



## BOTULINUM TOXIN & HEMIPLEGIA

Botulinum toxin (one type is often called Botox) injections are frequently offered to children with hemiplegia as part of their movement therapy programme. They act to reduce the stiffness or 'spasticity' of the muscles, improve range and function and decrease discomfort.

### IF YOU HAVE BEEN REFERRED FOR TREATMENT

You may have been referred to be assessed for botulinum toxin treatment by your child's physiotherapist or paediatrician to a team of health professionals. This team will have set realistic, individual functional goals for your child. If you all agree that botulinum toxin would be beneficial you will be given a date for your child's admission to hospital as a day case.

This information has been written to help you understand why your child has been recommended botulinum toxin, and also to answer common queries about how it works and possible side effects and safety concerns. We hope it will leave you feeling prepared, informed and better able to support your child through the process.

### HOW DO I KNOW IF BOTULINUM TOXIN INJECTIONS ARE RIGHT FOR MY CHILD?

The key to finding the right treatment for children with hemiplegia is to consider each child as an individual within their family environment. Different treatments will be appropriate at different times for different children. The age, type and degree of motor difficulties and the functional abilities of your child must guide the decision as to whether botulinum toxin injections are appropriate.

### HOW DO THE INJECTIONS WORK?

Children with hemiplegia have problems controlling movement. The brain is unable to control muscle activity by telling the muscle reflexes to turn off. This means that some muscles may have difficulty coordinating movement and generally lack the ability to relax.

Botulinum toxin reduces the stiffness of these muscles by preventing the nerve from over-stimulating the muscle. This allows tight muscles to relax, so that they can stretch and grow. Doing this may help to reduce the risk of permanent stiffening of the joints, improve the balance of movement across joints and help control pain.

#### Upper limbs

In upper limbs, botulinum toxin treatment can also improve the appearance of the affected arm and hand, which can be very important to children and young people. It could also be used to try and improve reach and grasp and reduce any thumb in palm position. Although botulinum toxin is not specifically licensed for use in the upper limb (the child's arm, wrist or fingers), it is often used by doctors in order to help improve position and function. You can read more about this kind of 'accepted unlicensed use' below.

#### Lower limbs

In the leg it is most often used in the calf (where its use is licensed) and hamstring muscles by reducing foot posturing (such as toe walking or in-toeing) and knee flexion (bending). This can promote a more balanced and fluid gait (walking pattern). Splints are often better tolerated once the foot is more relaxed. You can read more about the treatments that are often used alongside botulinum toxin below.

*"We were scared initially, more due to the anaesthetic than the injections themselves. However, our consultant and physio were excellent and worked hard to reassure us. The anaesthetic wore off quickly and after two weeks we definitely saw results."*

**Parent carer**

## **WHAT HAPPENS ON THE DAY OF TREATMENT?**

Every hospital and unit will have their own way of working and so procedures are likely to vary. Make sure you ask your doctor about anything that you're not sure of at the assessment.

It is important to minimise the emotional impact of having injections for your child and appropriate sedative medication should be discussed. Some children may need a general anaesthetic; others will prefer just a local anaesthetic, often combined with some sedation. Most children prefer sedation but what is right for your child will depend on your and their feelings. Sedation can be given by mouth, intravenously or by gas. Again, discuss the options with the team helping you with your child.

Most practitioners will use ultrasound scanning or other ways of guiding needle placement, but not all teams routinely provide this. It will depend on the practice of the individual practitioner and unit. However, the medical team involved should always have experience in the management of hemiplegia and the administering of botulinum toxin.

## **HOW DO BOTULINUM TOXIN INJECTIONS WORK WITH OTHER TREATMENTS?**

Botulinum toxin injections are not a stand-alone treatment and should only be considered as part of a wider movement management programme.

Botulinum toxin treatment works by reducing muscle tone, allowing the muscles in the targeted area to relax for approximately 12-16 weeks. In order to make the most of this 'window of opportunity', your child's therapy plan should carefully consider what other treatment options can be used during this time. This could include serial casting of a joint, splinting, occupational therapy and physiotherapy.

This focused combination of treatments aims to improve motor skills and can bring about meaningful benefits for individual children.

### **Physiotherapy**

Unless your child is in pain, it is particularly important that there is a period of muscle strengthening after the injections. The Association of Paediatric Chartered Physiotherapists (APCP) have produced their own guidelines on post-botulinum toxin treatment programmes.

Your child's physiotherapist will be able to advise you of the type and frequency of physiotherapy required. It is important to focus on strengthening muscles as much, if not more, than stretches.

### **Occupational therapy**

An occupational therapist might also be able to recommend some specific changes to your child's daily routine in order to incorporate greater involvement of the treated muscles. It is generally accepted now that regular specific therapy after injections is very beneficial.

### **Splinting**

Splinting involves the application of ankle foot orthoses (AFOs or splints) in order to help prevent unwanted and uncontrolled movements that result from muscle imbalance and increased tone in the lower leg and ankle. Hand or arm splints do similar things in the upper limb.

### **Serial casting**

Serial casting is a non-surgical approach aimed at reducing muscle tightness around a joint that is limiting functional mobility. A well-padded cast is applied and removed on a regular basis to gradually increase the range of motion in the affected joint.

When serial casting is used at the same time as botulinum toxin injections, the casts are changed more frequently and stay on for less time than when used alone. A physiotherapy programme is used alongside this treatment to increase effectiveness.

## **HOW LONG DO THE EFFECTS OF BOTULINUM TOXIN LAST?**

Botulinum toxin takes effect gradually within a few days to a few weeks. The peak of muscle relaxation occurs after about one month. The muscle activation is back to its previous levels four months after the injection.

