

Serious Eye Conditions Toolkit

Where to find help to access eye
health treatment (England)

March 2019

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See differently



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Introduction

Are you living in England and currently finding it difficult to get eye health treatment or services for conditions that can't be corrected by prescription glasses? Or have you had problems in the past? This toolkit is for you! There's advice about getting the most out of your meetings or appointments, talking to organisations, and steps to take if you're faced with barriers or delays.

The NHS, local government and charities all face funding squeezes, which can impact on the treatment and support offered to people with eye conditions, both directly, in limiting the specialist services provided, and indirectly, by adding barriers to accessing mainstream services.

The RNIB Helpline has a team of helpful experts who will point you to support or services you need to continue living life to the full when you have sight loss. It is available from 8am – 8pm weekdays and 9am – 1pm on Saturday on **0303 123 9999**, or via email on **helpline@rnib.org.uk**.

RNIB also has a range of guides covering different eye conditions (**<http://bit.ly/EyeCond>**) which explain what they are, how they are treated, and what you should expect.

If your condition isn't listed, or if you have any questions about your eye health, the RNIB Helpline can put you in touch with our Eye Health Information Service, or email **eyehealth.mailbox@rnib.org.uk**.



What's happening now?

While thousands of people receive excellent eye care in England, wide variations exist in waiting times and people's ability to access treatments. Even with guidance from the National Institute of Health and Care Excellence (NICE) stating what drugs the NHS should provide, and how people should be assessed, there is a "postcode lottery" across England to access timely treatment. RNIB believes that everyone should have fair access to the eye health services that benefit them.

Who does what

National Health Service (NHS)

NHS England is the body responsible for primary care services, which are provided in community settings, like GPs (General Practice doctors), dentists, optometrists (high street opticians) and pharmacies (chemists), and screening services for diabetic eye disease. Increasingly, they work with Clinical Commissioning Groups (CCGs) to plan and commission local GP services.

CCGs are local organisations, made up of the GP practices in an area plus nursing, hospital and 'lay' members, and are responsible for making decisions about the health services provided for patients. They commission most hospital services and some primary care services – which means deciding what health services should be provided, who will provide them, and how much should be spent on them. CCGs are also under pressure, spreading limited budgets amongst communities and different specialities with ever-increasing needs.

Most NHS hospitals in England are run by NHS Foundation Trusts, which provide the services. Hospitals are also under pressure, and have been known to delay or cancel elective (non-emergency) operations during busy periods, which can impact on people waiting for treatment for eye conditions. Current waiting times for ophthalmology (hospital eye clinic) services vary across the country.

Local authorities (councils)

Local authorities provide social care support services for children and adults, including habilitation for children and young people, and rehabilitation, personal care, occupational therapy and adult care homes.

What should be happening?

People should have their eye conditions, and any other medical conditions, treated on the basis of clinical need, and be able to easily access follow-up and support.

NHS providers – NHS England, CCGs and Foundation Trusts – should ideally be following best practice recommendations for the treatment of eye conditions produced by NICE and the Royal College of Ophthalmologists.

Getting the most from community eye care

You should be visiting your high street optometrist (optician) regularly – normally every two years, or more often if you are over 65, or they recommend it because of a serious eye condition or a family history that increases your risk of developing one. By having a regular eye examination, your optometrist can detect some problems developing, sometimes before you are even aware of them.

If you are unable to leave your house without assistance, some optometrists can organise home visits but, because not all of their equipment is portable, they won't be able to perform as many tests.

You should discuss your symptoms with the optometrist, who will be able to examine your eyes and refer you, if necessary, to a specialist for additional checks, or directly to a hospital eye clinic. Your GP can also refer you to a specialist based in a hospital for treatment.



As well as how your sight is affected, you should also discuss with your high street optometrist or GP how your eye condition is affecting your day-to-day activities and how your quality of life is affected. Common everyday experiences to relate to them are:

- you have difficulty recognising peoples' faces, reading or watching television;
- your vision has become cloudy or more washed out;
- you're not able to see things out of the corner of your eye, which makes getting around at home and in public less safe;
- edges of stairs or kerbs have become more difficult to see;
- you feel you need a lot more light to read smaller print.
- you don't feel safe to drive;

- bright lights, car headlights, or low sun dazzle you, or seem to glare more than they used to;
- colours look duller;
- activities that you do day-to-day, such as working, cooking and sewing become more difficult to do because of your vision, despite wearing the correct prescription glasses.

