employers if patients need this .

Shared decision making

- Involve patients as partners in decisions on care of their condition and ask what level of involvement in decisions the patient would like.

- Do not make assumptions on what the patient wants – talk to the patient to find out.
- When treatment options are discussed, 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 and engage carers in support.
- The patient may decide not to take a medicine – the health care professional must advise on risk and benefits if this could be harmful, and record the patient’s decision.
- People with glaucoma who are losing their sight despite treatment or have severe glaucoma should discuss the risks and benefits of early surgery using shared decision making.

Involvement in care

Using drops properly

- Inform patients how to use eye drops, including shaking the bottle, method (getting the drop in, tear duct blocking), expiry dates and storage.
- Demonstrate method of putting in drops, watch the patient or carer putting in drops and repeat education until they are successful. Recheck this from time to time.
- 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.
- Explain how, where and when to obtain repeat prescriptions, and their importance.
- Help patients to timetable their drop use or link this to activities of daily living.
- Keep treatment simple – as few bottles and as few times per day as safely possible, use combination drops to help.

Side effects

- Provide information about side effects of treatment.
- Check at every visit if the patient has side effects and:
 - discuss how the patient would like to deal with side effects;
 - discuss other treatment options so the patient can make an informed choice;

- consider adjusting the dose;
- consider switching to another medicine
- consider what else might help (e.g. timing of drops).

Are patients using treatment as advised?

- 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 tell you 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 opticians to help check drop use and provide support
- Include carers/family/friends to help.

What to do if problems

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

This standard should be read in conjunction with the UKOA-RNIB Patient Standards for Ophthalmology.