However, the benefits seen in daily use of the limb may actually last longer as the muscle has had a good long period of being stretched during physiotherapy. The improvements can therefore last for anything up to a year.

The frequency of any possible repeat injections is dependent on the reason they are being given. In more functional muscles the frequency tends to be less, but if it is used for pain it can often be necessary to be given every 3-4 months.

## **CAN ADVERSE EFFECTS OCCUR?**

As with all medicines there are possible adverse effects, however, treatment is generally well-tolerated. In clinical studies the side effects were rarely seen and dependent on the areas injected but included weakness, falls, abnormal walking pattern, incontinence,

diarrhoea and vomiting. If you see any side effects, they are usually mild and temporary.

The information leaflet in your medicine pack tells you more about the possible side effects. If side effects occur you should tell the doctor, or report them at: [yellowcard.mhra.gov.uk](http://yellowcard.mhra.gov.uk)

### IS IT SAFE?

All medicines have to demonstrate their quality, safety and effectiveness to the medicines evaluation authorities before they are approved for use in the UK.

All trial results, whether positive or negative, have to be submitted to the authorities before approval. After authorisation for use in the UK, the side effects of medicines are monitored through a variety of systems and you and your doctor can report any problems you encounter. The team who do the injections should work out the maximum safe total dose, numbers and areas of muscles to be injected and doses per muscle.

There are clear guidelines as to what accepted doses should be used and how often they could / should be given.

### WHAT IS 'ACCEPTED UNLICENSED USE'?

When botulinum toxin is injected in muscles other than the calf muscles of children (where its use is licensed) then this is unlicensed use of the medicine.

Some medicines needed by doctors for their young patients do not have a licence for use in children because, for complex ethical and practical reasons, formal clinical trials in young children have not been carried out.

Other medicines, like botulinum toxin, have certain uses approved from clinical trials conducted in children for a specific disease or illness, but not in other conditions, which remain unlicensed. Doctors can, at their discretion, prescribe medications for an unlicensed use if there is wide agreement within the medical profession for it to be used in that way in clinical practice.

There are a number of agreed international guidelines, called consensus statements, that doctors can use to make decisions about the use of botulinum toxin. There are also clear guidelines for their use provided by the National Institute of Health and Care Excellence (NICE).

All of this should be explained to you as part of the 'informed consent' that is obtained before the injections take place.

### WHY MIGHT BOTULINUM TOXIN NOT WORK FOR MY CHILD?

Physiological changes to muscles, for example less flexible, stiffness, or contracture (tightening or shortening of muscles) that develops with age may mean that injections might not work or become less effective. A few children develop a tolerance to the injections, which also decreases their effectiveness.

It is very important that a skilled multidisciplinary team is involved in assessing and reviewing the results as too much botulinum toxin, given too often, can be just as functionally limiting as none at all.

*"Botulinum toxin treatment works differently on different children and you can never guarantee the results. Our child had a growth spurt just after their injections which affected the results. It is important to always consult closely with a specialist."*

**Parent carer**

### DOES IT MATTER HOW OLD MY CHILD IS?

Botulinum toxin is only licensed for use in children with cerebral palsy aged two years or older. It is usually recommended that injections are started at as young an age as is feasibly possible. Younger children generally have a more significant response to botulinum toxin therapy because we all stiffen up with age.

Treatment is usually continued until the assessing team feels there would be no further need or no continued benefit. This is often midway through primary school for the lower limbs, and in the teenage years for the upper limbs.

Unless your child has a dystonic hemiplegic cerebral palsy, there is generally little benefit in repeat injections beyond the pre-teen growth spurt.

*"The short-term effects of the treatment were looser muscles and more movement. And a happier child! In the long-term she remains less stiff than before. Although it is necessary to repeat the procedure, we see a permanent improvement each time."*

**Parent carer**

## WHAT HAPPENS AFTER THE INJECTIONS?

It is usual for you to go and see your child's treatment team again about one month after the injections are performed. This is to see whether there should be any other changes to the movement programme. You will then usually be seen again between two and six months after this to discuss ongoing management.

The frequency and timing of injections depends on the individual child and the assessing team. Generally, where they are beneficial, injections are repeated annually until benefit is no longer seen.

Continuation of botulinum toxin therapy depends on whether the functional goals that were set during the assessment were reached during the treatment period. Treatment should be stopped if no improvements are seen.

## HOW CAN I PREPARE FOR THE TREATMENT?

The aim of these rehabilitation therapy interventions is to maximise the effect of the injections. They are likely to involve significant commitments of time and effort so it is important that you and your child feel prepared and informed.

It is also important to try and manage your expectations of the treatment and be aware that the effects can never be guaranteed. It is disappointing for everyone when the treatment is not as successful as hoped or when beneficial effects start to wear off. Make sure you talk to the team in charge of your child's treatment and have clear, realistic expectations about what is involved and what the outcomes might be.

*"We were able to book the time for the injections and the subsequent weeks in plaster so that they didn't impact on swimming or our family holiday. This made our daughter feel more in control and that it wasn't going to spoil anything she wanted to do."*

**Parent carer**



## HOW HEMIHELP CAN HELP

HemiHelp offers vital support, advice and information to families living with hemiplegia. Our services include a closed, moderated Facebook group, information resources, and events such as workshops and Meet Up and Try It Days. HemiHelp is part of the Contact family.

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

Thank you to all the parents of children who have been treated with botulinum toxin injections, whose quotes appear above. Last reviewed October 2019 by Dr Charlie Fairhurst, Head of Children's Neurosciences, Evelina London, UK



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