

Understanding NICE guidance

Information for people who use NHS services

Diagnosing and treating glaucoma and raised eye pressure

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care and treatment of people with chronic open angle glaucoma and the associated condition ocular hypertension (raised eye pressure) in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with glaucoma and people with eye pressure that is higher than normal who may be at risk of developing glaucoma. It may also be useful for their families or carers or for anyone with an interest in these conditions.

The booklet is to help you understand the care and treatment options that should be available in the NHS. It does not describe glaucoma or ocular hypertension or the tests or treatments for it in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. You can get more information from the organisations listed on page 11.

Contents

Your care	3
Glaucoma and ocular hypertension	4
Diagnosis	5
Monitoring and treatment for people with ocular hypertension or suspected glaucoma	6
Monitoring and treatment for people with glaucoma	8
Information	10
More information	11
About NICE	12

The advice in the NICE guideline covers the diagnosis, treatment and care of:

- adults (18 years and over) with a diagnosis of the condition known as 'chronic open angle glaucoma'
- adults with a diagnosis of ocular hypertension (raised eye pressure)
- adults who are at a high risk of developing glaucoma.

It does not specifically look at the treatment and care of:

- people under 18 years
- people with secondary glaucoma (glaucoma that is caused by other eye conditions, such as injury or inflammation)
- people with, or at risk of, types of glaucoma known as 'angle closure glaucoma (primary or secondary)' or acute glaucoma
- adults who have had glaucoma since birth or childhood.

Your care

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain glaucoma or ocular hypertension and the treatments for them simply and clearly.

The information you get from your healthcare team should include details of the possible benefits and risks of particular treatments. You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change. Your own preference for a particular treatment is important and your healthcare team should support your choice of treatment wherever possible.

Your treatment and care, and the information you are given about it, should take account of any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

If you agree, your family and carers should have the chance to be involved in decisions about your care. Family members and carers also have the right to the information and support they need in their roles as carers.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk/consent). Your healthcare professional should also follow the code of practice for the Mental Capacity Act. For more information about this, visit www.publicguardian.gov.uk

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about the specific treatments and options covered in this booklet, please talk to a member of your healthcare team.

Glaucoma and ocular hypertension

Glaucoma is the name for a group of eye disorders that involve damage to the optic nerve. People with glaucoma can lose their sight if their condition continues to get worse. The most common form of glaucoma is chronic open angle glaucoma. 'Chronic' means persistent or long-lasting, and 'open angle' refers to the drainage area of the eye where fluid (not the tears) normally leaves it. This form of glaucoma develops slowly and is often accompanied by increased pressure in the eye, although many people with glaucoma or suspected glaucoma have normal eye pressure.

Increased eye pressure can exist without any damage to a person's sight, in which case the condition is called ocular hypertension. Ocular hypertension can increase the risk of someone developing glaucoma, but doesn't necessarily lead to it.

In the early stages of ocular hypertension or glaucoma there are usually no symptoms, but progressive glaucoma (glaucoma that gradually gets worse) can cause blindness if left untreated. But if it is diagnosed and treated early enough progression can be delayed, with the aim of preserving sight. Glaucoma is more common with increasing age, and mainly affects people over 60. You may be at greater risk of developing glaucoma if you are of black African or black Caribbean descent or if you have a family history of glaucoma.

Questions you might like to ask your healthcare team

- Please tell me more about my condition and how it can be treated.
- Can you provide any information for my family/carers?
- Is there anything I can do to help myself?

Diagnosis

If your healthcare professional thinks you might have glaucoma or ocular hypertension, you should be offered tests to clarify the situation (see box 1). You should also have a photograph taken of the optic nerve heads (or optic discs) at the back of your eyes for future reference (box 1). If you are unable to have any of the tests (for example, if you have a physical or learning disability that makes this difficult for you), you should be offered alternatives. If tests show that you might have glaucoma, or some other problem affecting your optic nerve or field of vision, you should be referred to a consultant ophthalmologist for a diagnosis.

