Botulinum toxin use in cerebral palsy

Your questions answered
What is botulinum toxin?
Botulinum toxin is produced by a bacterium called Clostridium botulinum.

Alongside therapy, botulinum toxin can be used to manage spasticity (tight muscles) in cerebral palsy. It can cause botulism, a rare form of food poisoning. However, in tiny doses it is a very effective muscle relaxant.

What is botulinum toxin used for?
Botulinum toxin is licensed to treat tiptoe walking in cerebral palsy. Tiptoe walking is caused by spasticity in the muscles in the calf.

It can also be used for other muscles. This could be where spasticity is causing problems with walking or positioning, or interferes with personal hygiene and care.

How does botulinum toxin work?
Botulinum toxin stops the nerve endings from sending signals to the muscles. The effect is temporary because the nerves regrow new endings within a few months.

Why does my child need botulinum toxin?
If your child has been referred for botulinum toxin, it is because their spasticity is interfering with their day-to-day function or care, and possibly their quality of life.
Where is botulinum toxin injected?
Botulinum toxin is injected into the muscles which are causing the problem.

How often will my child need to come back to the clinic?
Your child will attend for an initial assessment to see if botulinum toxin is suitable. They will need to attend for the injections. After the course of treatment, your child will attend for a review.

Will botulinum toxin cure cerebral palsy?
No, botulinum toxin only helps spasticity. Spastic muscles are also weak, and botulinum toxin will not help the weakness. Only therapy and exercise can do this.

Does botulinum toxin need to be injected?
Yes. Unfortunately, there is no other way of giving botulinum toxin.

Is it painful?
Some children may feel anxious or worried about being in hospital and having injections, or they not like their limbs to be held securely during the injections. The medical and nursing staff understand this and they will do everything they can to calm your child and to put them at ease.
Your child may find the injection a little painful.
We reduce this by using local anaesthetic cream to numb the skin. The cream takes about an hour to work.

Some children may prefer a cold spray which also numbs the skin. This product acts quicker, but may be uncomfortable on more sensitive areas of skin.

We may sometimes combine this with some light sedation. If we are considering sedation for your child, let the medical and nursing staff know if your child snores in their sleep. This may be important, as your child may sleep deeply for a time after sedation.

We will consider the most appropriate sedation for your child. For example:

- **Midazolam**: In younger children, we can use midazolam. This is given a half hour before the treatment, and is absorbed through the cheek lining when held in the mouth. It is less effective if swallowed. The dose of this can be repeated if your child is not sedated with the first dose. This may make them more sleepy and prolong the time spent on the ward after injections.

- **Entonox**: In older children we can use Entonox, also known as laughing gas.

- **General anaesthetic**: We can organise injections under a general anaesthetic. If your child is to get a general anaesthetic for another reason, please let us know. We would try to make use of this for the injections procedure at the same time.
How long will the botulinum toxin take to work? Botulinum toxin usually takes a week or two to take effect. The effect peaks at about six to eight weeks and lasts for three months.

What happens before the injection? You and your child will come into the Children’s Assessment Unit in Ward 1A of University Hospital Crosshouse and the doctor will review your child. The doctor will mark the injection sites and the nurses will apply a local anaesthetic cream. The doctor may also prescribe sedation where needed.

What happens during the injection? The doctor use an ultrasound machine to find the right muscles to inject. Your child should lie as still as they can manage.

The nurse will help you to comfort your child if they become distressed.

If you feel your child needs a break, speak to the medical and nursing staff. They will then discuss with you whether to continue, give more sedation or reschedule the procedure so that your child can get an general anaesthetic.

What happens after the injection? Once the injections have been given, your child may need to rest if they have had sedation. The nurses will keep an eye on your child while they are sleepy,
and can also explain and answer any questions you may have.

Once your child is fully awake, or has had something to eat or drink, you can usually take them home.

Very occasionally, children need to stay overnight, but this is rare.

**How often does my child need to be injected with botulinum toxin?**

Every child is different, and so there is no single correct answer for this.

The botulinum toxin wears off within three months, and so further courses may be needed.

If there has been a good response, there may be no need for further treatment.

We have to wait at least three months before thinking about re-injection. Usually we would offer this treatment before six months to allow time for physiotherapy and to maximise gains towards a specific goal.

If a child does not respond to two complete cycles of treatment over 12 months, then we would not normally offer another course of botulinum toxin.
Are there any side effects of botulinum toxin?
Any treatment can have side effects.

Local side effects:

- reaction to the anaesthetic cream, including redness of the skin;

- local bruising and some discomfort at the injection site. You can give your child pain relieving medicine, such as paracetamol to relieve any pain or discomfort; and

- spread of the toxin to other muscles. Where the injection has been given in the upper leg, your child may experience mild and short-lasting loss of bladder control.

General side effects can occur and include:

- flu-like symptoms; and

- in rare cases, changes in swallowing can occur for a short time. This is more common in children who have been given large doses, and who already have feeding or swallowing difficulties.

Sedation can also cause side effects:

- Your child may become upset. This can be similar to how children can be when they are over-tired.

- The medicine needs to wear off before your child can go home. The nursing and medical staff will observe your child for a period of time.
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