

Your Spasticity Management Service: Managing spasticity with Botulinum Toxin A in children with cerebral palsy

This leaflet is for children and young people with cerebral palsy, and their parents and carers. It contains information on what spasticity is and how to manage it and provides you with an overview of the use of Botulinum Toxin A.

What is Botulinum Toxin A?

The injection of Botulinum Toxin A (better known as Botox) has been proven to be helpful in the management of spasticity. It provides a reversible means of treating individual spastic muscles.

Botulinum toxin type-A is produced by a bacterium called *Clostridium botulinum*, which is found in nature. It works by relaxing the muscle and if it is injected in very small quantities directly into the affected muscles, it will reduce excessive contraction.

How does Botulinum Toxin A work?

Normally, muscle contraction is stimulated by a chemical called acetylcholine, which is released from the nerve endings in the muscles. In some disorders, such as cerebral palsy, too much acetylcholine is released causing over-stimulation of the muscles, resulting in muscle spasm. Botulinum Toxin A blocks the release of acetylcholine from the nerve endings, close to where the injections are given; thereby relaxing the muscles.

How long do the effects of the injection last?

The effects of Botulinum Toxin A appear within 2-3 days, are most effective at 2-4 weeks and last for about 3-4 months. The benefits gradually wear off and muscle spasm returns as new nerve endings sprout from the nerves.

Deciding when to use Botulinum toxin A

The option to treat children with Botulinum Toxin A will be discussed in the outpatient clinic and will be agreed by you, the doctor and the therapists. Ideally, the injections are given to assist in the achievement of functional goals, such as improved sitting posture, walking

further with fewer falls, or to increase tolerance of splints which aid function. Some children benefit from relief of painful spasm and in others relief of spasm may help parents with dressing and daily care. Botulinum Toxin A injections may also help to counter the development of joint deformities, particularly if followed by the use of splints to assist in stretching the injected muscles.

What are the benefits of this treatment?

These will be discussed and agreed for each child, when the decision is made to give Botulinum Toxin A injections. The usual benefits are:

- To relieve muscle spasm and maximise function, e.g.
 - In the legs to reduce:
 - Tip-toe gait and improve stability in the stance phase of walking;
 - Dragging of toes, resulting in falls;
 - Scissoring of the legs;
 - Crouched gait pattern with flexed hips and knees, which is very tiring.
 - In the arms:
 - To reduce spasm of elbow and wrist flexors, forearm rotators and thumb muscles, to assist reach and grasp and use of the arm and hand for everyday tasks such as feeding and dressing;
 - To help counter the development of muscle contractures which lead to joint deformity;
 - To assist nursing care, e.g. changing nappy, dressing and skin care in flexures;
 - To relieve painful spasm of muscles, e.g. causing pain in hips that are unstable or dislocated.

Are there any possible side-effects to Botulinum Toxin A?

We use medicines to make our children better, but sometimes they have other effects that we don't want (side-effects).

Side-effects you must do something about

If your child has new swallowing difficulties, 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 healthcare professional or 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.
- Information about other side effects and what to do about them can be found in the Appendix on the last page of this leaflet.

How and when are the injections given?

- The injections are carried out at the Royal Berkshire Hospital on 2 days each month. Up to five children may attend on the same day and families should expect to stay at the hospital for about 6 hours.
- Day case admission - all children are admitted to the Kempton Day Bed Unit. As your child will be given sedation, you will be instructed to starve them for a minimum of 4 hours before their appointment.
- Consent – we will need to obtain parental consent for sedation and the injection. One of the doctors will ask you to sign a consent form.
- Injection sites - these are marked and local anaesthetic cream is applied to the injection sites 30-60 minutes before the injections to numb the skin. This is not needed if the injections are being given under a general anaesthetic (i.e. your child is asleep).
- Sedation/pain relief - oral sedation works well for most children, and a general anaesthetic is usually only needed for those having injections into special sites where they must lie still. Buccal Midazolam is the recommended sedative used for children and oral Diclofenac is used as pain relief. These are given approximately 30 minutes before the injections.
- A play therapist will help to distract your child during the injections.
- Up to two close family members can be present at the injection to provide support and reassurance to the child.
- Botulinum Toxin A injections are given at the sites chosen using ultrasound guidance.
- Your child is allowed to eat and drink after the injections.
- Your child can go home when he or she is sufficiently awake, usually about 1-2 hours later.
- If your child needs a plaster cast in addition, these are usually applied 3-4 days later when the muscles have started to relax.

Follow-up arrangements:

- Kempton Day Bed Unit staff offer a telephone call the following day to check for any problems.
- Physiotherapy - please inform your child's physiotherapist when the injections are due to be given, so that they can arrange a follow-up appointment.
- Orthotics - if splints are prescribed for your child, please make sure that they are worn regularly.
- Paediatric appointment - this will be arranged about 6-8 weeks after the injections to evaluate the outcome. It is very important to attend this appointment as it is the basis for planning future management.

Contact details

Dingley reception:	0118 322 5213	Orthopaedic secretary:	0118 322 7426
Kempton Day Bed Unit:	0118 322 7383	Orthotic Department:	0118 322 7552
Paediatric Secretary:	0118 931 5889	Plaster Room:	0118 322 7040

Further information

- SCOPE produces detailed fact sheets about the treatments described in this leaflet which can be accessed from their website www.scope.org.uk. Tel 0808 800 3333, Fax 01908 321051 Email: cphelpline@scope.org.uk
- Hemi Help, 6 Market Road, London N7 9PW
Tel: 08451232372 Website: www.hemihelp.org.uk/home
- CerebralPalsy.org.uk supporting children, adults and families affected by Cerebral Palsy
<http://www.cerebralpalsy.org.uk>

Royal Berkshire NHS Foundation Trust
London Road, Reading RG1 5AN
Telephone 0118 322 5111
www.royalberkshire.nhs.uk

This document can be made available in other languages and formats upon request.

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Appendix:

Further information on sedation

Possible side-effects to Midazolam

- Your child may be sleepy after having Midazolam. They should have a sleep if they want to.
- Your child may be confused. They probably won't remember having the procedure done.
- Your child's breathing may become a little shallow for a while. You do not need to worry about this. However, if you think your child is not breathing or if your child's lips get a blue tinge, please alert the nurse/doctor on the ward.

Further information on pain management

Side-effects to Diclofenac you must do something about

If your child gets bad stomach pain, brings up (vomits) blood or their stools (poo) are very dark, contact your doctor straight away or take your child to hospital. They may have an ulcer.

Other side-effects of Diclofenac you need to know about

- Diclofenac may cause stomach pain, indigestion and heartburn, and your child may feel sick or be sick (vomit). You can help to reduce this by giving Diclofenac with food.
- If these symptoms carry on, they may be signs of irritation to the stomach and oesophagus (food pipe). Contact your doctor if this happens.
- Your child may get diarrhoea.
- Diclofenac suppositories may irritate your child's bottom.

There may, sometimes, be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your doctor. You can report any suspected side-effects to a UK safety scheme at:

<https://yellowcard.mhra.gov.uk/>. Visit the website
www.medicinesforchildren.org.uk