Treatment

The first step is usually a controlled withdrawal of the drug causing the problem. If it is necessary to continue using DRBs, one of a class of newer, "atypical" DRBs (such as clozapine or olanzapine) may be a suitable substitute.

What other treatments are suitable will vary by individual and may include drugs commonly used to treat dystonia - for instance oral medications such as anticholinergic drugs (trihexyphenidyl) or baclofen. These drugs may have side effects such as sleepiness that need to be discussed with your doctor.

Botulinum toxin injections can also be helpful to manage involuntary movement in one or more specific areas. There is no clear way to predict which treatments will work for each person.

Where other treatments are not effective, deep brain stimulation (DBS) may be an appropriate alternative. In this procedure, electrodes are planted into the brain to help ‘rebalance' movement and to control posture. The electrodes are powered by a battery implanted in the chest.

The Dystonia Society provides information and support to people affected by dystonia in the UK. Services include a helpline, advocacy, self-management workshops and events across the UK.

Our website, www.dystonia.org.uk, has information on dystonia and a lively forum. Sign up on the website for our free e-newsletter.

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 to the Membership page on our website.

Helpline
0845 458 6322
Website
www.dystonia.org.uk
Tardive dystonia

Dystonia is a neurological movement disorder where uncontrollable and sometimes painful muscle spasms are caused by incorrect signals from the brain. The condition results in abnormal postures or movements, with or without tremor. Dystonia has a variety of causes one of which is an unwanted side effect of taking certain drugs used to treat other conditions. Where dystonia is caused by the side effects of drugs in this manner, this is called tardive dystonia.

There are number of different types of involuntary muscle activity that result from neurological conditions caused by the side effects of drugs. As a group, these are called tardive dyskinesias. Tardive dystonia is one type of tardive dyskinesia in which the involuntary movements tend to be slow and writhing. Other types of tardive dyskinesia include facial tics and irregular, dance-like movements called choreas.

Tardive dystonia is most commonly the result of side effects from a type of drug which is prescribed to treat schizophrenia and psychosis called a ‘dopamine receptor blocker’ (DRB). In recent years, DRBs have been improved to reduce the risk of causing tardive dystonia but unfortunately some risk still remains. Some DRBs are used to treat nausea and dizziness, not psychosis.

If the symptoms described below appear after taking oral medication, it is essential to discuss this immediately with the doctor who prescribed them. It may be necessary to discontinue the drug – but this must be done in a controlled manner under the supervision of a suitably qualified doctor.

Acute dystonic reaction

In most cases of tardive dystonia, the symptoms of tardive dystonia tend to be acute but short-lived. This is called an acute dystonic reaction. Such reactions usually affect the face causing strange movements of the face and/or mouth. In some but not all cases, the movements can cause problems with eating and swallowing (such movements are called oromandibular dystonia). It may also cause hyper-extension of the spine amongst other effects.

Fortunately the majority of these acute reactions can be successfully treated with injectable anticholinergic drugs which will usually terminate the attack.

If it is important for the patient to continue taking DRB drugs then the physician would be expected to look for different types of DRB drugs that hopefully will not cause a further acute dystonic reaction.

Many other drugs have been reported to cause acute dystonic reactions including anti-depressants of the type that inhibit the reuptake of serotonin, calcium antagonists (sometimes used to treat high blood pressure and angina), some anaesthetic agents, anticonvulsants such as carbamazepine and phenytoin and even illicit drugs such as cocaine and ecstasy.

Tardive dystonia

Tardive dystonia is a more taxing condition as it can be permanent. It is caused only by DRBs and usually only after people have taken the drugs for months or even years.

Symptoms can include one or more of involuntary movements of the face and/or mouth (oromandibular dystonia see above), involuntary eye closure (blepharospasm), voice problems, involuntary twisting or movement of the neck (cervical dystonia) and contortion of the trunk and limbs.

Occasionally, symptoms do disappear but unfortunately this is rare (around 1 in 10 cases). Research suggests that, if the drug causing the tardive dystonia has been taken for only a short period of time, remission of symptoms is more likely than if the drug has been taken for a longer period.