



# Tardive dyskinesia (TD)

Find information on what tardive dyskinesia is, what causes it and what you can do to manage it.

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# About tardive dyskinesia

This page covers:

- [What is tardive dyskinesia?](#)
- [Tardive dyskinesia as a side effect](#)
- [Finding help and support](#)

## What is tardive dyskinesia?

Tardive dyskinesia (TD) is a condition where your face, body or both make sudden, irregular movements which you cannot control. It can develop as a side effect of medication, most commonly [antipsychotic drugs](#).

- **Tardive** means delayed or appearing late – TD usually develops after you've been taking medication for a few months, or sometimes years.
- **Dyskinesia** means 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](#) can 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
- upset that you cannot control what your body is doing
- uncomfortable and restless
- tired or worn out if the movements happen a lot
- angry, particularly if you didn't know about TD as a side effect of medication
- that it's very hard or impossible to predict when you'll 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 dyskinesia as a side effect

Awareness of TD has improved, but unfortunately doctors don't always remember to tell people about this risk when prescribing antipsychotics. Doctors don't always have to tell you about every side effect. These are listed in the patient information leaflet (PIL) you get with medication too.

If your health condition is severe, your doctor may also think that the treatment is necessary, no matter the side effect. There are some situations where you can also be given [medication without your consent](#).

### Can I make a complaint if I get tardive dyskinesia?

If you begin to develop TD and your doctor does nothing about it, or doesn't spot the signs, this may be considered [clinical negligence](#). This means a healthcare professional has failed in their duty to take care of you, and you experienced damage or loss as a result of that failure.

For more information about complaints, see our page on [complaining about healthcare](#). You can also contact the [Patient Advice and Liaison Service \(PALS\)](#). This NHS service gives confidential, impartial advice on problems experienced in NHS healthcare.

For more information about what your doctor should do before giving you medication, see our page on [psychiatric medication](#).

**"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."**

### Finding help and support

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 England](#) by calling [111](#)
- [NHS Wales](#) by calling [111](#), or [0845 46 47](#) for the Cardiff and Vale area (calls cost 2p per minute).

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

# Tardive dyskinesia signs and symptoms

This page covers:

- [What are the signs of tardive dyskinesia?](#)
- [What symptoms can tardive dyskinesia cause?](#)
- [Similar conditions and diagnoses](#)

## What are the signs of tardive dyskinesia?

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

- you do not normally make
- are totally out of your control.

Normally, the first sign of TD is irregular tongue movements. These might be very small and you might not even notice them at first.

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

## What symptoms can tardive dyskinesia cause?

Some people have mild symptoms that they hardly notice, while others might find symptoms severely impact their day-to-day life. How much the symptoms of TD affect you can change over time. It may cause the following symptoms in your face or body, or both.

### Jerky movements

These are irregular movements which are not rhythmic. For example:

- lip smacking
- moving your mouth, jaw or tongue
- tapping or moving your hands or feet
- movement in your hips
- movement in your upper body
- blinking your eyes a lot

- puffing out your cheeks
- making noises or facial expressions you cannot control.

## Slow movements

These are slow and flowing movements. For example:

- writhing or squirming
- wiggling or twisting your fingers, arms, legs, neck or tongue.

## Muscle spasms

These are movements where your muscles suddenly tighten. They might last for a short time or longer periods. For example:

- making grunting noises
- having difficulty breathing or swallowing
- changes to your posture.

You might also hear this called **tardive dystonia**. For more information, you can visit the [Dystonia Society website](#).

**"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."**

It's really important to notice signs and symptoms early, as this can reduce the chance of TD becoming more severe. If you're taking antipsychotic drugs and experiencing any of these signs, speak to a doctor as soon as possible – even if the symptoms seem mild, or you're not sure what they are.

## Similar conditions and diagnoses

The symptoms of TD are similar to some other physical health conditions that can develop in adults. It's important to rule out these conditions so you can get the right treatment. These conditions include:

- [Huntington's Disease](#)
- [Parkinson's Disease](#)
- [Tourette's Syndrome](#).

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

# Causes of tardive dyskinesia

This page covers:

- [What causes tardive dyskinesia?](#)
- [Risk factors in developing tardive dyskinesia](#)

## What causes tardive dyskinesia?

Tardive dyskinesia (TD) is a side effect of medication, most commonly from [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
- severe nausea, vomiting or migraines, though this is less common.

TD can also be a side effect of other drugs used for treating physical conditions.

It is thought that TD develops because of the way these medications change levels of the chemical [dopamine in your brain](#).

