

# Botulinum Toxin injections for spasticity in children

Children's Services

This leaflet is intended to provide a better understanding of what Botulinum Toxin injections involve: the benefits, risks, and the alternative treatments available to you. Please feel free to ask a member of the team if this leaflet does not answer all your questions.

## What is botulinum toxin (BOTOX™)?

Botulinum toxin is a protein produced naturally by a bacterium called Clostridium. When botulinum toxin is injected into muscles, it makes them relax by blocking signals from the nerves.

## What are the benefits of the procedure?

In muscle spasticity, such as that found in cerebral palsy, the muscles contract too much and become stiff. When the muscles are injected with botulinum toxin, they relax. This can improve function, range of movement, and make daily activities easier and less painful. Sometimes botulinum toxin injection can allow a child to wear a splint that they would have previously struggled to get in to. The effects of an injection usually wear off after a few months.

## What are the risks and side effects of the procedure?

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. *If your child has new swallowing difficulties, hoarse voice, breathing problems or a chest infection soon after a botulinum toxin injection, contact your doctor straight away or take your child to hospital.*

Other side-effects you need to know about:

- Your child may have flu-like symptoms a few days after the injections (headache, aches and pains, fever (temperature above 38°C), diarrhoea, may be sick (vomit) or feel drowsy. If you are concerned, contact your doctor
- They may get itching, a rash, or pain or bruising at the site of the injection
- If the injection is into muscles near the hip joint, your child may have trouble controlling their bladder and may wet themselves (this is called incontinence). This is likely to be at its worst about 2 weeks after the injection and should then improve over the next 2 weeks or so. If it continues, contact your doctor

**The prevention of infection is a major priority in all healthcare and everyone has a part to play.**

- Please decontaminate your hands frequently for 20 seconds using soap and water or alcohol gel if available
- If you have symptoms of diarrhoea and/or vomiting, cough or other respiratory symptoms, a temperature or any loss of taste or smell please do not visit the hospital or any other care facility and seek advice from 111
- Keep the environment clean and tidy
- Let's work together to keep infections out of our hospitals and care homes.

## What are the alternatives?

Your doctor and therapist will discuss different treatment options for your child. The role of Botulinum Toxin therapy 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 treatment programme may include:

- Using splints, orthoses, and other physical aids, such as lycra suits
- A variety of medications: muscle relaxants or movement modifying (helping the fluidity of movement) medication can be tried, for example, Baclofen
- Surgery: muscle, tendon and/or bony orthopaedic surgery may be needed to improve the range of movement and function or to reduce pain
- More invasive interventions, such as intrathecal baclofen and selective dorsal rhizotomy can be helpful in specific situations

## Giving my consent (permission)

We want you to be at the core of any decision about your child's care and treatment. We must seek you and your child's consent for any procedure or treatment beforehand. Your doctor will explain the risks, benefits, and alternatives where relevant before they ask for your consent. If you are unsure about any aspect of the procedure or treatment, please do not hesitate to ask for more information.

The person signing the consent form should have 'Parental Responsibility' for the child or young person. Parental responsibility refers to the individual who has legal rights, responsibilities, duties, power, and authority to make decisions for a child or young person.

## What will happen before the procedure?

A few days before your botulinum toxin therapy is given, your child may be asked to attend a pre-operative assessment at New Cross Hospital. Here, a registered nurse will discuss your child's medical history with you and ensure that they are fit for the procedure. They will also tell you when your child is able to eat and drink on the day of the procedure.

## What will happen on the day of the procedure?

Your child will have the injections on the Day Case Unit at New Cross Hospital.

Depending on your child's age, the site and number of injections, we are usually able to give the injections under sedation (a medication given by mouth to make your child sleepy). We will also put some local anaesthetic ('magic cream') on the skin to numb it.

Sometimes your child may not fall fully asleep with the sedation, in which case we will discuss with you whether we can go ahead with the procedure, or whether it would be best to consider other options.

After the injections have been given, we will keep you on the Day Case Unit until your child has fully woken up and had something to eat; usually this is a minimum of 2 hours. It may be possible for you to go home quicker if no sedation has been given.

There may sometimes be pain and bruising around the injection sites. Simple painkillers such as ibuprofen or paracetamol can be useful if this occurs.

## What happens after the procedure?

You should notice that your child's muscle is less tight within about 2 weeks of the injection, and the effects last around four to six months.

For best results it is important that botulinum toxin be used with an Occupational Therapy or Physiotherapy programme, unless the injections are being used to help with care and comfort. Your child will be seen regularly by a therapist following the procedure. The programme for after injections is varied and will usually focus on strengthening some muscles and may include stretching, splinting or casting.

## 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 decide during follow-up whether the procedure will need to be repeated, and if so, how frequently.

## How to contact us

If you have any questions about the procedure, please contact the medical secretaries at the Gem Centre on 01902 446270 who will be happy to pass a message on to our team.

## Helpful links

### Cerebra



[www.cerebra.org.uk](http://www.cerebra.org.uk)

### Contact



[www.contact.org.uk](http://www.contact.org.uk)

### Scope



[www.scope.org.uk](http://www.scope.org.uk)

## English

If you need information in another way like easy read or a different language please let us know.

If you need an interpreter or assistance please let us know.

## Lithuanian

Jeigu norėtumėte, kad informacija jums būtų pateikta kitu būdu, pavyzdžiui, supaprastinta forma ar kita kalba, prašome mums apie tai pranešti.

Jeigu jums reikia vertėjo ar kitos pagalbos, prašome mums apie tai pranešti.

## Polish

Jeżeli chcieliby Państwo otrzymać te informacje w innej postaci, na przykład w wersji łatwej do czytania lub w innym języku, prosimy powiedzieć nam o tym.

Prosimy poinformować nas również, jeżeli potrzebowaliby Państwo usługi tłumaczenia ustnego lub innej pomocy.

## Punjabi

ਜੇ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ, ਜਿਵੇਂ ਪੜ੍ਹਨ ਵਿਚ ਆਸਾਨ ਰੂਪ ਜਾਂ ਕਿਸੇ ਦੂਜੀ ਭਾਸ਼ਾ ਵਿਚ, ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

ਜੇ ਤੁਹਾਨੂੰ ਦੁਭਾਸ਼ੀਏ ਦੀ ਜਾਂ ਸਹਾਇਤਾ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

## Romanian

Dacă aveți nevoie de informații în alt format, ca de exemplu caractere ușor de citit sau altă limbă, vă rugăm să ne informați.

Dacă aveți nevoie de un interpret sau de asistență, vă rugăm să ne informați.

## Traditional Chinese

如果您需要以其他方式了解信息，如易读或其他语种，请告诉我们。

如果您需要口译人员或帮助，请告诉我们。