Types and brands of toxin

There are two types of toxin used in the UK - types A and B. There is a small risk of becoming immune to one type of toxin. If this happens, the other type can be tried.

There are a number of different brands of toxin available. Once the right dose and site for the injections have been sorted out, the effectiveness of the different brands of botulinum toxin in mitigating symptoms is similar.

If the brand of botulinum toxin is changed, it can take a while to establish the right dosage of the new brand and this can result in some short-term disruption in the effectiveness of the treatment.

Who can receive botulinum toxin?

Botulinum toxin is usually used in adults. Although botulinum is not licensed for the treatment of dystonia in children, it is sometimes used at the Consultant’s discretion. Botulinum toxin should not be used in pregnant or lactating women, unless clearly necessary.

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

What the Society offers

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.

The Society is also committed to ensuring that everyone with dystonia has access to the treatments they need.

- Our helpline offers an opportunity to discuss concerns in confidence and to obtain information on dystonia.

Helpline: 0845 458 6322

- Our regional support groups run by volunteers provide an opportunity to share experiences and meet others.

- Our website has information on dystonia, a lively forum and you can sign up for our free e-newsletter. The address is www.dystonia.org.uk.

- Our helpcards can help you to explain your condition to people you meet.

- Join us – become a member and receive our quarterly newsletter. Call: 0845 458 6211 or email info@dystonia.org.uk or go the Membership page on our website www.dystonia.org.uk.

Supported by:

2nd Floor, 89 Albert Embankment, London SE1 7TP
Office no: 0845 458 6211
email: info@dystonia.org.uk
www.dystonia.org.uk
Registered Charity No: 1062595 and SC042127
Botulinum toxin injections are used to reduce the excess muscle activity caused by dystonia. Botulinum toxin is produced naturally by a bacterium called Clostridium botulinum which is also associated with causing botulism, a rare form of food poisoning. However, although botulinum toxin is exceptionally toxic, when it is purified and used in tiny, controlled doses, it can be used safely and effectively to relax excessive muscle contraction.

The injection enables the botulinum toxin to be targeted directly into the muscles affected by dystonia. The toxin has an effect on the nerves at their junction with the muscles. It acts as a blocker preventing release of the chemical messenger acetylcholine which is responsible for making the muscle contract. As a result, the signals that would normally be telling the muscle to contract are halted and the muscle spasms are reduced or eliminated.

Because each muscle affected by dystonia has to be injected separately, and also because there is a limit to the total quantity of toxin that can be injected into the body at one time, botulinum toxin is more suitable for treating dystonias which are focal to one or two areas of the body rather than generalised dystonia. However, sometimes the toxin is used to treat a specific part of the body in generalised dystonia as part of a wider treatment regime.

The injection process

Botulinum toxin injections are administered by trained medical professionals (usually a doctor, physiotherapist or dystonia nurse) and most commonly delivered at a local hospital. Some people find the injection hurts a little but others are not concerned about it at all. Depending on the location of the muscle spasm, doctors will either select the muscles by observing the abnormal postures or movements and feeling for the muscle spasm or will use an EMG (electromyography) machine which measures muscle activity.

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.

After the injection, the treatment takes effect gradually over 4–7 days, sometimes longer. Where it is a suitable treatment, botulinum toxin provides significant relief for the majority of people but it is not perfect - usually mitigating symptoms rather than completely eliminating them. The positive effects of botulinum toxin injections can last up to 16 weeks, sometimes longer; although many people find that the injections need repeating before this and usually attend a clinic around every 12 weeks.

Are there any side effects?

The advantage of botulinum toxin over oral medication is that the toxin can be targeted only at the muscles causing the dystonia.

However, as with all medicines there are possible side-effects and these can vary depending on the location of the injection. For instance, in neck dystonia some people can experience difficulties swallowing or speaking. For eye dystonia, the injection can result in droopy eyelids, blurred vision or over-production of tears.

Some people encounter unwanted or excessive muscle weakness around the injected muscle or experience flu-like symptoms or pain and bruising at the injection site. Usually these effects are mild and wear off relatively quickly. If the side-effects are a problem, then they need to be discussed with a doctor.