It may be, if you feel that your sight has deteriorated, that this can be improved simply with a prescription for new glasses. You can check whether you're entitled to free NHS eye examinations and optical vouchers (<http://bit.ly/NHSEyeT>) on the NHS web site. You can get your glasses made at any optician, but it's usually best to get them from the optometrist who carried out the eye check, to avoid problems if there are any complications with the prescription.



If appropriate, your optometrist or GP can also refer you to a Low Vision Clinic, who can provide you with advice about managing at home and specialist equipment such as magnifiers to help you with reading and close vision.

If you are diagnosed with cataracts, RNIB has developed a cataracts toolkit (<http://bit.ly/RestCat>) to help you access treatment.

If you have diabetes, you should be called for a diabetic eye screening appointment regularly, to check for any signs of diabetic eye disease. It's important to remember that this doesn't replace the need to go for regular eye checks at your local optometrist. If you haven't received a screening letter and are overdue for an appointment, contact your GP. If the scans of your eyes show that there might be a problem, you'll then be invited back for a follow-up check and treatment.



Urgent treatment

If you experience any of the following symptoms, you should make an urgent appointment with your high street optometrist or GP immediately, even if you've had an eye check recently:

- severe, sudden eye pain;
- recurrent pain in or around the eye;
- hazy, distorted, or blurred vision;
- double vision;
- seeing flashes of light or visual disturbances;
- seeing rainbows or halos around lights;
- seeing floating "spider webs" or spots;
- straight lines look wobbly;
- seeing a "curtain coming down" or "cup filling up with ink" in one eye, or momentary loss of vision;
- unusual, even painful, sensitivity to light or glare;
- swollen, red eyes;
- changes in the colour of the iris;
- white glow, reflection or pupil in the eye of a child;
- sudden development of persistent floaters;
- itching, burning, or a heavy discharge in the eyes;
- any sudden change in vision.

Some specially trained high street optometrists provide a Minor Eye Conditions Service (MECS), and can assess and treat less severe eye problems. Whether you see a MECS or your regular optometrist, you should explain your symptoms to the reception team, and make clear you are not asking for a regular eye examination, so that you get an urgent appointment.

Any optometrist or GP can refer you to a hospital specialist if they think it's necessary, after examining your eyes.

If you experience the symptoms above and cannot get a same day appointment with your optometrist or GP, you should call 111 or attend your local Accident and Emergency Department.

Getting the most from your hospital appointment

After being referred to a hospital for treatment, you will be given an appointment to meet with a more specialist hospital optometrist or an ophthalmologist (hospital eye doctor) to diagnose your condition and discuss your options.

The consultant will have limited time for your appointment, so you need to make clear to them any visual symptoms you may be having, and how long you have been noticing them, so they can diagnose the cause of your problem. You should also mention the effect your symptoms have on your day-to-day life.

It is a good idea to take a list of questions you have about your eye condition with you, to the appointment, so that you do not forget to ask anything.

If you need hospital information and correspondence in an accessible format (for example large print, or electronic documents via email), make sure to tell whoever is booking your appointment – good eye clinics will also be able to use this information to make reasonable adjustments that make the appointment easier for you.



Initial Treatment

The hospital ophthalmologist will decide and organise any tests that you need, and give you information about your diagnosis along with any treatment that is required and treatment options. They must involve you in deciding which treatment option is best for you.

You should discuss the risks of the proposed treatment with them, which could include prescription medicine, eye drops, injections or surgery depending on what the problem is. You should ask for advice and support around sticking to your treatment – for example, when pills or eye drops should be taken, should certain foods or alcohol be avoided, what to do if you forget or are ill, what about holidays, weekends etc

You should also discuss what you should expect your vision to be like afterwards.

Don't be tempted to play down your symptoms and their impact on you. Make sure you are honest with the ophthalmologist about the difficulties that your sight condition is causing you and, if you're not sure about what's best to do, you could take a family member or close friend to the appointment who can support you.

If your consultant is not recommending treatment or surgery it is a good idea to ask specifically why that is. While, in some cases, treatment for some eye conditions is being limited for non-clinical reasons – for example, surgery for cataracts – it may simply be that, unfortunately, you have other conditions that make the treatment too risky, or even that there is, sadly, no current treatment for your eye condition.



