

understanding



tardive dyskinesia

Understanding tardive dyskinesia

This booklet explains what what tardive dyskinesia is, what causes it and what you can do to manage it. It also provides guidance on how friends and family can help.

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What is tardive dyskinesia?

Tardive dyskinesia (TD) is a medical term that describes the involuntary sudden, jerky or slow twisting movements of the face and/or body caused as an unwanted side effect of medication (mainly antipsychotic drugs).

It means:

- **tardive** – delayed or appearing late (because it's a side effect that usually doesn't appear until after you've been taking medication for a while)
- **dyskinesia** – abnormal or unusual movements

"It started with uncontrollably blinking and stretching my nose/top lip. I remember myself and my close family being quite confused as to why I was doing it!"

Experiencing signs and symptoms of TD could have an impact on your physical ability to do day-to-day activities, although it's not normally this serious. However, it can often be very distressing emotionally and feel socially disabling. For example, you may:

- feel self-conscious about movements you make
- feel upset that you can't control what your body is doing
- find it very hard or impossible to predict when you will experience symptoms

"Having TD has made me very socially anxious and shy. I am constantly aware of my twitches and I wonder if people notice and, if so, what they are thinking..."

Tardive dystonia

Tardive dystonia is a particular type of tardive dyskinesia. 'Dystonia' is a medical term that specifically describes involuntary slow, writhing movements caused by incorrect signals to your muscles from your brain. Dystonia may have a variety of causes, but when it's an unwanted side effect of medication it's referred to as 'tardive dystonia'. (For more information see The Dystonia Society website.)

"It is very scary to have pieces of your body doing their own thing and it affects your sense of self. You are no longer in control of your basic human boundaries."

What does tardive dyskinesia look like?

The main sign of tardive dyskinesia (TD) is that you will make movements which you don't normally make, and are totally out of your control.

The kinds of movements caused by TD fall into three groups:

- **Jerky movements** which are irregular (not rhythmic or repetitive) and may flow from one muscle to the next. Can include:
 - lip smacking
 - moving your mouth or jaw
 - tapping or moving your hands and feet
 - movement in your hips
 - movement in your upper body
- **Writhing or squirming movements** which are involuntary, slow and flowing. Can include:
 - wiggling or twisting your fingers, arms, legs and neck

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- **Muscle spasms** which: are out of your control; might last a short time or for longer periods; and may be painful. Can include:
 - contracting, spasming muscles
 - making grunting noises
 - having difficulty breathing
 - changes to your posture

"My leg kept flexing at the knee in quite a big gesture and I had no control of it whatsoever. I also developed a slight tremor in my hands and arms which I still have to this day."

If you have a diagnosis of schizophrenia, you may have experienced unusual movements before taking any medication, including moving your legs and arms a lot or being restless. This might make it hard to recognise or pick out the symptoms of TD.

Detecting signs of TD early is really important for reducing the possibility that TD will continue. If you have started taking antipsychotic drugs and are experiencing any of these signs you should speak to a doctor, even if the symptoms are mild, or you're not sure what they are.

"I had neck stiffness for two weeks and then developed a twitch in my right arm. This quickly developed into both arms cramping regularly. My arm would cramp and spasm and my thumb would end up touching my shoulder."

What are the causes and risks?

Tardive dyskinesia (TD) is an unwanted side effect of medication, most commonly **antipsychotic drugs**. These drugs may be part of your treatment if you have a diagnosis of psychosis, schizophrenia, bipolar disorder, or (occasionally) severe depression or anxiety.

Some other drugs used for treating physical conditions like gut problems or nausea (feeling sick) can also cause TD as a side effect. If you'd like to know more about this, you can speak to your GP or pharmacist.

"I had a year-long psychosis as a teenager [...] Treating the psychosis was utterly prioritised – the side effects [of the medication] were not properly explained to me or my family as far as I can remember."

What are the risk factors?

Anyone taking antipsychotics drugs is at risk of developing TD. All drugs affect people differently; there's no way to tell in advance whether you'll get a particular side effect or not. But the following may affect your risk:

- **Which antipsychotic you take.**
 - Older (first generation) antipsychotics are particularly associated with causing TD.
 - Newer (second generation) antipsychotics were developed with the intention of causing less severe movement problems as side effects, including Parkinsonism and TD. Although these newer drugs are less likely to cause TD than older antipsychotics, they can still cause TD – especially if you take them at high doses for a long time.
- **How long you've been taking it for.** The longer you're on medication, the greater the risk that you might develop TD.
- **What dose you're on.** The higher your dose, the greater the risk that you might develop TD.
- **Other factors.** Some research suggests that the risk might also be greater if you're:
 - an older person
 - a person of African descent

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TD is most common if:

- You've been taking a moderate to high dose of antipsychotics for periods of six months to two years or more.
- You take your medication as a depot injection (a slow-release formulation given as an injection).