## Risk factors in developing tardive dyskinesia

Anyone taking antipsychotic drugs is at risk of developing TD. It's listed as a common or very common side effect for antipsychotic medication. All drugs affect people differently, so it's not possible to tell whether you will get a particular side effect. But the main risk factors are:

- **How long you have been taking antipsychotic medication.** The longer you are on medication, the greater the risk that you might develop TD.
- **What dose you are on.** Taking a higher dose makes developing TD more likely.
- **Which antipsychotic you take.** Older antipsychotics – known as [first-generation](#) – are particularly associated with causing TD. Newer antipsychotics – known as [second-generation](#) – were developed with the aim of reducing side effects like TD, but can still cause it. Although medical professionals think newer drugs are less likely to cause TD, the difference is still unclear.

Once you have TD, stopping and starting antipsychotics can also increase the risk of it becoming more severe. It's very important to talk to a doctor before [deciding to come off medication](#). It is also possible to develop TD after you stop taking medication.

Some research suggests that you may be more likely to develop TD if you:

- are over the age of 50

- are female
- are post-menopause
- are Black
- have a drug or alcohol addiction
- have diabetes
- have a learning disability
- have a brain injury.

The risk may be greater if more than one of these applies to you.

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

## Parkinson's symptoms and drugs

Antipsychotics – particularly older, first-generation ones – can also cause other side effects that affect your movement. For example:

- symptoms that mimic Parkinson's disease, such as **shaking, stiffness, slow movements** and **restless legs** – also called Parkinsonism
- **akathisia**, which means extreme restlessness.

If you develop either of these side effects, you may be more likely to develop TD. You're 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 have already developed Parkinsonism as a side effect of your antipsychotic medication
- 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](#).



# Treating and managing tardive dyskinesia

This page covers:

- [Changing or coming off your medication](#)
- [Additional drugs and treatments for tardive dyskinesia](#)
- [Managing your day-to-day tasks](#)

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 reducing its impact on your day-to-day life.

## Changing or coming off your medication

As antipsychotic medication is one of the main [causes of TD](#), making changes or coming off this medication can help some people. Different things work for different people, so coming off medication entirely might not be an option for everyone. What will work, or what you want to try, is completely up to you.

### Changing 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 feel unsure about what will help you the most in the long term.

Before you decide to stop taking medication, you and your healthcare professional may consider changing medication instead. You might be able to:

- take a lower dose of medication
- change your medication, particularly from a [first-generation](#) to a [second-generation](#) antipsychotic.

Your doctor should then monitor how you're getting on and whether any changes are regularly affecting you.

There is no single medication that works best for everyone – we all respond to them differently. It might take some trial and error to find out what medication works best for you.

**"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."**

## **Coming off medication**

If you identify the signs of TD early and are able to stop or change your medication, it might eventually go away completely. However, this doesn't happen for everyone and could take a long time. For some people, TD may never go away, even after stopping or changing medication.

It's also important to remember:

- It's possible that you may only **get TD when you start to come off antipsychotics**. 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've been taking a drug, the more likely you are to feel withdrawal** effects, and find it harder to come off. You may need to reduce your dose very gradually to minimise these effects. For more information, see our pages on [coming off medication](#).

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

## **Deciding whether to come off medication**

If changing your medication doesn't work for you, you might consider coming off medication altogether.

You might want to think about these questions before doing this:

- 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 as TD?
- How likely are you to [relapse](#) if you come off your medication entirely?

Talk these over with your healthcare professional. They may have suggestions to help you cope with or minimise problems. For example:

- coming off [anti-Parkinson's drugs](#) may reduce the risk of getting TD, if you're taking these in the first place
- [learning self-care tips](#) to help you better 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 is important to do it safely. For information on how to do this and where to get support, see our pages on [coming off medication](#). For more details about withdrawal from these drugs, see our pages on [antipsychotics](#).

## Additional drugs and treatments for tardive dyskinesia

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

### Drugs on prescription

In the UK, there are not many approved treatments for TD. But trials are being carried out on certain medications that already have approval in other countries.

At the moment, the only drug licensed for treating TD is **Tetrabenazine**. It's a drug used to treat movement disorders. However, common side effects of this drug include [Parkinsonism](#), [anxiety](#) and [depression](#), so you may want to think carefully before considering this option.

### Medical procedures

Some researchers are looking into treating TD through the use of:

- [Deep Brain Stimulation \(DBS\)](#)
- **botulinum toxin**, which is also called Botox.

However, studies have not yet been able to confirm if these treatments are safe for TD, or whether they work. DBS is sometimes used to [treat symptoms of Parkinson's](#), and Botox for symptoms of [dystonia](#).