Follow-up treatment

For many eye conditions, follow-up treatments are as critical as getting in quickly to see a consultant for the first time.

The Ask and Tell campaign (<http://bit.ly/Ask-Tell>), run by RNIB in partnership with the Macular Society, International Glaucoma Association and Royal College of Ophthalmologists aims to help patients avoid delayed or cancelled appointments.

Make sure to ask your consultant if you need to have ongoing appointments within a specific time, and then book your appointment with the eye clinic reception or booking staff – ideally before you leave the hospital. If you're unable to book an appointment within the time your consultant recommends, then first contact your consultant or their secretary to let them know and, if you still have a problem, see below in the "Take action" section for the steps you can take.

Certificate of Visual Impairment

If your sight in both eyes is significantly affected by your condition, an ophthalmologist should talk to you about a "Certificate of Visual Impairment" (CVI), and registration with your local council. You should be offered the option of a CVI as soon as your sight warrants it.

Neither certification nor registration are compulsory, but the process usually means you are able to claim discounts on your TV licence, prescription costs, council tax and personal tax. Registration also means you should be offered a social care assessment by your local council to see what they might be able to provide to help keep you independent. It also usually makes it easier to claim some welfare benefits and concessions.

RNIB has information about certification and registration (<http://bit.ly/RegAsVI>) on its web site.

Just over half of the eye clinics in England have an Eye Clinic Liaison Officer (ECLLO), who is there to help you understand a diagnosis, provide emotional and practical support, and signpost you to useful services. If there is one, you should try to make time to talk to them after speaking to your hospital ophthalmologist, if you are concerned about what happens next. You can make an appointment yourself, and most will be happy to talk to you without one if they aren't busy.

Take action

If you are having problems getting referred, getting seen, or getting treatment, here are some tips on what action you can take. There are many reasons you might want to raise an issue, for example:

- the attitude or behaviour of a member of staff;
- a refusal to assess or refer you for a treatment or service;
- unreasonable or repeated delays in making a decision or providing a treatment or service;
- discrimination – for example, if a provider doesn't produce information for you in an accessible format;
- an unreasonable decision, or one that goes against agreed best practice or standards, or an organisation's own policies;
- badly delivered services.

This isn't a complete list, and you can still consider making a complaint even if the reason isn't shown above.

Contact the provider

As a first step, it's usually a good idea to raise your concern with the organisation providing the service – for example, the GP practice, optometrist, or hospital eye clinic – and ask them to confirm the reason in writing, in your preferred format. Often a problem can be resolved easily by clear communication with them. If your concern is around treatment be sure to state clearly the impact of your eye condition on your day to day life.

They should be willing to consider your situation based on the impact that the condition is having on your day-to-day life and vision, unless there is a good reason why the treatment or support isn't suitable.

If they still won't agree to treatment or service, you should consider talking to an organisation like your local PALS or Healthwatch about the decision if you think the reason given is wrong. You should also talk to them if you're unhappy with how you're being treated. They can help resolve a situation, if possible, and advise you on how you can proceed.

If you decide to make a complaint, all public services have a process which you will need to follow before taking a complaint further.

Organisations that can help with a complaint

Any of the following organisations will be able to help you in making a complaint about a decision that stops you from getting treatment or support, if you have been waiting a long time, or had cancelled appointments.

Patient Advice and Liaison Service (PALS)

It can be helpful to talk to someone who understands complaints process in different services, and to make sure that you're taking up your issue with the right organisation. PALS is independent of the hospital they're based in, can provide confidential advice, support and information, and can help you to make a complaint if you'd like them to.

You can find PALS in your local hospital, ask your GP surgery for information, phone NHS 111 or visit the NHS PALS search web page (<http://bit.ly/Find-PL>) to find out their contact details.



NHS Complaints Advocacy

This service is independent of the NHS, and they can provide you with advice on making complaints and what your options are. Their advocates are trained to assist people with sensory impairments, and can help you make your complaint, should you want them to.

To contact them, you can phone their helpline on **0300 330 5454**, browse the NHS Complaints Advocacy website (<http://nhscomplaintsadvocacy.org>) for more information or you can email them at nhscomplaints@voiceability.org.

