

PATIENT INFORMATION

ETHAMBUTOL TREATMENT AND THE RISK OF OPTIC NERVE DAMAGE



Ethambutol Treatment and the Risk of Optic Nerve Damage

What is ethambutol?

Ethambutol is an antibiotic medicine that works well against bacteria such as Mycobacteria. These bacteria can cause infections such as tuberculosis (TB). For best results, ethambutol is given in combination with other antibiotics.

What is the Optic Nerve?

The optic nerves carry the messages for vision from the eyes to the brain. Each nerve has about a million fibres but it is normal for us to lose some of these as we grow older. An optometrist (optician) or ophthalmologist (eye doctor) can check the nerves at the back of the eyes.

What is Optic Neuropathy?

Damage to the optic nerve is called optic neuropathy. It has many causes, such as glaucoma, poor blood supply and multiple sclerosis. It can also be a side effect of some medications, such as ethambutol. In the early stages of damage from ethambutol, the nerve does not work so well, but may still appear normal when examined. Some recovery may be possible. Later, the fibres in the nerve begin to die. Dead nerve fibres cannot be replaced so that the nerve gradually becomes pale ('optic atrophy').

What is the risk of ethambutol treatment causing Optic Neuropathy?

With modern care, the risk is thought to be about 1 in 100. The risk is less for those who only need to take ethambutol for 8 weeks, and greater for people who need it for longer than this.

Does anything increase the risk of Optic Neuropathy?

You could be at higher risk if:

- the prescribing doctor was not aware that you were losing weight, or that your kidneys were not working so well. (Your dose of ethambutol might need adjusting.)
- you have an optic nerve that is already affected by disease, or is at risk of damage due to poor diet, or due to your particular genes.
- there is something else causing stress to your optic nerves, such as smoking or taking particular prescribed medications (your pharmacist or doctor can advise you about this).

What should I avoid while taking ethambutol?

Avoid tobacco (the risk from vaping is thought to be much less). Carbon monoxide can damage the optic nerves, so if you use a gas or oil-fired boiler, or an open fire, you can reduce the risk of this by using warning alarms. There might be a small risk from using chloramphenicol eye drops or eye ointment, and from quinine (which is usually taken for muscle cramp). Although the risk from these treatments is not proven, we suggest you either avoid them or discuss the risk with your GP in case an alternative treatment may be suitable.

How might Optic Neuropathy affect me?

Optic neuropathy affects the vision, which may become blurred or dim. Sometimes this is only noticeable in parts of the vision rather than in the 'whole picture'. Colours may seem less bright or 'washed out'. The loss of vision often starts in one eye but the other eye is at risk of losing vision soon afterwards. The loss of vision tends to develop over a few days, but the onset may appear to be sudden if the loss of vision is not noticed until it is already quite bad.

What about other eye symptoms?

The following symptoms are **not** due to ethambutol. If you get any of the following symptoms, do not contact the TB specialist nurse. If you are concerned, contact your optometrist or GP in the normal way.

- pain in the eye
- seeing 'floaters'
- seeing abnormal 'lights'
- blurred vision that clears on blinking or on resting the eyes
- straight lines appear bent
- double vision (seeing two separated pictures).

How should I check myself for Optic Neuropathy?

Find a suitable magazine (or wall calendar or something similar) and choose a particular bit of small print and a particular bit of large print and a particular multi-coloured picture. Use these as test 'targets' and use the same targets every time you check your eyes. Use a room with bright electric lighting, such as the kitchen. While wearing any appropriate glasses or contact lenses, check your vision every day, in each eye separately. Check your eyes one at a time by using a piece of card to cover the other eye. Do this for each of two tests:

Test 1. Look at the words in small print from a normal reading distance. Alternatively, look at the words in large print from a distance of about 3 metres. Check that your vision in each eye is as clear and sharp as you would expect it to be.

Test 2. Look at the multi-coloured picture and check each eye. Are the colours as bright as you would expect them to be, or do they look dull or 'washed out'?

When you do these tests at the start of ethambutol treatment they will give you a 'baseline' for your eyes, showing you what is 'normal' for you. Repeat the tests each morning as 'self-screening'. If you notice any definite change, contact the TB specialist nurse (telephone 01562 512316). (If you are not sure, repeat the tests after an hour or two before deciding if you think there has been a definite change.)

What should I do if I find it difficult to check myself?

If you think 'self-screening' (checking your own vision) might be difficult for you, is there someone who could help you do it? Sometimes a telephone call reminder is all that is needed. Ideally, self-screening is done once a day, but once every 3 or 4 days would still be useful. You can also contact the TB specialist nurse for advice (telephone 01562 512316).

What should I do if I think I might be getting Optic Neuropathy?

You should immediately stop taking ethambutol and urgently contact the TB specialist nurse (telephone 01562 512316). At a weekend or on a bank holiday, stop taking ethambutol immediately and telephone on the next working day.

If I have to stop taking ethambutol what will happen next?

When you contact the TB specialist nurse, she will talk to you about your concerns. If appropriate you will be referred to the eye clinic for urgent cases ('Acutes') at Kidderminster Treatment Centre. In this clinic, your eyes will be examined to see if ethambutol is the probable cause of your symptoms, or whether there is another explanation. When attending the eye clinic, take your glasses (if you wear them). You may need to have eye drops, which may prevent you driving for a few hours. You may need further visits to an eye clinic (which may be in a different hospital).

The TB specialist nurse will get advice from the consultant and arrange for any necessary alternative treatment.

Does Optic Neuropathy recover when ethambutol is stopped?

In most cases there will be some recovery, but usually the vision does not return to being completely normal. Sometimes, loss of vision may continue to progress for some weeks after stopping ethambutol. It may be a few months before it is clear how much visual recovery will occur. Ethambutol optic neuropathy can cause permanent blindness but this is very unlikely if the ethambutol is stopped as soon as the loss of vision is noticed. However, it is possible that loss of vision could lead to loss of a driving license.

Is it safe to take ethambutol?

All medicines have possible side effects. In each case, we have to balance the possible risks against the expected benefits. The consultant will prescribe the lowest effective dose. If there are particular concerns, an eye doctor may be asked to check your eyes at (or before) the start of ethambutol treatment. In most cases, the risk of optic neuropathy is low and the benefits of treatment make ethambutol the best choice.

Contacts

TB Specialist Nurse - Telephone 01562 512316

Acutes Eye Clinic at Kidderminster Treatment Centre - Telephone 01562 512382

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.