Box 1 Tests you should be offered if you have or are suspected of having glaucoma, or if you have ocular hypertension

You should be offered tests to assess:

- your eye pressure, which is also called intraocular pressure (the test is called tonometry)
- the thickness of your cornea – the clear covering over the front of your eye
- the drainage area in your eye (angle) where fluid leaves it (the test is called gonioscopy)
- your field of vision – how much you can see when looking forward, including at the edges of your vision (the test is called perimetry)
- the appearance of your optic nerve (sometimes also referred to as the nerve head or optic disc; it is at the back of the eye and carries electrical impulses to the brain).

Questions about finding out what is wrong (diagnosis)

- Please give me more details about the tests/investigations I should have.
- What do these tests involve? Will they hurt?
- How often will I need to have them?
- Where will these be carried out? Will I need to have them in hospital?
- How long will I have to wait until I have these tests?
- How long will it take to get the results of these tests? Will I get to know what the results are?

Monitoring and treatment for people with ocular hypertension or suspected glaucoma

Monitoring

If your healthcare professional thinks you're at risk of developing glaucoma (whether you are having treatment or not), you should be offered regular monitoring, using tests similar to those used to diagnose glaucoma.

How often you have these tests will depend on how high your risk for glaucoma is. You might have to take eye drops for your treatment – this is covered in the following section. If you have just started taking eye drops, or if you have recently changed your eye drops, your eye pressure should also be tested 1 to 4 months after starting the new treatment.

If you don't need to use eye drops, your healthcare professional should still test your eyes regularly. How often you need to have these tests will depend on your risk of sight loss from glaucoma. If monitoring tests show that there is no deterioration in your eyes after 3 to 5 years (or earlier if tests confirm your eyes are normal), you may be discharged because you do not have glaucoma. But you should still visit your optician every year to be checked by the optometrist so that any future changes can be detected.

Treatment

If you have raised eye pressure your healthcare professional may offer you treatment to reduce the risk of developing glaucoma. The type of treatment you are offered will depend on how likely you are to develop glaucoma. The main aim of treatment is to reduce the risk of future sight loss by reducing the pressure inside the eye. To determine how likely you are to develop glaucoma your healthcare professional will test your eye pressure and the thickness of your cornea (the clear covering over the front of your eye). They will also take into account your age, because the risk of developing glaucoma increases with age. They will decide whether you will benefit from treatment, and if so, which one.

If you are offered treatment it will usually be with medicines called prostaglandin analogues or beta-blockers, in the form of eye drops. Prostaglandin analogues help the eye's internal fluid drain out more quickly, whereas beta-blockers reduce the pressure in the eye by slowing down the build up of fluid inside it.

If you have been having treatment but your eye pressure is still too high, you should be offered alternative eye drops. For example, you may be offered beta-blockers if you have been using prostaglandins, and vice versa. If your eye pressure is still too high after this, you may be referred to a consultant ophthalmologist to discuss other treatment options. You should also be offered alternative eye drops if your current medicine is causing you problems. If you are allergic to preservatives and have a high risk of developing glaucoma, you should be offered eye drops that don't contain any preservatives.

Stopping treatment

In some circumstances you may be able to stop using eye drops. For example, if your eye pressure isn't too high or if you're unlikely to ever develop problems with your sight (some people with ocular hypertension don't develop problems with their sight), you may be able to stop having treatment. You may also be able to stop using eye drops when you reach a certain age if the risk to your vision becomes so small that eye drops are no longer necessary. Your healthcare professional should discuss the benefits and risks of stopping treatment with you. If you do decide to stop, he or she should offer to test your eye pressure 1 to 4 months later. Depending on the health of your eyes you may need to carry on having tests to make sure any future changes are picked up.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team.

Monitoring and treatment for people with glaucoma

Monitoring

If you have been diagnosed with glaucoma, you should be offered regular monitoring with tests similar to those used to diagnose your condition.