Your local Healthwatch

Healthwatch listens to the views of local people, and makes recommendations and reports on health and care services to drive improvements locally.

Some local Healthwatch organisations will act as an advocate for you if you want to make a complaint about NHS. If your local Healthwatch doesn't investigate individual complaints, it can still give general advice and support about complaints.

You can find your local Healthwatch (<http://bit.ly/Find-HW>) by visiting their website and entering your postcode.

Local advocacy service

Councils don't have to help find an advocate who can help with a complaint, but they must give you information about local advocacy services you could use. Your local Healthwatch should also have details of local independent advocates, and a Citizen's Advice Bureau can also help with an individual complaint.

Local politicians

Everyone will have a local Member of Parliament (MP) elected to represent them. Although they aren't the person making the decision about your treatment or support, they can help make your case and represent your complaint to the relevant body.

You can email, phone or write a letter to your MP, either outlining your problem or to request a meeting with them. Meeting face-to-face is usually best to explain more complex issues.

Elected officials will often hold regular advice surgeries for their constituents, for which you may need to book an appointment in advance. You can let them know about your experience and what assistance you need, and they will be able to tell you what they'll try to do for you.

You can find out who your local MP is, and their contact details, by visiting the Houses of Parliament MP search page (<http://bit.ly/Cont-MP>) and entering your postcode. You can also check in your local public library or town hall.

Where to go if your complaint isn't resolved

The final say in your complaint, short of your raising a legal case against an organisation, will rest with the official ombudsman. You will only be able to approach them if you have exhausted an organisation's own complaints process first.

Parliamentary and Health Service Ombudsman (PHSO)

If, after raising a complaint about NHS services through one of the organisations above, you still haven't been able to resolve your problem, you can contact the PHSO. You can also contact them if you've been waiting more than six months for an explanation of how your complaint has been investigated, and information about what's being done as a result.

You can phone them on **0345 015 4033**, get them to call you back by texting **your name and phone number to 07624 813005**, or find out more about their services at the PHSO website (<https://www.ombudsman.org.uk>).

If you're thinking about raising your complaint with the ombudsman, it can be helpful to get a copy of your records and your complaint through a "subject access request" (<http://bit.ly/ICO-RoA>) – the Information Commissioner's Office website has advice on how to do this.

Other ways of raising your issue

As well as raising a complaint, there are other things you can do to raise awareness of the problems you are facing.

Discuss the problem with the RNIB Connect Community

RNIB Connect is a welcoming online and real-world community, led by blind and partially sighted people, that offers a supportive environment to talk to other people affected by visual impairments.

You can share your problem, ask questions, and get advice from people in, or who have experienced, similar situations.

There's more information on the RNIB Connect webpage (<http://bit.ly/RNIBCct>), where you can find an application form to join the RNIB Connect community (<http://bit.ly/Join-CC>), or you can find out more from the RNIB Helpline.



Write to your local newspaper

Wherever you live, your local paper is there to report on the issues that matter to local residents like you.

If you don't mind other people knowing about your situation, one way of raising awareness about problems you are facing is by writing a letter to the editor of your local paper. Local papers have a 'letters to editors' section where letters from readers are published. You can choose whether you want yours published with your name or anonymously.

The Hold the Front Page website lists all of the UK's daily and weekly newspapers (<http://bit.ly/HoldTFP>) – remember that space is usually limited, so try to keep your letter to the point, to give it the best chance of being used.

If your local paper thinks yours is an interesting story, for example because of the time you've had to wait or the impact your problem is having on your quality of life, they may even contact you to write an article on your situation, which can help raise awareness still further.

How RNIB can help

Our Helpline Advisors can also help if you'd like advice about what to do if you're having problems getting treatment or support, and is available from 8am – 8pm weekdays and 9am – 1pm on Saturday on **0303 123 9999**, or via email on **helpline@rnib.org.uk**.

If you'd like to speak to someone about your eye condition, contact our Eye Health Information Service through the RNIB Helpline or email **eyehealth.mailbox@rnib.org.uk**.

If your local area is restricting access to treatment or support, let our campaigns team know – again, just contact us through the RNIB Helpline or via email at **campaigns@rnib.org.uk**. Your feedback helps inform our campaigning work to ensure people can get treatment or services when they need them. We'd also love to hear your experience of using this toolkit, or if you'd like to receive it in an alternative format.

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