

# Botulinum toxin injections

**This leaflet explains more about using botulinum toxin injections in children and young people, including the benefits, risks and alternatives. It also provides information on what you can expect when your child comes into hospital. If you have any further questions, please speak to the doctor, therapist or nurse caring for your child.**

## What is botulinum toxin type A?

Botulinum toxin type A is a toxin produced naturally by the bacteria *Clostridium*. It blocks the nerve that talks to muscles or glands, by stopping the release of a chemical – acetylcholine. It works in the body for around three to six months and then the effects wear off.

It can be used in the treatment of movement disorders, especially spasticity (muscle tightness) in cerebral palsy to help relax muscles, to improve function and range of movement, to make daily care or activities easier and/or to reduce pain from spasms.

It can also be used to stop the production and release of dribble/saliva from saliva glands if this is a problem for your child or young person.

## Why should my child have botulinum toxin type A injections?

Botulinum toxin type A injections are a recognised part of treatment programmes for movement disorders and saliva-control problems as outlined in NICE guidelines.

When used for movement disorders, your doctor or therapist will discuss the specific goals for treatment for your child. Depending on the pattern and severity of movement difficulties, it can be used to improve the pattern and amount of walking, help two-handed tasks or ease comfort and care. It is often used as part of a more comprehensive treatment programme and it is important to discuss with your teams, both at Evelina London and also locally, whether any change in your child's therapy programme is needed in order to make the most of the time of relaxation.

## What are the risks?

Generally, treatment with botulinum toxin is well tolerated but, as with all medicine, there is a risk of side effects. Your child's doctor or therapist performing the procedure will discuss these with you. You are encouraged to ask any questions or raise any concerns.

We have clear, internationally agreed, guidelines on the maximum dose we can use in each muscle or gland, as well as a total dose, to minimise any risks or side effects.

Side effects are rare, but the most common we see are short-term pain and bruising at the injection site, and weakness in the muscle injected. This is to be expected as the injection causes the muscle to relax. This can rarely and temporarily lead to an increase in falls, abnormal walking pattern or reduced function, but these settle and improve over the next few weeks.

Other, even rarer, side effects that are reported, but have not been encountered here, include incontinence, skin rash, or flu-like symptoms. These are usually mild and temporary, and are usually dependent on the site of injection.

In one or two cases world-wide over the last 20 years, the botulinum toxin has spread and caused weakness of other muscles in the body. These are **not** cases where the international guidelines have been used. If this does happen, side effects could include excessive muscle weakness, difficulty swallowing and possibly a chest infection. Immediate medical treatment should be sought if any of these problems occur.

## What is its role in my child's treatment programme?

### Movement disorders

Your doctor and therapist will discuss different treatment options for your child. Many work on the whole body, and some just on a particular area. The role of botulinum toxin type A injections in your own child's treatment pathway may change over time, and not every treatment is appropriate for every child.

Other parts of your child's motor treatment programme may include:

- using splints. These may be useful if they help with function and comfort, particularly at the arm, hand, ankle or spine.
- equipment to help comfort and function. These can help in lying, sitting, and standing positions, or for wheelchair mobility and/or walking.
- a variety of medications. Muscle relaxants or movement modifying (helping the fluidity of movement) drugs can be tried, for example, baclofen or trihexyphenidyl.
- surgery. Muscle, tendon and/or bony orthopaedic surgery may be needed to improve the range of movement and function, reposition joints that have dislocated, or to reduce pain.
- more invasive interventions. These are rarely used, but:
  - the use of small medicine pumps that work on the spine to cause relaxation – intrathecal baclofen (ITB) pumps.
  - cutting nerve roots can permanently cause relaxation. This is selective dorsal rhizotomy (SDR)
  - implanting stimulators into the brain can reduce extra movements. This is deep brain stimulation (DBS).

### Saliva control

Using botulinum toxin type A injections to reduce the amount of saliva your child produces is part of the careful pathway of care we have developed that is recognised in the NICE guidelines and internationally. It is used in children with severe problems of dribbling or aspiration, in terms of frequency, severity and when it impacts on your child's or family's quality of life.

Other treatment options include:

- conservative measures such as dabbing (not wiping) and using non-foaming toothpastes
- medicines such as glycopyrronium bromide or hyoscine patches or inhaled ipratropium bromide
- surgery to redirect the draining ducts or reduce the bulk of the glands.

You will have been given our leaflet, **Saliva control service**, in clinic. It explains these and other options in more detail.

## **Other uses**

Botulinum toxin type A injections have also been used to help with bladder and bowel problems, excess sweating and in the treatment of migraines. Your doctor will discuss these with you if appropriate.

## **How can I prepare my child for the botulinum toxin type A injections?**

Your doctor and therapist will discuss how and where your child will be given their injections. Depending on their age, the site and number of injections, they are usually given using sedation (medication to make them sleepy). Though you or your child may be anxious about the procedure, it is no more painful than having an immunisation and is over very quickly. If sedation is used it is important not to give your child anything to eat and drink beforehand – more information will be sent to you about this.

If your child is having saliva gland injections, please do not put any creams or lotions on their face on the day.

