



Tardive dyskinesia (TD)

Explains what tardive dyskinesia is, what causes it and what you can do to manage it.

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Tardive dyskinesia: Key Facts

- TD is a possible **side effect** of [antipsychotic medication](#).
- It causes your face and/or body make **sudden, jerky or slow twisting movements** which you can't control.
- **Anyone taking antipsychotics drugs may develop TD**, but some people may be [more at risk than others](#).
- For some people TD may **continue indefinitely**, even after stopping or changing medication.
- **If you notice any [signs of TD](#)**, talk to your doctor right away. Spotting it early gives you the best chance of [managing or getting rid of it](#).
- If you live with TD, [there are lots of things you can do](#) to help yourself cope day-to-day. There's also [a lot friends and family can do](#) to support you.
- Our pages on [coping with side effects](#) and [coming off medication](#) can help you manage your choices around medication safely.

What is tardive dyskinesia?

Tardive dyskinesia (TD) is a condition where your face and/or body make sudden, jerky or slow twisting movements which you can't control. It can develop as a side effect of medication, most commonly [antipsychotic drugs](#).

- 'Tardive' means delayed or appearing late (because it usually only develops after you've been taking medication for at least a few months and sometimes years).
- 'Dyskinesia' means abnormal or unusual movements.

Awareness of TD has improved over the years, but unfortunately doctors don't always remember to tell people about this risk when they prescribe antipsychotics.

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](#) may make it hard to do day-to-day activities. It can also be very stressful or upsetting. For example, you may:

- feel self-conscious about movements caused by TD

- 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...

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 TD look like?

The main sign of tardive dyskinesia (TD) is making movements which:

- you don't normally make, and
- are totally out of your control.

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.

TD can cause:

- **Jerky movements** – irregular movements which aren't rhythmic or repetitive. For example:
 - lip smacking
 - moving your mouth or jaw
 - tapping or moving your hands or feet
 - movement in your hips
 - movement in your upper body
 - blinking your eyes a lot.
- **Slow movements** – movements which are slow and flowing, including writhing or squirming. For example:
 - wiggling or twisting your fingers, arms, legs, neck or tongue.
- **Muscle spasms** (also called **tardive dystonia**) – movements where your muscles suddenly tighten, which might last a short time or for longer periods. For example:
 - making grunting noises
 - having difficulty breathing
 - changes to your posture.

The [Dystonia Society website](#) has more information on [tardive dystonia](#).

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.

It made me feel stupid and very depressed. It was funny sometimes, however it soon became painful. I didn't want to go outside as I felt embarrassed.

Noticing signs of TD early can be really important for reducing the chance of it continuing. If you are taking [antipsychotic drugs](#) and are experiencing any of these signs, it's important to speak to a doctor as soon as possible – even if the symptoms seem mild, or you're not sure what they are.

What causes TD?

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](#)
- severe [depression](#) or [anxiety](#) (though this is less common).

Some other drugs used for treating physical conditions can also cause TD as a side effect.

If you're taking any medication and think you might be experiencing TD, it's important to **speak to a doctor or pharmacist for advice**. To speak to someone right away you can contact NHS 111 (in England) or NHS Direct (in Wales).

You can also report side effects to the Medicines and Healthcare Products Regulatory Agency (MHRA) via their [Yellow Card Scheme](#).

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, so it's not possible to tell whether you'll get a particular side effect or not. But the risks may depend on:

- **Which antipsychotic you take:** older (first generation) antipsychotics are particularly associated with causing TD. Newer (second generation) antipsychotics were developed with the aim of reducing side effects like TD, but can still cause it – these newer drugs are thought to be less likely to cause TD, but the difference is still unclear.
- **How long you've been taking it.** The longer you're on medication, the greater the risk that you might develop TD.
- **What dose you're on.** Taking a higher dose increases the risk that you might develop TD.
- **Other factors.** Some research suggests that the risk might also be greater if you're aged over 50 or of African descent.

TD is thought to be particularly common if:

- You've been taking a moderate to high dose of antipsychotics for six months or more.
- You take your medication as a [depot injection](#) (a slow-release, slow-acting form given as an injection).

Stopping and starting antipsychotics can also increase the risk of TD continuing once you have it – so it's very important to talk to a doctor before [deciding to come off medication](#). It's also possible to develop tardive dyskinesia during or after you stop taking medication.

