

Providing injections is a complex process and no injector can get it exactly right for every patient. You do not automatically have the right to a second opinion, but most medical professionals will accept that if the injections do not seem to work and there is no explanation why the treatment isn't working then it is worth asking another medical professional to review the case.

Other treatment and support

If a way cannot be found to make the injections work, there are a number of other approaches that can be tried.

1. A number of **medications** are used to treat dystonia. Medication is not for everyone as taking medicine to treat dystonia requires patience and persistence and there can be side effects. The medicines only work for some people and are more likely to be successful in children and young adults than in the elderly. However, some people can gain relief so it may be worth discussing medication with your consultant if the botulinum toxin isn't working.

2. Many people with neck, hand or generalised dystonia benefit from **physiotherapy**. Because of the specialised nature of the movements in dystonia, this treatment needs to be provided by a specialist neuro-physiotherapist who has a knowledge of the condition. Physiotherapy can only be successful if there is a commitment by the patient to do the regular exercises prescribed by the physiotherapist.

3. Some types of dystonia are associated

with high levels of pain. In these cases, **pain management programmes** can often be helpful. These programmes give guidance on coping via emotional and physical techniques that can help manage pain.

4. Dystonia is also associated with higher levels of stress, anxiety and depression for some people – if this is the case **psychological support** such as counselling and cognitive behavioural therapy can be helpful.

5. The treatment of last resort for dystonia is **deep brain stimulation (DBS)**. This is usually only provided for severe cases of generalised dystonia, neck dystonia or dystonic tremor and is more effective for primary dystonias. DBS is a surgical procedure in which two fine electrodes are inserted into the brain. They are connected to a subcutaneous power source which delivers a constant, painless, signal which blocks the signals that cause the disabling symptoms of dystonia. A number of other **surgical treatments** (such as peripheral denervation) are also sometimes used.

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When botulinum toxin injections are not working

The
dystonia
society

When toxin injections are not working

Botulinum toxin injections are used to treat many kinds of focal dystonia and are also sometimes part of a treatment regime for more generalised dystonia. They are an effective treatment and provide significant relief for the majority. However, around a third of patients report receiving limited relief. This can be a distressing experience.

People do sometimes become immune to the toxin but this is quite unusual (only a few percent of all those being injected) so for the majority of people where the injections are not working well there is another explanation.

Discussing with the injector

If injections are not working well, it is important to document precisely the effect of the injections (percentage of improvement, duration of benefit, side effects) and then in an open discussion with your injector detail what has improved and not improved in your daily life since the last injections. People are sometimes frightened that treatment will be withdrawn if they express their concerns - but, as explained below, there are a number of steps that may help to improve the situation. These can only be put in place if you and your injector jointly agree how to progress.

If you have recently started having injections

When injections are started, it can take a few injection cycles for them to become effective. There are a couple of reasons for this.

First, dystonia can involve a number of different muscles and it may take more than one trial by the injector to establish the right muscles to be injected.

Second, injectors usually start with low dosages of toxin to minimise the risk of side effects (such as swallowing difficulties or droopy eyelid). Once they have established that a patient can tolerate higher dosages, they can inject more toxin and so the injections may become more effective.

It may be necessary to try at least 2 or 3 cycles of injections (which can take in total around a year) to establish how effective the toxin treatment can be.

If the injections lose their effectiveness

The severity of dystonia fluctuates. One possibility is that it has recently worsened, following a stressful event. This may be worthwhile to discuss with your injector.

Sometimes also the injections lose effectiveness and different strategies can be used to optimise the treatment

1. The injector may **review which muscles are being injected** and also **increase the dosage**

of toxin – although there is a maximum amount of toxin that can be injected on any one occasion because of the risk of side effects.

2. The injector can also try a **different toxin brand** – there are 3 brands of type 'A' toxin (Botox™, Dysport™ and Xeomin™) and one brand of type 'B' toxin (Neurobloc™). In general, there is no reason that any of these will be more or less effective than any other but some people find that switching to a different toxin can help if their current toxin stops working.

3. If the muscles being injected are deep below the skin, such as some neck muscles, then the injector may guide the injection by using an **electromyographic (EMG) or ultrasound machine** which help locate the dystonic muscle.

4. If none of the above has worked, then the injector can check if the patient is immune using a **Frontalis test** – where small amounts of toxin are injected into the forehead. You should not conclude you are immune to the toxin until this test has been done. If the test is positive (no visible effect of the injection), the patient may try a period (from 6 months to 2 years) without toxin. Sometimes, this causes the immunity to disappear – but unfortunately in other cases the immunity can be permanent.

5. Finally if nothing has worked and the Frontalis test shows there is no immunity, it may be necessary to get a **second opinion**.