## Over-the-counter supplements

Studies suggest that some supplements or herbal medicines which you can buy over the counter – meaning without a prescription – may help with TD. However, more research is needed to be sure.

Some of these supplements include:

- **Vitamin E** – a supplement that may help to stop TD from getting worse, but has not been shown to stop the condition entirely.
- **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 medication**. This includes over-the-counter drugs, as some drugs could interact badly with each other. It's also important to always follow the instructions on the packet or patient information leaflet.

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

## Managing your day-to-day tasks

Changing medication or getting other treatments might not work for everyone. Sometimes, it means that TD may be a condition you have to learn to live with.

Some people with TD find that it impacts their life significantly, but others might not. Some symptoms might impact your ability to:

- eat, drink or prepare food easily
- carry items
- write with a pen, pencil, or use a smartphone
- get around by yourself – if you normally drive, you might need to tell the DVLA if you're no longer [fit to drive](#).

If your symptoms are having this kind of impact on your life, your TD might be considered a disability under the [Equality Act 2010](#). This means you may be eligible for additional help, such as:

- **a blue badge** if you drive – for more information on this, visit the [Parkinson's UK website](#)
- **grants or loans** to make your home accessible
- **benefits** to help with your financial needs
- **reasonable adjustments** at work, in education, or when using services – for more information on what you might be eligible for, see our legal page on [reasonable adjustments](#).

**"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."**

### **Disability discrimination**

Some people experience discrimination due to TD. This can include being treated differently in situations such as:

- job interviews
- the workplace
- being a customer in a restaurant or shop.

This kind of discrimination is unlawful under the [Equality Act 2010](#). For more information, see our pages on [discrimination](#).

# Coping with tardive dyskinesia

Living with tardive dyskinesia (TD) can be really difficult. But even if you experience it for a long time, there are still things that could help you manage symptoms and cope day-to-day.

This page covers some self-care suggestions for you to consider:

- [Try to reduce stress](#)
- [Build your support network](#)
- [Look after your physical health](#)
- [Adapt activities and tasks](#)
- [Find specialist support](#)

Everyone experiences TD differently – not all of these suggestions will help everyone. What's important is finding what works best for you.

## Try to reduce stress

Many people with TD find that symptoms are worse or more difficult to manage in times of stress. Stress can sometimes be unavoidable, but it may help to find ways to manage stress when possible.

For more information on what you might find helpful, see our pages on [how to manage stress](#). You might also find it useful to read our information on [relaxation techniques](#).

## Build your support network

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

**"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."**

## Look after your physical health

Looking after your physical health can [reduce stress](#). As well as this, some people find it can also make TD easier to manage. Try to:

- get enough [sleep](#)
- do some [physical activity](#)
- spend time in [nature](#).

These factors can all help your physical health. They are also beneficial to your mental health in general.

For more information on looking after your physical health, see our information on [everyday living](#).

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

## Adapt activities and tasks

Some people with TD find that the symptoms make certain tasks very difficult to manage. To help with this, adaptations for activities and tasks can include:

- **Planning ahead** for activities that you might need more time to do, or need someone to help you with.
- **Getting specialist tools** for eating, drinking and cooking. A list of equipment that some people find useful is available on the [Parkinson's UK website](#).
- **Trying voice activation and dictation** if you have a smartphone or tablet. These features allow you to use your device without needing to press buttons on the screen.
- **Using pens or pencils with a thick or padded grip**, which can be really helpful when writing.
- **Taking a trolley when shopping**, or considering shopping online and getting it delivered, if available.
- **Talking to your bank** about ways you can make signatures easier if you find writing difficult. This could include using photo ID, changing your signature, or using telephone and online banking.
- **Swapping to electrical appliances** such as an electric razor for shaving, or an electric toothbrush for cleaning your teeth.
- **Ordering food that is easier to eat** when going out for a meal, such as foods that do not need to be cut up.

The National Tremor Foundation website offers a longer list of [tips for everyday living](#).

For more suggestions on adapting tasks to make them easier, see [Parkinson's UK](#) and the [National Tremor Foundation](#).

Some of these suggestions involve purchasing equipment. If your TD is considered a [disability](#), you may be able to get grants or [benefits](#) to help with the costs. For more information, see our pages on [money and mental health](#).

**"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."**

## Find specialist support

You could try contacting a specialist organisation for support for your symptoms, or your diagnosis. You might also find it useful to connect with others who have experienced TD.