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

If you don't feel your doctor fully informed you about the risk of side effects before prescribing you medication, it's understandable to feel frustrated or angry. Our legal pages on [complaining about health and social care](#) have some information on how you can challenge your healthcare team.

Parkinson's symptoms and anti-Parkinson's drugs

Antipsychotics (particularly older, first-generation ones) 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
- akathisia (extreme restlessness).

If you develop either of these side effects, you may be more likely to develop TD. You are also likely to be offered anti-Parkinson's drugs to help control these symptoms. However, **anti-Parkinson's drugs themselves are also associated with the development of TD.**

You should only be offered anti-Parkinson's drugs if you've already developed Parkinsonism as a side effect of your antipsychotic medication, and the symptoms are very troublesome.

(For more information on anti-Parkinson's drugs and their side effects, see our page on [anti-Parkinson's drugs](#), or visit [Parkinson's UK](#).)

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

Can I get rid of TD?

There's no typical or guaranteed treatment for TD – what will work, or what you want to try, will be individual to you. This page covers:

- [Will TD disappear if I come off medication?](#)
- [Can additional drugs and treatments help?](#)

If you think you might be experiencing [signs and symptoms of tardive dyskinesia \(TD\)](#), it's really important to **seek help as soon as possible**. This will give you the best chance of getting rid of them.

But even if you continue having TD symptoms, there are still lots of [things you can do to help yourself cope](#).

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 TD disappear if I come off my medication?

If you identify the signs of TD early and are able to stop or change your medication, it might eventually go away completely. TD symptoms do improve in about half of people who stop taking antipsychotics – although they might not improve right away, and may take up to five years to go.

However, for some people **TD may continue indefinitely**, even after stopping or changing 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 to stay on your medication.
- Sometimes, **withdrawal can cause involuntary muscle movements or movement disorders** that look like TD, but this often gets 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. (Our pages on [coming off medication](#) have more information.)

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.

Deciding whether to come off medication

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, especially if you're unsure what will best help you in the long run.

Here are some questions you might want to think about:

- How does TD affect you and your day to day life?
- How does your medication help you and your day to day life?
- Do you experience other unwanted side effects from your medication as well?
- How likely are you to relapse if you come off your medication entirely?

It's important to talk these over with your health care professional. They may have suggestions to help you cope with or minimise any problems. For example, you might consider:

- switching to a different antipsychotic, which might cause less severe side effects
- coming off [anti-Parkinson's drugs](#) (if you're taking these), which may reduce the risk of getting TD
- [learning self-care tips](#) to help you cope with your symptoms

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.

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

Can additional drugs and treatments help?

Evidence suggests that the following treatments could help you manage symptoms of TD.

On prescription

You could ask your doctor if any of these could be a treatment option for you:

- **Clonazepam** – a [benzodiazepine tranquilliser](#) used in epilepsy.
- **Tetrabenazine** – a drug used to treat movement disorders (most commonly Huntington'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** – a drug licensed for insomnia (being unable to sleep). Your doctor may be willing to prescribe this 'off label' for TD as some evidence suggests it can be beneficial.

Over the counter

Studies suggest that some supplements or herbal medicines which can be bought over the counter (without a prescription) may help with TD, although more research is needed to be sure.

These include:

- **Vitamin E** – a supplement that may help prevent TD, but isn't thought to help if you already have TD.
- **Vitamin B6** – a supplement that might help with TD.
- **Ginkgo biloba** – a herbal medicine that might help with TD.

It's important to **talk to a doctor or pharmacist** before taking any new medications, including over-the-counter drugs, as some drugs could interact with each other badly. It's also important to always follow the instructions on the packet.

(See our page on herbal remedies for more information.)

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.

How can I cope with TD?

