

Tardive dystonia

Sometimes dystonia can arise as an unwanted side effect of taking certain drugs used to treat other conditions.

This dystonia can arise in two ways:

- A serious but short-lived acute dystonic reaction
- A long-term side effect which can cause permanent dystonia, when it is known as '**tardive dystonia**'.

Drugs causing dystonia

Since the 1950's certain strong drugs have been widely used for serious mental health conditions such as schizophrenia or psychosis where they have been found in many cases to have a positive effect. These drugs may also be used for the treatment of some movement disorders such as severe chorea and tics. This family of drugs are called 'dopamine receptor blocking' drugs (DRBs) and they are by far the most common drugs causing dystonia.

On a concerning note, DRBs are not only prescribed for the treatment of psychosis, they are still in use for more common conditions such as depression and anxiety. In addition, DRBs such as metoclopramide and prochlorperazine are commonly prescribed for the treatment of nausea and vertigo. One study suggests that over 20% of patients may have been prescribed DRBs for conditions such as these where alternative treatments might have been appropriate. It is generally accepted now that there are much better and safer alternatives to treating long-term nausea, dizziness and anxiety than using DRBs.

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Acute dystonic reactions

Such reactions to DRBs usually take place within a few days of first taking the drug. Typically this dystonia affects the oromandibular (jaw area) and may cause hyperextension of the spine amongst other effects. Treatment in these cases is clinically urgent as serious consequences can result. 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 ie. newer versions that hopefully will not cause a further acute dystonic reaction. Many other drugs have been reported to cause acute dystonic reactions including antidepressants 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 dyskinesia

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

DRBs can also cause another non-dystonic movement disorder known collectively as tardive dyskinesia. The movements associated with tardive dyskinesia tend to be of the mobile 'fidgety' type in the facial area while tardive dystonia usually produces strong spasms in the axial (trunk and neck) muscles as well as arm and leg muscles.

Patients can actually have a combination of both sorts of movement disorder. There appears to be a greater likelihood of tardive dystonia in younger people, while an older age of onset is more usually associated with tardive dyskinesia.

Tardive dystonia seems to be more common in men than women (2:1) though this may just reflect the fact the schizophrenia is more common in men and generally has a younger age of onset in men than in women.

How many people are affected?

There have, as yet, only been a small number of studies of tardive dystonia in the medical literature. These point to around 1% to 2% of those taking DRBs developing either tardive dystonia or dyskinesia. However with 100,000s of people taking these drugs this can turn into a significant number. It is believed that around 6,000 people of the 40,000 people conservatively estimated to have dystonia in the UK, have tardive dystonia. Contrast this with the 25,000 people affected by cervical dystonia (neck dystonia) and the approximately 12,000 people with blepharospasm (dystonia of the eyelids).

Spontaneous remission

Unfortunately spontaneous remission from tardive dystonia is rare. In the few studies published, remission was seen in only 10% of cases during a period of seven years. The two factors that do seem to have a positive effect on remission rates are discontinuation of DRB therapy and a shorter length of exposure to DRBs. One piece of research has shown that people with exposure to the DRB drugs of less than one year were five times more likely to have a remission than those who had been exposed for more than ten years.

Causes of tardive dystonia

No one is quite sure why DRBs and other drugs cause symptoms of dystonia but currently the leading theory is that as the DRBs block dopamine transfer in the brain, this causes the brain to react and to produce more dopamine receptors so that areas controlling movement become hypersensitive to dopamine, in effect to 'overreact'. These changes seem to quickly become irreversible.

Reducing the risks

One important way in which physicians can seek to minimise the likelihood of tardive dystonia is by using the newer range of second generation DRBs. These are known as 'atypical' DRBs (in contrast to the first generation drugs known as 'typical') and have names such as olanzapine, risperidone and quetiapine.

Despite the impression that the older generation of DRBs are more likely to produce tardive dystonia, it is clear that there are no 'safe' DRBs. Even the newer 'atypical' DRBs are capable of producing the condition. However, the modern trend towards use of atypical DRBs is important in reducing the risk of incidence of drug induced movement disorders.