Depending on what sort of support you find useful, you could contact:

- [The Dystonia Society](#). Although dystonia is a different condition to TD, they have lots of information on coping with involuntary movements.
- [The National Tremor Foundation](#) supports people experiencing all forms of tremor, but doesn't specifically cover tardive dyskinesia. You might find their information and support groups helpful if you are affected by tremor-like movement problems.
- [Parkinson's 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](#). The [Hearing Voices Network](#) supports anyone experiencing [psychosis](#). For more information and useful contacts for different diagnoses, search our [A-Z of mental health](#).

For more information, see our page on [useful contacts for TD](#).



# Supporting someone with tardive dyskinesia

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

This page covers:

- [Practical tips for you](#)
- [Supporting their wellbeing](#)

It can be really worrying if your friend or relative has tardive dyskinesia (TD). Or maybe 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.

## Practical tips for you

You can try to:

- **Learn more about TD and antipsychotics.** It might feel helpful to understand more about their medication and what they're going through. This could also make your friend or family member feel more supported. You could start by reading through all our [information about TD](#) and our pages on [antipsychotics](#).
- **Be aware of the signs and symptoms of TD.** Early detection is important to help your friend or family member [manage TD](#). 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. To help start the conversation, you could show them our page on the [signs and symptoms of TD](#).
- **Offer them practical help.** TD can make some practical activities difficult, such as cooking, carrying things, or keeping up with housework. You could ask your friend or family member if they need any help with these kinds of tasks.
- **Look after yourself.** Supporting someone else can be difficult, so it's important to take care of yourself too. For more information, see our pages on [how to cope when supporting someone else](#), [how to improve and maintain your wellbeing](#), and [supporting someone else to seek help](#).

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

## Supporting their wellbeing

To better support your friend or family member, you could try the following ideas:

- **Support and encourage them to seek help.** It might help to reassure them that it's OK to ask for help. This is true even when 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 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. They may not realise when they are happening. Try to stay calm and supportive – this can be really helpful if your friend or family member is feeling upset.
- **Help them to continue having a social life.** If your friend or family member is feeling distressed or embarrassed, they may need encouragement to keep up with 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 pursue hobbies they enjoy.
- **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 symptoms or draw unnecessary attention to them. The exceptions are helping them make sense of their symptoms, or making them aware of any changes you've noticed.

**"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."**

# Useful contacts for tardive dyskinesia

## Mind's services

- [Mind's helplines](#) provide information and support by phone and email.
- [Local Minds](#) offer face-to-face services across England and Wales. These services include talking therapies, peer support and advocacy.
- [Side by Side](#) is Mind's support online community for anyone experiencing a mental health problem.

## Other organisations for tardive dyskinesia

### Bipolar UK

[bipolaruk.org](http://bipolaruk.org)

Information and support for people affected by bipolar disorder, hypomania and mania. Offers telephone and online peer support services

### The Dystonia Society

[dystonia.org.uk](http://dystonia.org.uk)

Information and support for anyone experiencing dystonia (a type of tardive dyskinesia). Includes a helpline, online forum and support groups.

### Hearing Voices Network

[hearing-voices.org](http://hearing-voices.org)

Information and support for people who hear voices or have other unshared perceptions, including local support groups.

### Medicines and Healthcare Products Regulatory Agency (MHRA)

[mhra.gov.uk](http://mhra.gov.uk)

Regulates medicines in the UK and runs the Yellow Card scheme for reporting side effects.

## The National Tremor Foundation

[tremor.org.uk](https://tremor.org.uk)

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

## NHS 111 (England)

[111](https://111.nhs.uk)

[111.nhs.uk](https://111.nhs.uk)

Non-emergency medical help and advice for people in England.

## NHS 111 (Wales)

[111](https://111.wales.nhs.uk) (Hywel Dda, Powys, Aneurin Bevan and Swansea Bay (including Brigid) Health Boards)

[0845 46 47](https://08454647.nhs.uk) (all other areas of Wales)

[111.wales.nhs.uk](https://111.wales.nhs.uk)

Non-emergency medical help and advice for people living in Wales. The contact number for this service differs depending on which area of Wales you are in.

## Parkinson's UK

[0808 800 0303](https://08088000303.parkinsons.org.uk)

[parkinsons.org.uk](https://parkinsons.org.uk)

Information and support for anyone affected by Parkinson's disease and Parkinson's symptoms, including support groups and an online community.

## Patient Advice and Liaison Services (PALS)

[nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service](https://nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service)

Offers confidential advice, support and information on health-related matters. You can find services by [searching on NHS UK](#) or asking a doctor or healthcare professional for their details.

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References are available on request.