Living with tardive dyskinesia (TD) can be really difficult. But even if you can't [get rid of TD](#), there are still things that could help you manage the symptoms and cope day-to-day. This page has some suggestions for you to consider:

- [look after your physical health](#)
- [focus on your wellbeing](#)
- [build your support network](#)
- [find specialist support](#)

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

- **Try to get enough sleep.** Sleep can give you the energy to cope with difficult feelings and experiences. (See our page on [coping with sleep problems](#) for more information.)
- **Think about your diet.** Eating regularly and keeping your blood sugar stable can make a difference to your mood and energy levels. This can mean you feel more able to cope with TD. If your symptoms affect your ability to eat, it might help to focus on the types of foods you're more able to swallow. (See our page on [food and mood](#) for more information.)
- **Spend time in green space.** Being outside or doing activities in green space can reduce stress and improve your wellbeing. (See our pages on [nature and mental health](#) for more information.)
- **Try to do some physical activity.** Exercise can be really helpful for your mental wellbeing. (See our pages on [physical activity](#) for more information.)

Focus on your wellbeing

- **Learn ways to manage stress.** Living with TD can be really stressful – and feeling stressed can make it feel more difficult to manage your symptoms. There are lots of things that could help you cope with feeling stressed. (See our pages on [managing stress](#) for more information.)
- **Try relaxation techniques.** Relaxation can help you look after your wellbeing when you are feeling stressed. 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 pages on [relaxation](#) for lots more ideas.)

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

Build your support network

- **Talk to someone you trust.** It could help to share your worries, and they might be able to help recognise signs that your symptoms are starting or changing, or help with physical activities you find difficult (like carrying shopping or doing housework).
- **Try peer support.** Peer support brings together people who've had similar experiences to support each other. For example, you could try talking to people who have also experienced TD or have taken the same medication. (Our pages on [peer support](#) have more information.)

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.

Find specialist support

You could try contacting a specialist organisation for 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. While they don't specifically cover tardive dyskinesia, you might find their information and support groups helpful if you're affected by tremor-like movement problems.
- [Parkinsons UK](#) has information on coping with movement disorders, including some types of dyskinesia and anti-Parkinson's 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](#) supports anyone experiencing [psychosis](#). (Search our [A-Z of mental health](#) to find more information and useful contacts for different diagnoses.)

How can other people help?

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

It can be really worrying if your friend or relative has tardive dyskinesia (TD), or they've started taking [antipsychotic medication](#) and you're worried they might develop it in the future. But there are lots of things you can do that might help:

- **Learn more about TD and antipsychotics.** It might feel helpful to understand more about their medication and what they're going through – and this could also make your friend or family member feel more supported. You could start by reading [the rest of our pages on TD](#), and take a look at our pages on [antipsychotics](#) for more information.
- **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 our page on [signs and symptoms of TD](#) to help start the conversation.
- **Support and encourage your friend or family member to seek help.** It might 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. (For more information, see our page on [supporting someone else to seek help](#).)

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!

- **Try not to judge them.** It can be really difficult watching someone you love develop TD, but it's important to remember that they aren't choosing to have these symptoms and may not realise when they're happening. Trying to stay calm and supportive can be really helpful if your friend or 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. You could try asking them what sorts of activities they'd like to do, inviting them to family or social events, or helping them to keep up with hobbies they enjoy.
- **Offer practical help.** TD can make some practical activities difficult (such as cooking, carrying bags and objects, or keeping up with housework). You could ask your friend or family member if they need any help with these kind of tasks.
- **Look after yourself.** Supporting someone else can be difficult, so it's important to take care of yourself too. (See our pages on [how to cope when supporting someone else](#), [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's services

- **Helplines** – all our helplines provide information and support by phone and email. Our Blue Light Infoline is just for emergency service staff, volunteers and their families.
 - Mind's Infoline – 0300 123 3393, info@mind
 - Mind's Legal Line – 0300 466 6463, legal@mind
 - Blue Light Infoline – 0300 303 5999, bluelightinfo@mind
- **Local Minds** – there are over 140 local Minds across England and Wales which provide services such as [talking treatments](#), [peer support](#), and [advocacy](#). [Find your local Mind here](#), and contact them directly to see how they can help.
- **Elefriends** is a supportive online community for anyone experiencing a mental health problem. See our [Elefriends page](#) for details.

Who else could help?

Bipolar UK

bipolaruk.org.uk

0333 323 3880

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

The Dystonia Society

dystonia.org.uk

020 7793 3650

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.

Hearing Voices Network

hearing-voices.org

0114 271 8210

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

Medicines and Healthcare Products Regulatory Agency (MHRA)

mhra.gov.uk

Information about herbal medicines registration and registered products.

Visit yellowcard.mhra.gov.uk to report side effects and withdrawal effects.

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References are available on request.