How often you are monitored will depend on how likely your condition is to get worse. You will normally have the monitoring tests at intervals of between 2 months and a year. But if you have just started taking eye drops, or if you have recently changed your treatment, your eye pressure should also be tested 1 to 4 months after starting the new treatment.

Treatment

The main aim of treatment for glaucoma is to preserve your sight by reducing the pressure in your eye. But the treatment will not bring back sight that has already been lost. If you have just been diagnosed with early or moderate glaucoma and there is a risk you may develop significant loss of sight you should be offered treatment with a prostaglandin analogue in the form of eye drops. Your healthcare professional will then monitor your condition to see whether the eye drops are working.

You should be offered other treatments if your eye pressure remains too high, your field of vision gets worse, your optic nerve becomes more damaged or your eye drops are causing you problems. These other treatments will depend on your condition. They can include alternative eye drops, laser treatment (to help drain the fluid from the eye or stop the eye producing as much fluid) or surgery (to improve drainage).

If your glaucoma is at an advanced stage when you are diagnosed you should be offered surgery to stop your sight getting worse.

If you decide to have surgery you should be offered treatment with a prostaglandin analogue while you are waiting for surgery. If your eye pressure is still high after having recovered from surgery you should be offered eye drops, further surgery or laser treatment. If you prefer not to have surgery or if surgery is not suitable for you, you should be offered eye drops or laser treatment.

If a treatment described in this booklet appears suitable for you, but it is not available, you should talk to your local patient advice and liaison service (usually known as 'PALS') in the first instance. If they are not able to help you, they should refer you to your local independent complaints advocacy service.

Questions about the monitoring and treatment

- Please tell me why you have decided to offer me this particular type of treatment.
- What are the pros and cons of having this treatment? What are the possible side effects?
- Please tell me what the treatment will involve.
- How will the treatment help me? What sort of improvements might I expect?
- How long will it take to have an effect?
- What if I forget to put in my eye drops or use too much?
- Will all the tests mentioned in this booklet be done at each monitoring visit?
- What should I do if I have a bad reaction to my eye drops?

Information

You should be given the opportunity to discuss your diagnosis and prognosis (what your sight may be like in the future) with your healthcare professional. You should also be offered relevant information (some examples of topics are given in box 2). If you are offered surgery you should be given information about the pros and cons of the surgery so that you can make an informed decision.

Box 2 Information you may be offered

Your healthcare professional should offer you information. This could include information on the following:

- your specific condition, its lifelong implications and the likelihood you will keep your sight
- that most people who are treated for glaucoma will not go blind
- that glaucoma in the early stages, raised eye pressure (ocular hypertension) and suspected glaucoma have no symptoms
- that once lost, sight cannot come back
- that glaucoma can run in families and that family members may wish to be tested for the disease
- the importance of your role in your own treatment, how to apply eye drops, and devices to help you to take your eye drops
- the different types of treatments and the need for regular monitoring
- the different types of tests used to diagnose your condition
- how long each appointment will take and whether you'll need any help to attend
- support groups
- the Letter of Vision Impairment (LVI), Referral of Vision Impairment (RVI) and Certificate of Vision Impairment (CVI) registration – these can help you get practical support from your council
- Driver and Vehicle Licensing Agency (DVLA) regulations about requirements to drive legally.

More information

The organisations below can provide more information and support for people with glaucoma or ocular hypertension. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- International Glaucoma Association, 01233 648164
www.glaucoma-association.com
- Royal National Institute of Blind People (RNIB), Helpline 0303 123 9999
www.rnib.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may also be able to give you further information and support.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of the guideline aimed at healthcare professionals are available at www.nice.org.uk/CG85

You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1847 for the standard print version and N1858 for the large print version). The NICE website has a screen reader service called Browsealoud which allows you to listen to our guidance. Click on the Browsealoud logo on the NICE website to use this service.

We encourage NHS and voluntary organisations to use text from this booklet in their own information about glaucoma and ocular hypertension.