

# What is botulinum toxin?

Botulinum toxin is produced naturally by the bacterium *Clostridium botulinum*. This bacteria is associated with causing botulism, a rare form of food poisoning, but, when purified and used in tiny, controlled doses, it is safely used to relax excessive muscle contraction.

## Is botulinum toxin a new medicine?

No, botulinum toxin has been used successfully as a medicine for over 15 years.

## How does botulinum toxin work?

Botulinum toxin has an effect on nerves at their junctions with muscles. There is a chemical 'messenger' called *acetylcholine* that is released from the nerve endings to make the muscle contract; botulinum toxin stops this release happening. The effect of botulinum toxin is to help reduce some of the abnormal muscle contraction and so the muscles become less stiff.

## Does botulinum toxin have to be injected?

Yes it does.

## How is botulinum toxin injected?

Botulinum toxin type A is diluted in saline (*sodium chloride*) for injection.

## Who should administer botulinum toxin?

Botulinum toxin should only be administered by appropriately trained medical professionals.

## Where is botulinum toxin injected?

Botulinum toxin is injected directly into the affected muscles.

## Will the injection hurt?

People vary in how they feel about the injections. Some people find that the injection hurts a little and others are not concerned about it at all. If it is a problem then your doctor may offer you a local anaesthetic cream or a medicine to help the pain.

## How often do I have to be injected with botulinum toxin?

This will vary according to how severe your dystonia is. The positive effect of botulinum toxin can last for up to 16 weeks, causing weakness in the muscle for 3 – 4 months in most cases, sometimes longer. Most people with dystonia attend a clinic every 3 months for their injections. Your doctor will decide how long you need to be treated with botulinum toxin.

## How long does botulinum toxin take to work?

Botulinum toxin treatment takes effect gradually over 4–7 days, sometimes longer.

## How many injections will I need?

The number of injections will vary depending on the severity of your dystonia. Talk to your doctor about the number of injections you will need.

## Are there any side-effects of botulinum toxin?

As with all medicines there are possible side-effects. Unwanted or excessive muscle weakness may occur. Some people experience swallowing problems, voice changes, dry mouth, droopy or swollen eyelids, double vision, dry eyes and tearing.

Others have 'flu-like symptoms or pain and bruising at the injection site. Usually these effects are mild and wear off relatively quickly.

Your information leaflet in the medicine pack tells you more about the possible side-effects. If the side-effects are a problem for you, then you should tell your doctor.

## Do I have to come to hospital for my treatment?

Yes you will, but your doctor will tell you when and where this will happen.

## How long does it take to have the injection?

The injection will only take a few minutes.

# Botulinum toxin treatment

## What the Society can offer

- The **Dystonia Society** is dedicated to providing information and support to everyone affected by dystonia in the UK and to raising awareness of the condition and the needs of everyone affected. The Society is committed to ensuring that everyone with dystonia has access to the treatments they need.

**Helpline: 0845 458 6322**

- Our **Helpline** is open Mondays – Fridays between 10am – 4pm and offers an opportunity to discuss concerns in confidence, and to obtain information on dystonia and its various treatments, including ways of making living with dystonia easier.
- **Local support** is provided via the Society's regional support groups run by the Society's team of volunteers.
- The **organisation** encourages and supports research into treatments and practical ways of coping with the condition.
- **Join us** – become a member and receive our quarterly newsletter. Call: 0845 458 6211.



## What should I do if I need further information?

At your next appointment you should speak to your doctor who will be able to answer your questions.

## Can I expect to get botulinum toxin via the NHS?

Your GP will have referred you to a neurologist at a hospital. If the neurologist decides that you need to receive botulinum toxin, then you will usually be able to be treated via the NHS.

## Can botulinum toxin be used to treat dystonia in children?

The safety and effectiveness of botulinum toxin in the treatment of children with dystonia has not been demonstrated.

## Can botulinum toxin be used in pregnancy?

Botulinum toxin should not be used in pregnant or lactating women, unless clearly necessary.

## Is there any reason I shouldn't receive botulinum toxin?

You should not be given botulinum toxin if you have had a previous allergic reaction to it or any of its ingredients.

*your questions answered*



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The **dystonia** society

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