

# Botulinum toxin injections

A close-up photograph of a young child with light brown, wavy hair, lying in a hospital bed. The child is smiling broadly, showing their teeth. They are wearing a blue hospital gown with a colorful graphic that includes the word 'OMG' and a cartoon character. The child is resting their head on a white pillow. The background is a plain white wall.

Information for families

Great Ormond Street Hospital  
for Children NHS Foundation Trust

**Your child has been assessed in the Movement Disorder Clinic at Great Ormond Street Hospital (GOSH) for their suitability for Botulinum Toxin injections. This leaflet provides you with some information about Botulinum Toxin injections and what to expect when your child comes to GOSH for treatment.**

### **What is botulinum toxin?**

Botulinum toxin is produced naturally by the bacterium *Clostridium botulinum*. When purified, it can be used in tiny, controlled doses to relax excessive muscle contraction. It has been used as a medicine for over 15 years in the UK. It is used in the treatment of several conditions in children including cerebral palsy and other neurological causes of muscle stiffness and pain.

### **How does it work?**

When injected into muscles, botulinum toxin has a local and controlled effects. It blocks the messages between the nerve endings and muscle fibres around the injection site, causing weakness of the nearby muscle. Injections usually take effect within a few days, with peak relaxation four to six weeks later, although this can vary from child to child. These chemical effects last for approximately three months. However the functional benefits may last for longer, in some cases, up to one year after the injection.

### **Are there any side effects?**

Since botulinum toxin injections have been routinely used in children, serious adverse events have rarely been reported. As with all prescription medicines there may be some associated side effects – the team caring for your child will minimise the chance of any of these happening by carefully calculating the correct dose and injection sites for your child.

The most common side effects reported are:

- Soreness at the injection site.
- The injections cause weakness in the injected muscles and sometimes nearby muscles. This weakness is temporary but in the short term may make balance more difficult.
- Some children complain of mild flu-like symptoms in the days after injections, which may be treated with paracetamol if necessary.
- Very occasionally, temporary difficulty with bladder control and swallowing is seen.

## Preparing for the injection

Botulinum toxin treatment at GOSH usually involves two appointment sessions: one assessment appointment before the injection and then one appointment six weeks after the injection.

At the initial appointment before the injection, the team caring for your child will discuss with you in more detail what having these injections will involve. They will finalise specific muscles to be injected, method of sedation to be used for the injections and identify common goals for the treatment together with you, your child and your local team.

In order to assess the effects of treatment, the team caring for your child will carefully examine your child's range of movement both before and after the injection. A physiotherapist will perform a detailed movement test and where appropriate take a video recording before treatment and at the follow-up appointment after the injection. These assessments generally take an hour to perform. The GOSH physiotherapist will also liaise closely with your local therapist about your child's treatment.

## Injection day

Your child will need to come to the ward for the day – your admission letter will confirm the time.

The most appropriate sedation and pain relief to reduce your child's anxiety and discomfort will have been discussed at the pre-injection session. There are usually three options:

**Oral sedation with midazolam (medicine)** – this will make your child drowsy and forget the procedure. Your child will also have local anaesthetic cream applied to the injection site to help numb the skin.

*OR*

**Nitrous oxide sedation with Entonox® (gas and air)** – this is most suitable for older children. It tends to be used alongside ethyl chloride spray (cold spray) at the injection site.

*OR*

**A general anaesthetic** is very occasionally required.

If your child has oral sedation with midazolam, they will need to stop eating or drinking for a few hours before the procedure.

You will have been given the last times that your child should eat and drink before the injection at the assessment appointment. It is important to follow the fasting instructions carefully otherwise your child's injection may need to be delayed or even cancelled.

When you arrive at the ward, your child will be met by their named nurse and, once settled in to their bed on the ward, they will be reviewed by the injecting team. This is to ensure that your child is fit and well and all is in place for the injections to proceed. The injections are carried out in the treatment room on the ward and all our injections are performed under ultrasound guidance. Parents and carers are welcome to stay with their child throughout the procedure.

Following the injections, once your child has had something to eat and drink, you will be able to take them home, usually within a few hours. When at home, the team does not advise any special restrictions and your child can return to school when ready.

## When you get home

- Your child may be sleepier than usual over the next 24 hours. This is due to the sedation or anaesthetic and your child should soon recover fully.
- Your child may experience pain or discomfort around the injection site. This should only last for a couple of days and paracetamol is usually enough to make your child feel more comfortable.
- Occasionally some children experience side effects after the injection, most commonly weakness in the muscles near the injection site or flu-like symptoms. These should be temporary. However, if you are concerned please call your family doctor (GP) or contact your neurology consultant at GOSH.
- Your child may have mood changes, which can make him or her irritable. This is temporary and is a result of the anaesthetic or sedation given.
- If your child takes any medication regularly, give this as usual.
- Usually your child should feel well enough to return to school the day after the injections.
- If your child is unduly sleepy or difficult to rouse, make sure that they are in a safe position on their side and seek further medical support.

If you need to cancel your injection session or your child is unwell on the day of injections, please call 020 7405 9200 and ask for the ward stated on your child's admission letter.

For general enquiries regarding botulinum toxin treatment please contact the Movement Disorder Service on 020 7405 9200 ext 1140

### **Useful dates**

Pre-injection

Injection day

Post-injection

### **Questions to ask**

## Notes

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