Very rarely it is necessary to use a general anaesthetic. If this is needed you will be asked to attend a pre-assessment clinic, where we will make sure your child is well enough for the anaesthetic.

Usually, you will be sent information in the appointment letter about what will happen on the day of your child's injections. You and your child will get the chance to ask any questions you may have.

Please make sure you bring a list of any medication that your child may be taking to the Day Care Unit, including any over-the-counter or alternative (herbal) medicines.

## **Giving my consent (permission)**

We want you to be at the core of any decision about your child's care and treatment.

The doctor and therapist will carefully go through what you should expect before, during and after the procedure, and what the risks and benefits are. If you are happy to go ahead, they will ask you to sign a consent form.

If you foster a child, it will be necessary for the team to get this consent from Social Services and so it is vital you let the team know if this is the case at the time of your appointment.

If you would like more information about our consent process, please speak to a member of staff.

## **What happens during the procedure?**

Your child will have the injections on the Day Care Unit.

It may be necessary to have some assessments on the same day, to help the team make the correct plan for your child.

If the procedure is being done under local anaesthetic (your child will be awake but we will minimise their discomfort), you will see the team who will make a plan with you of what procedure is appropriate, and any change in your child's treatment pathway. A local anaesthetic cream or spray will be used to numb the site of the injections. You will be free to go home after the injections.

If sedation is used you will be with us for a few hours. It is vital your child has nothing to eat or drink before the procedure – more information will be sent to you about this.

The team on the Day Care Unit will make sure your child is well enough to have sedation, and the doctor or therapist will see you to go over the procedure or any changes in the treatment programme. We use either inhaled nitrous oxide (laughing gas), or oral/gastrostomy-given midazolam. Local anaesthetic – in the form of a cream or spray – will also be used to minimise the discomfort as with injections given without sedation.

You will need to stay in the department until your child wakes up from the sedation and has had something to eat.

The number and site of the injections will be discussed with you. Sometimes, particularly in saliva glands, we use an ultrasound machine to check where we are injecting. The procedure itself takes less than a minute and you are welcome to stay with your child.

If your child needs sedation, then it will be discussed at the time of the clinic appointment. If sedation is needed, you will also be able to leave on the same day as the injections, but are likely to need to be on the ward for slightly longer to make sure your child has recovered from the anaesthetic.

### **Will my child feel any pain?**

Sometimes there may be some pain and bruising around the injection site(s). Simple painkillers such as ibuprofen or paracetamol can be useful if this occurs. Follow the dosage instructions on the packet.

### **What happens after the botulinum toxin type A procedure?**

The length of time before any changes can be seen vary from child to child. Botulinum toxin type A should start to work in two to three days, reaching its maximum effectiveness in around two to four weeks, but it can take up to six weeks. The effects generally last about three to four months, but the benefits can last far longer in some children.

For best results as part of movement therapy it is important that botulinum toxin type A be used with a physiotherapy or occupational therapy programme, unless the injections are being used to help with care and comfort. This will have been discussed with you by your doctor and therapist before the treatment.

Your child will be seen regularly by a therapist following the procedure. The programme for after the injections is varied. It will certainly focus on strengthening some muscles and may include stretching, or splinting. It may also require your child to spend some time in a plaster cast in order to get the best effect. The team at Evelina London will guide you through this.

Generally, we see the benefits of reduced saliva last for about six months. Sometimes it is necessary to reduce the other medicines, such as glycopyrronium, to stop the saliva getting too thick, but in other children the two work well together. If you are concerned, please contact your GP.

## Will my child have a follow-up appointment?

Your child will have a follow-up appointment to see how effective the treatment has been, and to check if any changes need to be made to the therapy programme. The timing of this will be discussed at your clinic appointment. Your doctor will also decide whether the procedure will need to be repeated, and if so, how frequently.

## Useful sources of information

**NICE** **w:** [www.nice.org.uk](http://www.nice.org.uk)

**CEREBRA** **t:** 0800 328 1159, **w:** [www.cerebra.org.uk](http://www.cerebra.org.uk)

**HEMIHELP** **t:** 0845 123 2372, **w:** [www.hemihelp.org.uk](http://www.hemihelp.org.uk)

**SCOPE** **t:** 0808 800 3333, **w:** [www.scope.org.uk](http://www.scope.org.uk)

### Contact us

If you have any questions or concerns about the procedure or anything afterwards, please contact Dr Fairhurst or Dr McDonald, **t:** 020 7188 4003, or Dr Cadwgan, **t:** 020 7188 4284, Monday to Friday, 9am-5pm.

Out of hours, please contact the Paediatric neurology on-call team. Call the hospital switchboard, **t:** 020 7188 7188 and ask for the bleep desk. Ask for bleep 1139 and wait for a response. This will connect you to the paediatric neurology registrar, or their overnight cover, directly.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)

### Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

**t:** 020 7188 3003 10am to 5pm, Monday to Friday      **e:** [letstalkmedicines@gstt.nhs.uk](mailto:letstalkmedicines@gstt.nhs.uk)

### Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS)      **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)  
**t:** 020 7188 3514 (complaints)      **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

### Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch. **t:** 020 7188 8815      **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)



**Leaflet number: 4676/VER1**

Date published: January 2019

Review date: January 2022

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A list of sources is available on request