

Botulinum Toxin treatment for children and young people

Information for patients and carers



Riverbank Unit: Maidstone Hospital

☎ 01622 220241/ 220242

Open Monday – Friday, 7.30am – 6.00pm

Woodlands Ambulatory Unit: Tunbridge Wells Hospital

☎ 01892 638032/ 633346

Open 7 days a week, 7.00am - midnight

Hedgehog Ward, Inpatient Ward: Tunbridge Wells Hospital

☎ 01892 633525

Open 7 days a week, 24 hours a day

This leaflet has been produced to give you information about botulinum toxin treatment (sometimes called 'botox'); however, it is not a complete guide so if you have any questions or you require further explanation, please do not hesitate to ask a member of staff.

What is Botulinum Toxin treatment?

Botulinum toxin is produced naturally by the bacterium *Clostridium botulinum*. When purified, it can be used in tiny doses to relax excessive muscle contraction. It is used in treatment for children with cerebral palsy and other neurological causes of muscle stiffness, pain and impairment.

Why do I need botulinum toxin?

If some of your muscles are stiff or painful, you might find that this interferes with the way you move.

The botulinum toxin injections can relax stiff muscles, making it easier to move. In order to get the best effect, a motivating goal is needed, usually followed by a block of therapy to optimise its benefits. You will need to tell us if you have had botulinum toxin ('Botox') injections at another hospital in the past.

How does it work?

When injected into muscles, botulinum toxin has a local and controlled effect.

It works by temporarily blocking the messages from the nerve to the muscle. This causes muscle weakness, which helps to reduce pain and stiffness. It can also give other muscles time to strengthen and so improve how you can use your limb (for example, legs, arms or hands) in play and with day-to-day activities, such as dressing or walking.

Injections usually take effect within a few days, with peak relaxation four to six weeks later; although this can vary from person to person. These chemical effects last for approximately three to six months and then wear off. 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 used in children and young people, serious adverse events have rarely been reported.

As with all prescription medicines there may be some associated side effects – the team caring for you will minimise the chance of any of these happening by calculating the correct dose and injection sites.

The most common side effects reported are:

- Soreness or bruising at the injection site.
- The medicine causes weakness in the injected muscles and sometimes nearby muscles. This weakness is temporary but in the short term may make movement more difficult.
- Some people complain of mild flu-like symptoms in the days after injections.
- Very occasionally, temporary difficulty with bladder control and swallowing is seen.

Injection day

You will visit the hospital as a day case, which means you will be there in the morning and / or afternoon, and then go home when you have recovered. You will receive information about what time you need to arrive, what you need to bring and if you need

to fast beforehand. When you arrive at the ward, you will be met by a member of staff, and once settled in to your chair/ bed, you will be reviewed by a clinician from the injecting team. This is to ensure that you are fit and well and all is in place for the injections to proceed.

The most appropriate pain relief for your age, diagnosis, anxiety levels and discomfort will have been discussed and agreed with you, at clinic. Options include:

- Nitrous oxide Entonox® (gas and air) – when it is time for you to have the injections, you will be shown how to use a machine to breathe a gas that will relax you during the procedure.
- Ethyl chloride spray (cold spray) at the injection site. This temporarily numbs the skin at the injection site, and is sprayed on immediately before the procedure.
- Local anaesthetic ('magic cream') at the injection site. To find the right place to put the cream, the doctors will sometimes use an ultrasound machine, which does not hurt. When they find the right place, they mark it with a dot, and then put on the cream. The cream will be kept in place by a plaster and will numb the area.
- A general anaesthetic is occasionally required. You will receive additional information for this.

When you are relaxed, the doctor will look at your muscles with an ultrasound machine. This helps them find the exact position to place the injection. This won't hurt but the gel feels cold.

Most injections are carried out in the treatment room on the ward. A very fine needle is used and it doesn't usually take long.

Parents and carers are welcome to stay with their child throughout the procedure unless they are under general anaesthetic.

When can I go home?

Once you've eaten and you're feeling fine, the nurses will let you know when you can go home. At home, you might feel a bit sore where the injections were given. You could take paracetamol. You should feel fine again the next day.

As the botulinum toxin medicine starts to work, your muscles will start to relax. This may make you feel a bit wobbly at first. This will get better but tell someone if you are worried.

For the next few months, work extra hard on your therapy programme, exercises and stretches as this will help the botulinum toxin medicine work even better.

You will come back to see the doctor or therapist after the injections to see how the injections have helped.

Advice for parents/carers when you get home

Your child may be sleepier than usual over the next 24 hours if they had a general anaesthetic, but they should soon recover fully.

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 the MTW Complex Paediatric Upper Limb Service / Orthopaedic Service on 07718587842.

If your child takes any medication regularly, give this as usual unless otherwise agreed. Your child should feel well enough to return to school the day after the injections.

Children who have had a general anaesthetic may need an additional day of rest. If your child is unusually sleepy or difficult to rouse, make sure that they are in a safe position on their side and seek further medical support.

What happens next?

The hospital may invite you back for a follow-up appointment to review your progress around six to ten weeks after you received the injections.

They will discuss your goals and whether the injections have made things easier or helped in any way. They will ask you whether you'd like to have the injections again in the future.

Where can I find out more?

If you want to know more about the injections, you can ask the doctor or therapist from the Complex Paediatric Upper Limb Clinic.

This leaflet only gives general information. You must always discuss individualised treatment with the appropriate member of staff.


Do not rely on this leaflet alone for information about you/ your child's treatment. This information can be made available in other languages and formats if requested.

Please use this space to write any notes or questions you may have.

Further information and advice can be obtained from:


Contact.org - Botulinum toxin and hemiplegia (contact.org.uk)
Scope.org Botox treatment for CP | Disability charity Scope UK

NHS 111
NHS Choices online

 **111**
www.nhs.uk

MTW NHS Trust is committed to making its patient information accessible in a range of languages and formats. If you need this leaflet in another language or format please ask one of your clinical care team or the Patient Advice and Liaison Service (PALS). We will do our best to arrange this.

Maidstone and Tunbridge Wells NHS Trust welcomes all forms of feedback from our service users. If the standard of service you have received from the Trust does not meet your expectations, we want to hear from you. Please speak with the ward manager or the nurse in charge in the first instance, or you can contact the **Patient Advice and Liaison Service (PALS)** on:

Telephone:  01622 224960 or  01892 632953

Email: mtw-tr.palsoffice@nhs.net

or visit their office at either Maidstone or Tunbridge Wells Hospital between 9.00am and 5.00pm, Monday to Friday.

You can be confident that your care will not be affected by highlighting any areas of concern or making a complaint. The Trust will retain a record of your contact, which is held separately to any medical records. If you are acting on behalf of a patient, we may need to obtain the patient's consent in order to protect patient confidentiality. More information on PALS or making a complaint can be found on the Trust's website: www.mtw.nhs.uk or pick up a leaflet from main reception.

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