

Botulinum toxin



This information sheet explains about injections of a medicine called botulinum toxin. It also tells you what to expect when you come to Great Ormond Street Hospital (GOSH) for the injections.

Information for young people

What is botulinum toxin?

Botulinum toxin is a medicine used to help people with cerebral palsy and other conditions that cause muscle pain or stiffness.

It works by temporarily blocking the messages from the nerve to the stiff muscle. This causes weakness in that muscle which helps to reduce pain and stiffness. It also allows your other muscles to work better.

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 relax the stiff muscles, making it easier to move.

How do I have the botulinum toxin medicine?

You will come into hospital and take medicine (sedation) or gas (entonox) to make you feel more relaxed. The skin will be made numb with cream or a cold spray, and the medicine will be given by injection straight into the muscle. The needle used is very small and it is like having a vaccination.

What happens exactly?

If you decide to go ahead with having botulinum toxin, you will be seen at GOSH a few weeks before injection day. At this appointment, you will see a doctor and physiotherapist. They will ask you which movements you find difficult, and then have a look at the way you walk and use your arms. They may video this part so they can look at the video later. Often they will use the video to compare your movement before and after the injections. They will measure your joints and then have a discussion with you about which muscles will be injected. They will ask you or your parents to think of one or two specific things you want to be able to do better, so they can see if the injections help.

You can ask as many questions as you need at this appointment.



What happens on the day of the injections?

You will visit the hospital as a day case, which means you will be there in the morning and afternoon, and then go home when you feel ok. You should aim to be at the hospital by about 9.30am.

There are different ways to prepare for the injections:

- **Entonox® gas** (medicine you breathe in to make you sleepy)
- **Oral sedation** (medicine you take by mouth to make you sleepy)

Entonox®

If you decide to use Entonox®, on the day of treatment you should stop eating and drinking an hour before the injections. When you arrive, you will be given a bed, and then your doctors and physiotherapists will check that you are well. While you wait to have the injections, you can move around the ward and watch videos. You may want to bring things with you to keep you entertained.

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. When you are relaxed, the doctor or physiotherapist 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 they use feels cold.

Once they have identified the area to be injected they will spray the area with cold spray to make the skin numb. When you are ready and comfortable, they will begin the injections.



Oral sedation

If you take medicine to make you sleepy ('oral sedation'), you will need to have an early breakfast on the day of your appointment. After this (the team will tell you exactly what time) you will not be able to eat or drink anything until after the injections.

When you arrive, you will be given a bed, and then your doctors and physiotherapists will check that you are well. They 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 they use feels cold. Once they have worked out which area to inject, they mark it with a pen and put some cream on the skin to numb it. The cream is kept in place with a plaster.

The cream needs about 45 minutes to work, so while you wait to you can move around the ward and watch videos. You may want to bring things with you to keep you entertained.

When your skin is numb, you will take some medicine to make you feel relaxed. When you feel sleepy, you will go into another room with the same doctors and physiotherapists to have the injections.



What happens afterwards?

Once you have had your injections you will go back to the ward. When you wake up, you can have something to eat and drink.

Once you're feeling fine and have had something to eat, you can let the nurses know that you're ready to go home. In most cases you will be able to go home just a few hours after your procedure.



Does it hurt?

The doctors will also use a local anaesthetic cream or cold spray so that the injection will not hurt so much. You might feel a bit sore where the injection was given. Some people feel a bit cold and achy afterwards. If this happens, you can take paracetamol to make you feel better. Some people may feel a bit weak and wobbly or trip and fall more often than usual. If this happens, don't worry, just let us know.

What happens next?

The hospital will invite you back for a follow-up appointment around six weeks after you received the injections to chart your progress. They will talk about your goals and whether the injections have helped you do things better. They will ask you whether you'd like to have the injections again.

In the majority of cases the injections begin to take effect within a few days. For most people the muscles will be at their most relaxed four to six weeks later, although this can vary from person to person. The chemical effects of the medicine last for about three months but, in some cases, the muscles can have improved movement for up to one year after the injection.

Where can I find out more?

If you want to know more about the injections, you can ask your doctor or physiotherapist.

Notes

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Ref: 2014C0135

Compiled by the Movement Disorder Team in collaboration with the Child and Family Information Group. We thank all the families involved in the production of this leaflet and the Bowtell family for their generous donation which funded the printing of this leaflet. All photographs © UCL Medical Illustration Services.

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