Parent Information

Botulinum toxin treatment for squint in children

Information for parents and children about undergoing botulinum toxin injections for squint under general anaesthesia or sedation.

Botulinum toxin can be used in the treatment of squint (misaligned eyes) in both adults and children. Sometimes it is a one off treatment and sometimes a course of injections are needed. Your doctor will be able to explain which applies to your child.

1. What is the effect of botulinum toxin?
Botulinum toxin temporarily weakens the muscle it is injected into. This is called paralysis.

2. How long has it been in use?
It has been used to treat eye disorders for more than 30 years.

3. Will it affect the general health?
Although the toxin is manufactured from the bacteria that cause a type of food poisoning called botulism, the treatment is safe and there is no risk of developing that illness. All medication carries a small potential risk of a serious allergic reaction (anaphylaxis). An anaesthetist will be carrying out the anaesthetic or sedation and is ideally trained for managing any allergic reaction. In more than 20 years of using Botulinum toxin in Moorfields none of our patients have experienced a general health problem with it.

4. Who will I see when I attend the clinic?
Your child will be examined in clinic by an orthoptist and will see one of the doctors a few weeks before the injection day. You will choose with your child and the doctor whether the injection will be done with full (general) anaesthesia or with sedation (an injection which makes your child calm and sleepy) and you will be asked to read and sign a consent form. You will then go to
see one of the nurses on the children’s ward for an anaesthetic pre-assessment.

5. What will happen on the day?
Your child will be admitted to the ward by a children’s nurse and see the anaesthetist and a member of the surgical team who will answer any questions you may have and confirm with you that you wish to go ahead.

Local anaesthetic eye drops (to numb the eye) will be given to children having sedation. These drops are very effective in stopping pain in the eye, but children might still experience a short moment of discomfort when the injection is given.

You will go with your child to the anaesthetic room in the operating theatres where they will be prepared for the procedure and will lie down on a trolley. If they have a general anaesthetic you will stay till they go to sleep. If they have sedation they will be aware of what is happening but you will not stay with them for the procedure.

Your child will have some wires attached to their forehead which connect to a loudspeaker. This allows the injection to be precisely placed in the muscle by monitoring the muscle’s electrical activity, which is heard as a noise from the loudspeaker.

Awake children will be asked to lie still and keep their head still throughout, to look to one side with their eyes while the injection is placed and then to the other side to make the muscle work. They will hear a loud noise from the loudspeaker before the toxin is injected. The injection will be held in place for 35 seconds. Children having injections under general anaesthetic often have more than one muscle injected.

6. What happens after the injection?
Your child will be brought to the recovery area and, when fully alert, back to the children’s ward. The eye is very numb after being injected with sedation, so needs to be protected with a pad for about three hours in case dust blows in and scratches it. Later you can take it off and protect the eye with their glasses or sunglasses.

Some children may feel an ache in the eye after the injection and can take a painkiller if required. When they have fully recovered, you will be allowed home.

7. When should I expect to see an effect from the treatment?
You will usually notice the effect starting about two days after the injection.

8. How long does the effect last?
This varies a lot. In some children the effect wears off after a couple of months and in others it produces changes in
muscles that create a long term improvement in the squint. To begin with there is often a temporary reversal of the squint (e.g. from in-turning to out – turning), followed by gradual straightening of the eyes as the effect wears off. In children with a very new squint the brain can sometimes lock the eyes back in alignment as the toxin wears off so that the eyes remain straight long term.

9. What are the possible side effects?
Nearly all side effects are temporary and improve with time.

- Temporary reversal or change in the direction of squint
- Temporary double vision – this is more common in teenagers and older children
- Temporary drooping of the eyelid – this usually recovers after a few weeks.
- Bruising of the surface of the eye – the eye looks red (subconjunctival haemorrhage)
- Bruising around the eye affecting the lids - looks like a black eye.
- Rarely there may be a scratch on the front of the eye (cornea) from the anaesthetic used before the injection or from minor injury whilst the eye is still numb.
- Very rarely the injection can cause permanent paralysis of the injected muscle.
- There is an extremely rare possibility of the needle perforating the eye or causing serious eye or vision damage. The risk is no greater than one in 10,000 injections.

10. When do I return to the clinic?
We like to see patients one to three weeks after the injection. If the first injection did not produce enough effect, we may need to organise a repeat injection.

Any other important information I should know?
Although Botulinum toxin was originally introduced for the treatment of squint in 1979 (with our clinics successfully treating patients since 1982), the manufacturers have never applied for a drug product licence. We use it where required to satisfy individual patient need, and records are kept of all injections and patient details. This is one of many examples of a drug with a product license for one condition being used safely and successfully for another condition.

If you are not clear about any aspect of this treatment or have any questions, please ask the doctor or orthoptist to explain further. Please keep this information sheet for future reference.
Your right to treatment within 18 weeks
Under the NHS constitution, all patients have the right to start their consultant-led treatment within 18 weeks of being referred by their GP. Moorfields is committed to fulfilling this right, but if you feel that we have failed to do so, please contact our patient advice and liaison service (PALS) who will be able to advise you further – see above for contact details. For more information about your rights under the NHS constitution, please visit www.nhs.uk/choiceinthenhs.

Moorfields Eye Hospital NHS Foundation Trust
City Road, London EC1V 2PD
Phone: 020 7253 3411
www.moorfields.nhs.uk

Moorfields Direct telephone helpline
Phone: 020 7566 2345
Monday-Friday, 9am-9pm
Saturday, 9am-5pm
Information and advice on eye conditions and treatments from experienced ophthalmic-trained nurses.

Patient advice and liaison service (PALS)
Phone: 020 7566 2324 or 020 7566 2325
Email: pals@moorfields.nhs.uk
Moorfields’ PALS team provides confidential advice and support to help you sort out any concerns you may have about the care we provide, guiding you through the different services available at Moorfields. The PALS team can also advise you on how to make a complaint.