

An increasing number of children with hemiplegia are being given botulinum toxin injections as part of their movement therapy programme.

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

This information has been written to help you and your child understand why your child has been recommended botulinum toxin, and also answer common queries about how it works, side effects and possible safety concerns. We hope it will leave you feeling prepared and 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, degree of motor difficulties and 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 with the central neurological control of movement. Because of these problems, the peripheral muscles have difficulty in coordinating movement and generally lack the ability to relax. The brain is unable to control muscle activity by telling the reflexes to turn off.

Botulinum toxin reduces the stiffness of muscles by preventing the nerve from over-stimulating the muscle. This allows tight muscles to relax, stretch and grow. By doing this it may help to reduce the risk of permanent stiffening of the joints. Other benefits may include improved function and comfort, a reduction in pain and the correction of position and posture problems. Hopefully, this may allow surgical intervention to be delayed or even avoided in some children.

A number of different muscles often have to be targeted to make sure the lower limb and pelvis are aligned in the best way. Although botulinum toxin is not licensed for use in children's arm, wrist or fingers, it can be a useful treatment as it allows them to be stretched. Botulinum toxin can even sometimes be used in the neck to prevent twisting.

What happens on the day of treatment?

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

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 obviously important to minimise the trauma of having injections for your child and appropriate sedation medication should be discussed. Some children may need a general anaesthetic, but others will prefer a local anaesthetic. Most will need a degree of sedation but what is right for your child will depend on your and their feelings.

Ultrasound scanning can be used to guide the positioning of the injection but not all doctors use this and it will depend on the individual practitioner and unit. The medical team involved should always have experience in the management of hemiplegia and the administering of botulinum toxin.

How long do the effects of botulinum toxin last?

Botulinum toxin takes effect gradually within two 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 benefit may actually last longer as the muscle has had a good long period of being stretched. The improvements can therefore last for anything up to a year.

Can adverse effects occur?

As with all medicines there are possible adverse effects, however, treatment is generally well-tolerated. In clinical studies the common side-effects were leg muscle weakness, falls, abnormal walking, incontinence, diarrhoea and vomiting. If the side-effects are seen, 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 www.yellowcard.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 monitoring systems and you and your doctor can report any problems you encounter.

What is 'accepted unlicensed use'?

When botulinum toxin is injected in muscles other than the calf muscles of children, 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, clinical trials in young children have not been carried out.

Other medicines, like botulinum toxin, have 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 this is a peer-accepted basis for clinical practice.

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

After the treatment, our daughter's ankle foot orthosis (AFO) had less wedging so fitted into her shoes better. She had a wider choice of shoes and could finally wear party shoes as her heel didn't jump out of the back of them!

Why might Botulinum Toxin not work for my child?

Physiological changes to muscles, for example those that develop 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, too often can be just as functionally limiting as none at all.

Does it matter how old my child is?

Botulinum toxin is only licensed for use in children aged 2 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.

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.

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 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 and physiotherapy. This focused combination of treatments leads to an improvement in motor skills and can bring about meaningful benefits for individual children.

What is strengthening 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.

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.

What are splinting and serial casting?

Splinting involves the application of foot or ankle orthoses in order to help prevent unwanted and uncontrolled movements that result from muscle imbalance and increased tone in the lower leg and ankle.

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 weekly 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 stay on for less time than when used alone and the treatments work together to maximise muscle stretch.

My one tip would be: teach EVERYONE about the extra stretches!! It is really important to do lots of stretches of the calf muscle and the Achilles tendon and the more people who can help you to do them, the better.

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 is dependent on the individual child and the assessing team. Generally, where they have been seen to be beneficial, injections are repeated annually until benefit is no longer seen.

Continuation of botulinum toxin therapy is dependent on whether the functional goals that were set during the assessment were reached during the treatment period and treatment should be stopped if there is an inadequate response.

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.

How can I prepare for the treatment?

The aim of these interventions is to maximise the effect of the injections. They are likely to entail 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.

HemiHelp would like to thank Dr Charlie Fairhurst, Consultant Neuropaediatrician at Guys' and St Thomas' Hospitals and Chailey Heritage Clinical Services for writing this leaflet. We would also like to thank the families who gave kind permission for their children's photos to appear on the printed Botulinum Toxin leaflet and the HemiHelp members, all parents of children who have been treated with botulinum toxin injections, whose quotes appear above.

HemiHelp has a range of information sheets for both families where there is a child with hemiplegia and adults with the condition, as well as a Useful Names and Addresses List to help you contact other organisations.

***Hemiplegia** is a neurological condition that weakens one side of the body and affects one child in a thousand. It is sometimes described as a form of cerebral palsy and the effects are similar to those of a stroke. **HemiHelp** is a membership organisation offering information and support to children and adults affected by hemiplegia and their families.*

HemiHelp is happy for you to make photocopies of any part of this document.

Helpline: 0845 123 2372 (Mon-Fri 10am-1pm)

Admin: 0845 120 3713 • Fax: 0845 120 3723

Email: support@hemihelp.org.uk • Web: www.hemihelp.org.uk

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