Anti-convulsant - Carbamazepine
This drug is used principally for epilepsy but has been shown to be very effective for some cases of the rare condition of paroxysmal dystonia.

Anti-convulsant - Gabapentin
This is a drug used mainly for epilepsy but also pain, particularly associated with neuropathy (damage to nerves in arms and legs). It has been tried in dystonia although there are no clinical trials and the evidence is anecdotal and whether it is truly effective is unknown. It can help where there is chronic pain associated with dystonia.

Important points about these drugs
Taking these medicines requires patience and persistence on the part of the patient, their family and the physician.

// It is a fact that medications are more likely to be successful in children and young people where a significant proportion can improve dramatically through talking the right combination.

// While medications are an option, they are less likely to be effective and so botulinum toxin treatment is often the best option for adults with focal dystonias.

// Most of these medicines have side effects. If you are concerned by these, you must speak to your doctor.

// Talk to your GP or neurologist before stopping a course of medicine as this may cause side effects too.

// Remember to update all your doctors, nurses and specialists on what you’re taking including any over-the-counter remedies as well as herbal and homeopathic remedies. This is to ensure you are not duplicating medicines or taking things that do not agree with each other.

Important note
The contents of these pages are provided only as information, and are in no way intended to replace the advice of a qualified medical practitioner. The Society strongly advises anyone viewing this material to seek qualified medical advice on all matters relating to the treatment and management of any form of medical condition mentioned. Furthermore, rapid advances in medicine may cause information contained here to become outdated after some months.

Helpline
0845 458 6322

March 2015
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
Drugs used for dystonia

The symptoms of dystonia can be challenging to manage and it can often take some time to get the balance of medications right to achieve benefits for a person with dystonia. This leaflet is designed to provide a brief guide to the principal drugs used to provide relief from the symptoms of dystonia.

**Dopaminergic drugs - Levodopa (Sinemet, Madopar etc)**

Patients with the rare dopa-responsive dystonia (DRD) can find a dramatic, sustained improvement in their dystonia by taking small doses of levodopa. This condition is found primarily in dystonia affecting children or young adults. In these instances, a trial of levodopa is often proposed as an initial therapy by the physician. In cases of adult-onset dystonia, a physician is much less likely to propose levodopa for a patient unless there may be a history of early-onset dystonia in their family. Most people with dystonia can tolerate these drugs and side effects are uncommon.

**Anticholinergic drugs - Trihexyphenidyl (Broflex), Biperiden, Procyclidine**

This medicine belongs to the anticholinergic family of drugs and helps control muscle spasms and the tremor by blocking the effect of a chemical messenger in the brain called acetylcholine. It is especially helpful for childhood-onset and the more severe cases of dystonia. However, people with adult focal dystonia do sometimes also respond to the medication and find it effective.

To minimise the likelihood of side effects, the physician will increase the dosage slowly. Benefits may not appear for many weeks on a constant dose, so lengthy trials are more likely to be productive. Side effects can include a dry mouth and sometimes sleepiness. In higher doses they can also cause urinary problems, especially in men, and worsen certain types of glaucoma. Short-term memory loss and confusion have also been reported. Talk to your GP or neurologist if you have problems. It is important there is no abrupt withdrawal from anticholinergics as dystonia may significantly increase.

**GABA Agonist - Benzodiazepine (Clonazepam (Rivotril), Diazepam (Valium))**

These drugs are frequently used in the treatment of dystonia. They work by boosting levels of GABA (gamma-aminobutyric acid) a chemical which inhibits the transmission of nerve signals in the brain so acting as muscle relaxants. Patients can sometimes tolerate very large dosages if the doses are increased slowly. A number of side-effects have been reported including sleepiness and sedation, and withdrawal symptoms on stopping the medication (which is why it is important that dosages are not lowered rapidly).

**GABA Agonist - Baclofen (Baclospas and Lioresal), Tizanidine (Zanaflex)**

As muscle relaxants, Baclofen and Tizanidine have been shown to ease the painful muscular spasms and cramps and to be of marked benefit in a significant minority of children with dystonia and also a small minority of adults with focal dystonia. While children can often tolerate high dosages of Baclofen, its side effects are a limiting factor for adults with dystonia. These include lethargy, upset stomach, dizziness and dry mouth etc. Baclofen should never be discontinued abruptly. Very occasionally, baclofen is given via a pump directly to the spinal cord region (intrathecal baclofen).

**Tetraabenazine, risperidone**

These medicines can help control tremor and involuntary spasms or movements by suppressing release of chemical messengers in the brain such as dopamine and serotonin. They are usually used for more severe cases of dystonia and can also cause sedation and occasionally depression. Higher doses of tetraabenazine also have a risk of causing parkinsonism. If you’re taking tetraabenazine, and you experience fever, sweating and increased heart rate, stop taking the medicine and phone for medical help straight away. Risperidone has a small risk of causing tardive dystonia so is usually used only to manage dystonic storms in generalised dystonia.