No one can say for certainty when and if a patient may exhibit the symptoms of dystonia but it is clear that the longer a patient takes the drugs, the higher the risks of getting symptoms. Onset is usually after drugs have been taken for a number of years but tardive dystonia has been known to start after short episodes on DRBs – even months in some cases.

Treatments for tardive dystonia

The most important 'treatment' is one of prevention by ensuring that DRBs are only used when absolutely necessary, and then for the shortest time possible. This is important because experience shows that there is a real risk of symptoms progressing if a patient stays on these drugs. It is important that any change in a patient's medication is done under the guidance of the physician as these drugs cannot just be 'stopped'. To do so may cause real difficulties for a patient.

But matters become complicated as there is increasing evidence that some patients with tardive dystonia may paradoxically actually benefit from the re-introduction of particular DRBs. Clozapine is the drug most often given in these situations. It should be noted that treatment with clozapine requires strict monitoring of blood counts on a weekly basis. It is also possible that the re-introduction of even the newer atypical DRBs may worsen the dystonia so this treatment is generally only considered when all other treatments have failed. However, in cases where DRB treatment is still needed to manage the psychosis, then clozapine or the atypical drugs are often tried.

For those with focal or segmental dystonia or with more widespread dystonia, botulinum toxin injections can be helpful.

A further line of treatment chosen by the neurologist may be to use drugs commonly used for dystonia such as the anticholinergic drugs or baclofen amongst others. There is no clear way to predict whether they will benefit an individual other than trying them and a combination of two or more agents may be necessary.

A new treatment option is appearing now: **Deep Brain Stimulation (DBS)**. This is a form of non-destructive surgery on the brain by way of inserting very fine electrodes through which a tiny current is passed to counteract the spurious signals causing the nerves to fire abnormally. Though there have as yet only been 20 – 30 cases in the medical literature of people with tardive dystonia having DBS, the results appear very encouraging with most individuals benefiting from the surgery.

Communicating with the doctor

The earlier the symptoms of tardive dystonia are identified, the more that alternative treatments can be tried and the better the prognosis for the patient. It is thus essential that the physician prescribing the DRB has a broad understanding of tardive dystonia. One difficulty arises because the physicians who really have the greatest experience and understanding of tardive

dystonia are that (small) band of neurologists with specialist expertise in movement disorders. It is important that patients see a neurologist who is movement disorder specialist. Only then can the full range of options be considered.

In the case of the consultant psychiatrists who prescribe the DRBs in psychiatric hospitals and the GPs in the community, their remit is of necessity so broad that tardive dystonia may not be understood in detail. In many instances psychiatrists do not refer patients to movement disorder neurologists who may be able to address the symptoms of tardive dystonia.

'Golden rules'

The Dystonia Society proposes some 'golden rules' for physicians to help reduce to the minimum the likelihood of tardive dystonia.

- **Prescribe well.** Prevention is the best option, so only use DRBs where really necessary and use the newer generation of 'atypical' drugs wherever possible.
- **Explain the possibility of side effects:** It is important that physicians make patients, carers and primary care professionals aware of the possibility of dystonic side effects and direct them as to what to look for.
- **Monitor carefully and regularly:** The earlier any symptoms of dystonia are detected, the earlier that alternative treatments can be considered and the greater likelihood that the symptoms may not progress and may go into remission.
- **Listen to the patient:** The patient is likely to detect signs of dystonia before anyone else. It is important that they are encouraged to report these signs and are taken seriously. The physician will need to make allowances for the state of mind of patients taking DRBs for serious conditions.
- **Don't prescribe...** Metoclopramide or Prochlorperazine as long-term treatments for nausea or dizziness. Both are DRB drugs. There are better alternatives.

What the Society may 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 also committed to ensuring that everyone with dystonia has access to the treatment they need.

Our Helpline is open Mondays to Fridays between 10am and 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.

Call our helpline on:
0845 458 6322

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.

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Dystonia caused by certain drugs

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