TD rarely occurs if you have been taking a low dose for less than six months, although there have been a few reports of people getting TD after taking low doses for a relatively short period.

Stopping and starting antipsychotics may also contribute to the risk of TD persisting once it has developed.

(For more information about older and newer antipsychotics, side effects and what to know before starting medication, see our web pages on psychiatric medication and antipsychotics.)

"I firstly experienced finger and small muscle twitches and spasms which gradually got worse."

Parkinson's symptoms and anti-Parkinsons drugs

Antipsychotics (particularly the older drugs) can also cause other side effects that affect your movement, such as: symptoms that mimic Parkinson's disease, such as shaking, stiffness, shuffling walk and restless legs; and akathisia (extreme restlessness). If you develop either of these side effects, you are more likely to develop TD.

You are also likely to be offered anti-Parkinson's drugs to help control these symptoms. However, anti-Parkinsons drugs themselves are also associated with the development of TD. (For more information on anti-Parkinson's drugs and their side effects, see our page on anti-Parkinsons drugs, or visit Parkinson's UK.)

If you think you have developed signs and symptoms of tardive dyskinesia (TD), the most important thing you can do is to **seek help as soon as possible**. This will give you the best chance of getting rid of them.

"Thankfully I saw an understanding GP who took me off the antipsychotic and contacted my psychiatrist to change me to another more suitable medication."

Will it disappear if I come off my medication?

If you identify the signs of TD early, and stop taking the antipsychotic that's causing them, then your TD might eventually go away completely. TD symptoms do improve in about half of people who stop taking antipsychotics – although they may not improve immediately, and may take up to five years to go.

However, for some people TD may continue indefinitely, even after stopping taking medication.

It's also important to bear in mind:

- It's possible that you may only get TD when you start to come off antipsychotics, and in this case you may decide it's better to stay on your medication.
- Sometimes, withdrawal can cause involuntary muscle movements or movement disorders that look like TD, but often this will get better with time.
- The longer you have been taking a drug, the more likely you are to get withdrawal effects, and find it harder to come off. You may need to reduce your dose very gradually in order to minimise these effects.

"Over a period of a couple of years my psychiatrist made medication changes and the symptoms eventually abated. I know I run the risk of them returning as I still am on quite a lot of medication."

How do I make my decision?

If you've found an antipsychotic that helps you manage your mental health problem, you may not want to stop taking it. This can be a difficult decision – ultimately you have to choose which course of action will best help you lead your life the way you want to.

You might want to consider the following questions:

- What negative impact does TD have on you and your day to day life?
- What positive impact does your medication have on you and your day to day life?
- Do you experience other unwanted side effects from your medication as well?
- Might a lower dose of medication, which may reduce the TD symptoms, still be effective?
- How likely are you to relapse if you come off your medication entirely?

You might find it helpful to discuss these things with your health care professional. They may have suggestions to help you cope with or minimise any problems. For example, you could also consider:

- switching to a different antipsychotic, which might cause less severe side effects
- coming off anti-Parkinson's drugs (if you're taking these), as use of these is linked to developing TD
- learning self-care tips, such as those in this booklet, to look after yourself and cope with your symptoms better

Remember: **If you do decide to come off your medication, it's important to do it safely.** See our web pages on coming off medication for information about how to do this safely, and get support. Also see our web pages on antipsychotics for more details about withdrawal from these drugs.

"I gradually stepped down my antipsychotics over two months using diazepam to help with the muscle pain/ spasm and mindfulness to help focus my moods and anxiety."

Can additional drugs and treatments help?

Unfortunately, there's no typical treatment for TD. What will work, or what you want to try, will be individual to you. There is evidence that the following treatments may help you manage symptoms of TD.

On prescription

You can talk to your doctor about whether any of these could be a treatment option for you:

- **Clonazepam** (a benzodiazepine tranquilliser used in epilepsy).
- **Procyclidine** is a drug used to treat Parkinsons and dystonia. It's also used to treat movement disorders caused by antipsychotics, so your doctor may be willing to prescribe them for your TD.
- **Tetrabenazine** is a drug used to treat movement disorders (most commonly used to treat Huntingdon's disease). However, the most common side effect of this drug is depression, so you may want to think carefully before considering this option.
- **Melatonin** is a drug licensed for insomnia (being unable to sleep), but your doctor may be willing to prescribe it 'off licence' for TD as there is some evidence it can be beneficial.

