

PATIENT INFORMATION

BOTULINUM TOXIN INJECTIONS FOR BLEPHAROSPASM



What is blepharospasm?

People have 'blepharospasm' when they cannot keep their eyes open because the muscles that close the eyes are working too hard. This may be a normal reaction to irritation of the eye, for example, if there is a piece of sand in the eye. However, in some people, there is no apparent reason for blepharospasm that keeps happening. Many of these people have a disease called 'Benign Essential Blepharospasm' or 'BEB'. This is called 'benign' because it is not a sign of a more serious disease. It is called 'essential' because it is not due to any other cause. BEB may start as a mild twitching in one eye but then it gradually gets worse and affects both eyes. If untreated, it can interfere with vision, for example, leading to loss of a driving licence.

Blepharospasm also occurs as part of a different disease called 'hemifacial spasm'. In this disease, there is abnormal contraction of the muscles in the whole of one side of the face. Hemifacial spasm is sometimes due to something (usually a blood vessel) pressing on the nerve that supplies the muscles (the 'facial nerve'). So, unlike BEB, if you have hemifacial spasm, the doctor may want to do further tests.

BEB and hemifacial spasm are not painful but they are often troublesome enough that treatment is a good idea.

What are the possible treatments for benign essential blepharospasm (BEB) and hemifacial spasm?

Firstly, it is important to deal with any causes of irritation in the eyes. Some people find it helpful if they can reduce 'stress'. Wearing tinted glasses (perhaps a rose-pink colour) may also help. You may prefer not to have treatment, particularly if the disease is not affecting you badly. You can have treatment if it gets worse in the future. Some treatments usually work better than others. Some treatments have possible side effects that are common or possibly serious.

For BEB, most people are helped by injections of botulinum toxin to the muscles around the eyes. On rare occasions, if botulinum toxin is not effective, surgery may help.

For hemifacial spasm, the best treatment is usually injections of botulinum toxin to the affected muscles. Some people may be helped by medicines taken by mouth. Occasionally, surgery is appropriate but this has significant risks.

What is botulinum toxin and how does it affect muscles?

Botulinum toxin is a chemical that is produced by a type of germ - Clostridium botulinum bacteria. When a tiny amount of the toxin is injected into a muscle, the signal between the nerve and muscle is blocked, so that the muscle does not contract properly. The muscle is therefore paralysed (weakened), either partially or completely. Botulinum toxin is manufactured and sold as 'Botox', 'Dysport', 'Xeomin', etc., which are all similar medicines. Whichever type of botulinum toxin is used, the treatment effect usually lasts between 2 and 4 months. The toxin has been used by doctors for several decades.

What is the treatment like?

Treatment is usually given in an outpatient clinic. If it is your first treatment, it may be best to arrange transport so that you do not have to drive yourself home afterwards. However, when patients know what to expect, most of them who drive a car would feel safe to drive home after subsequent treatments. The pain of the injections is usually mild so that most patients do not need any anaesthetic. Treatments involve a few small injections of low-dose toxin into local muscle tissue. This is usually very well tolerated and takes only a few minutes. You will be asked to sign a consent form. If you need the same treatment repeated, it is not necessary to sign a new consent form for each repeated treatment.

What happens after treatment?

The treatment usually starts to work a day or so after the injection but it may take up to 10 days to reach its full effect. Further, 'top-up' injections can be given, if required. The duration of the effect of the toxin is variable, but it typically lasts 2 - 4 months. In general, an appointment will be made for you to be seen again after this period.

What are the possible side effects?

Some of the possible side effects are listed below:

- The following effects can be caused by the injection of any fluid: A skin mark like a pin-prick at the injection site. Mild local ache and swelling for 1 or 2 days, occasionally with local redness. Local bleeding and / or bruising. Effects due to being 'nervous' of needles.

- Dry eye and / or exposure of the cornea (the 'window' at the front of the eye). The natural flow of your tears may be reduced, or it may increase (due to irritation of the eye). The eye may not close properly when you blink or when you are asleep. Your vision could be blurred. You may need to use artificial tear eye drops and / or ointment. If you already have a tendency to dry eye you might need to use these treatments long-term, otherwise it is more likely that you would need them for a few months after the treatment.
- Drooping of the upper eyelid, possibly leading to the eye being closed. This will usually recover by itself, but rarely, it may be appropriate to have surgery to correct it.
- Drooping of the face on the side of the injection (e.g. affecting the corner of the mouth). This will usually recover by itself.
- Double vision – you should not drive if you have double vision. It is important that you discuss this risk with the doctor before having the treatment if this is of particular concern to you. Double vision will usually recover by itself. While waiting for recovery, it may be possible to control the double vision with a prism stuck to the lens of glasses. In rare cases, the double vision fails to recover and an operation to try and correct it may be appropriate.
- Cold sores (herpes simplex) – these generally only occur in people who have had them before.
- Your body could make antibodies against the toxin (causing repeated injections to become less effective).
- The following side effects are rare:
 - An injection around the eye could damage the eye or cause loss of vision, e.g. due to injury, infection, bleeding or 'acute glaucoma'.
 - There is a very small risk of a serious allergic reaction (anaphylaxis)
 - Botulism – weakening or paralysis of muscles throughout the body. The risk of a healthy person developing widespread muscle weakness from this treatment is extremely small. This is because we only use very small doses to produce local effects at the site of the injections and hardly any toxin reaches the bloodstream.

Is this treatment suitable for everyone?

Please discuss with the doctor before having the treatment if you think any of the following may apply to you:

- Allergy to botulinum toxin
- Neurological conditions (such as myasthenia gravis or problems with swallowing)
- Easy bruising or taking an anticoagulant (medicine that 'thins the blood')
- Taking an antibiotic that is called spectinomycin or that is in a group called 'aminoglycosides'
- Pregnancy or breast feeding

Contact telephone numbers for the Eye Departments

If you have any concerns that you feel have not been answered, please contact us: -

- Worcester (01905) 733569
- Redditch (01527) 507915
- Kidderminster (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.