Over the counter

You can buy these treatments without a prescription:

- **Vitamin E and Vitamin B6** are supplements available in most high street chemists. Take them according to the instructions on the package.
- **Ginkgo biloba** is a herbal medicine available in high street chemists and complementary medicine shops. Take it according to the instructions on the package. You might want to talk to a qualified herbalist for more information about this and other herbs.

Remember: **always talk to your doctor or pharmacist** before taking any other medications alongside your antipsychotic, including over-the-counter drugs, in case they could interact with each other badly.

"I have been on and off procyclidine (under supervision) over the years, having used it to treat the TD successfully."

"I have been prescribed clonazepam for agitation whilst unwell, which helped the TD. [This] was not the reason it was prescribed, although it was a 'happy side effect' as such."

"I was put on procyclidine [...] but this did not work."

How can I cope with the symptoms?

If you can't get rid of tardive dyskinesia (TD), there are still things you can do to help you manage the symptoms and cope with living with TD.

Look after your physical health

- **Get good sleep.** If you're not sleeping well, you might find it harder to cope with your symptoms, both physically and emotionally. (For tips on getting better sleep, see our web pages on coping with sleep problems.)
- **Eat a healthy diet.** Eating a balanced and nutritious diet can help you feel well, think clearly, and give you more energy. This can mean you feel more able to cope with your TD. (See our web pages on food and mood for more information.)
- **Exercise regularly.** Exercise is good for your general health, and if you're struggling with symptoms of TD, finding some gentle exercise you can do can help you feel more in control of your body. (See our web pages on physical activity and our Get Set to Go campaign for more information.)

*"I have never found anything to help me manage TD but as I have grown older I have found it slightly easier to cope with.
Look after your physical health"*

Focus on your wellbeing

- **Manage stress.** Experiencing stress can make it feel even more difficult to manage your symptoms. For some people, stress can make the symptoms worse. There are lots of things you can do to make sure you don't get stressed or look after yourself when you do. (See our web pages on managing stress for more information.)
- **Take time to relax.** Making time in your day to relax and focus on looking after yourself can make a big difference to how well you can cope with your symptoms. If you know that a certain activity helps you feel more relaxed – such as having a bath, listening to music or taking your dog for a walk – make sure you set aside time to do it. (See our web pages on relaxation for lots more ideas.)

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- **Try alternative treatments.** You may find that treatments such as ecotherapy and mindfulness can help you feel better able to manage your emotions, and become more able to cope with TD. You might also want to try alternative therapies such as acupuncture, aromatherapy or massage. (See our web pages on ecotherapy, mindfulness, and complementary and alternative therapy for more information.)

"My wife massaged my neck and arms after the episodes to help with the discomfort."

Seek extra support

- **Friends and family.** Having the support of friends and family can be really important in helping you manage your symptoms. The kind of support they can offer includes:
 - being able to recognise signs that your symptoms are starting or changing
 - helping you look after yourself by keeping routine or thinking about diet
 - listening and offering understanding
 - helping you with physical activities you find difficult, like carrying your shopping or helping with the housework.

"My 'gurning' has become a bit of a joke in the family and although not everyone can, I find it helps to just laugh about it! Although this doesn't help with the physical pain it helps with the anxiety TD brings."

- **Peer support.** Making connections with people with similar or shared experiences can be really helpful. You could try talking to other people who have experienced TD, take antipsychotics or have the same diagnosis as you to share your feelings find new ideas for looking after yourself. To find peer support:
 - Contact **our Infoline** or a local Mind to see what support there is in your area.
 - Try an online peer support community, such as **Elefriends**. (See our web page on finding support online for more ideas, and guidance on how to do this safely.)
 - Contact a specialist organisation (see below).
- **Specialist organisations.** You could try contacting a specialist organisation to seek support for your symptoms, or your diagnosis. You might also find this a way to connect with other people who've experienced TD. Depending on what sort of support you would find useful, you could think about contacting:
 - **The Dystonia Society.** Although dystonia is a different condition to TD, they have lots of information on coping with involuntary movements and managing movement disorders.
 - **The National Tremor Foundation** supports people experiencing all forms of tremor. Although they don't specifically cover tardive dyskinesia, if tremor-like movement problems are affecting you, you might find their information and support groups helpful.
 - **Parkinsons UK** has information on coping with movement disorders, including some types of dyskinesia and anti-Parkinsons drugs.
 - Some organisations also provide support for specific mental health problems. For example, **Bipolar UK** can help if you experience bipolar disorder, and the **Hearing Voices Network** support anyone experiencing psychosis. (Search our A-Z of mental health to find more information and useful contacts for different diagnoses.)

(See 'Useful contacts' at the back of this booklet for details of all these organisations.)

How can other people help?

This section is for friends and family who want to support someone who experiences tardive dyskinesia (TD).

If your friend or relative has recently started taking antipsychotic medication, or has developed TD, there are things you can do to help:

- **Learn more about TD and antipsychotics.** Your friend or family member could feel more supported if you understand their medication and what they're going through. You could read the rest of our web pages on TD, and take a look at our web pages on antipsychotics to get familiar with these topics.
- **Be aware of the signs and symptoms of TD.** Early detection is important to help your friend or family member have the best chance of getting rid of TD, so if you notice they're developing new symptoms it's important to gently let them know – even though you may not want to worry them or make them feel self-conscious. You could show them the section 'What does tardive dyskinesia look like?' in this booklet to help them think about their own symptoms.
- **Support and encourage your friend or family member to seek help.** You can help to reassure them that it's ok to ask for help, even if their symptoms are mild or not having a big impact on them right now.

"[My friend] encouraged me to talk to my CPN [community psychiatric nurse], offered support and reminded me to take both my medication for psychosis and also the side effect tablets. [They also] reminded me that I've got through bouts of illness before and that I would get through them again!"

- **Stay positive.** Developing TD can be really emotionally challenging, so staying calm and supportive can be really helpful if your friend and family member is feeling upset.
- **Be sensitive.** If your friend or family member is experiencing TD, they may feel very self-conscious or worried that people are looking at them. Try not to focus on their unusual movements or draw attention to them unnecessarily (unless you are helping them make sense of their symptoms, or making them aware of any changes you've noticed to support them to seek help).

"I would say show empathy each and every step. [...] General non-judgmental, positive support and understanding that you are not mad [is] a big help."

- **Help them to continue having a social life.** If your friend or family member is feeling distressed or embarrassed, they may need some encouragement to keep up social activities. Social contact is really important to our mental wellbeing, so try inviting them to take part in social events, and help them to keep up hobbies they enjoy.
- **Offer practical help.** If the symptoms are severe then TD can make some practical activities difficult (such as cooking or carrying bags and objects). You could ask your friend or family member if they need any help with these kind of tasks.
- **Look after your own wellbeing.** Supporting someone else can sometimes be tough, so it's important to make sure you take care of yourself. (See our web pages on how to cope as a carer, how to improve and maintain your wellbeing, and how to support someone else to seek help for more information.)

"There has nothing anyone has been able to do to help me manage it, but they have done a lot to help me cope."

Useful contacts

Mind

Mind Infoline: 0300 123 3393
(Monday to Friday, 9am to 6pm)
email: info@mind.org.uk

text: 86463

web: mind.org.uk

Details of local Minds, other local services and Mind's Legal Line. Language Line is available for languages other than English.

Bipolar UK

tel: 020 7931 6480

web: bipolaruk.org.uk

Support for people with bipolar disorder and their families and friends.

The Dystonia Society

tel: 0845 458 6322

web: dystonia.org.uk

Information and support for anyone experiencing dystonia (a type of tardive dyskinesia). Includes general information on how to manage movement disorders, support groups, a helpline and an online forum.

Elefriends

web: elefriends.org.uk

A supportive online community for people experiencing a mental health problem.

Hearing Voices Network

tel: 0114 271 8210

web: hearing-voices.org

Information and support for people who hear voices or experience other unshared perceptions.

The National Tremor Foundation

web: tremor.org.uk

Help, support and advice for anyone living with any form of tremor.

Parkinson's UK

tel: 0808 800 0303

web: parkinsons.org.uk

Information and support for anyone affected by Parkinson's disease and Parkinson's symptoms. Provides information on anti-Parkinson's drugs and drug-induced parkinsonism, support groups and an online community.

Further information

Mind offers a range of mental health information on:

- diagnoses
- treatments
- practical help for wellbeing
- mental health legislation
- where to get help

To read or print Mind's information booklets for free, visit mind.org.uk or contact Mind Infoline on 0300 123 3393 or at info@mind.org.uk

To buy copies of Mind's information booklets, visit mind.org.uk/shop or phone 0844 448 4448 or email publications@mind.org.uk

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Providing information costs money. We really value donations, which enable us to get our information to more people who need it.

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If you would like to support our work with a donation, please contact us on:

tel: 0300 999 1946

email: dons@mind.org.uk

web: mind.org.uk/donate

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References available on request
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web: mind.org.uk

Mind

We're Mind, the mental health charity for England and Wales. We believe no one should have to face a mental health problem alone. We're here for you. Today. Now. We're on your doorstep, on the end of a phone or online. Whether you're stressed, depressed or in crisis. We'll listen, give you advice, support and fight your corner. And we'll push for a better deal and respect for everyone experiencing a mental health problem.

Mind Infoline: 0300 123 3393 / Text: 86463
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