# Tics and Tourette's syndrome

Understanding Treatment Options



#### What are tics?

Tics are unexpected twitches, movements or sounds that happen often and are hard to control. They can happen many times each day, and could happen every day.

There are two different kinds of tics:

- motor tics, which are movements you can't control
- vocal tics, which are words or sounds you can't control

Certain things can make tics more likely to happen. For example, some people find that their mood affects their tics (e.g. that their tics happen more if they are anxious, excited or tired), while others find that tics happen more often in certain places (e.g. happening more often at home than at school) and many people with tics experience them more often if people notice and focus on them.

Tics are quite common and often start at around age five. Many people find that their tics improve over time and don't need treatment, but they can get in the way of everyday activities.

# What is Tourette's syndrome?

Tourette's syndrome affects the nervous system and this can cause people to have tics. Tourette's syndrome can run in families. It usually starts when children are young and is often noticed by about 7 years old. As you get older, you might start to be able to control your tics and sometimes they can stop entirely as you become an adult.

# How can I get help?

Often tics only last a few months and most children and young people who experience tics do not have Tourette's syndrome. However, if your tics don't stop on their own then you should talk to your GP.

Your GP will be able to give you advice on whether you need more specialist help. If they think that you could have Tourette's syndrome then they might refer you to a specialist. They will try to understand whether your tics could be part of Tourette's syndrome or a symptom of another health condition, or whether they are unrelated to either of these. They will also ask about the impact of your tics on your everyday life (including at school, with your family and your friendships).

If you have Tourette's syndrome and need support with another mental or physical health condition then you could be referred to CAMHS or child health services depending on the specific problem.

#### Planning treatment

Tics often do not need any treatment. If you do have treatment, this will not cure the tics but can make them less frequent or more manageable. It's also important to remember that tics can come and go, which can make it difficult to tell whether a treatment is helpful.

If you need treatment, then your options will depend on how the tics are affecting you and whether you have any other mental or physical health conditions.

Treatment options for tics are similar whether or not they are part of Tourette's syndrome. These options include:

- **Psychoeducation**, which everyone should be offered after being diagnosed with Tourette's syndrome
- Behavioural therapies, which are usually suggested as a first treatment option
- Medication, which is usually suggested as a second treatment option

#### Other treatments include:

- botulinum toxin injections for tics in a particular area of the body
- surgery for severe tics that have not improved after other treatments, but this is usually only for adults

# **Psychoeducation**



# Strong evidence

Psychoeducation usually involves both you and your family. Your professional will give you information about what tics are, what causes them and what can help (including self-help strategies).

If your tics happen at school (especially if they are causing problems at school) then it can be helpful for you and your parents or carers to talk about some of this information with your teachers.

Sometimes it can also be helpful for you and your parents or carers to explain to other people who you see regularly that you have tics and anything that might help you. For example, it can be helpful to tell people to ignore the tics and not focus on them when they happen.

# Behavioural therapies



# Strong evidence

Behavioural therapies are usually provided by a psychologist or a specially trained therapist. They all start with psychoeducation and aim to teach you ways to control your tics.

There are several different types of behavioural therapy which can help to reduce tics:

- Habit reversal training (HRT), which involves working out the feelings and situations that trigger your tics and noticing when you have an urge to tic. Your professional will then help you to find an alternative, less noticeable way of relieving the urge to tic.
- Exposure with response prevention (ERP), which aims to help you control your urge to tic by recreating the urge to tic and then training you to tolerate the feeling (without doing the tic) until the urge passes.
- Comprehensive behavioural intervention for tics (CBIT), which involves parts of both HRT and ERP in addition to a functional analysis. A functional analysis aims to identify anything in your life that makes your tics worse. Your professional will also help you to understand what tends to happen before and after your tics and any activities you do to reduce the tics in particular situations, to help you to anticipate and control your tics.

As behavioural therapies are often effective and can help you to feel more in control, they are usually recommended as a first treatment option. They also don't have the side-effects that people can experience when taking medication. Behavioural therapies might not be available in your local area, so your professional might suggest online versions of these treatments.

#### Medication



# Strong evidence

Your professional might offer you medication as a second treatment option if behavioural therapy wasn't available, you didn't want to try behavioural therapies or you didn't find behavioural therapy helpful.

Medication won't completely stop all your tics, but can help your tics to happen less frequently or be less intense. It can be difficult to tell whether medication is helping because tics can come and go, so it's not always clear why you might be experiencing fewer tics.

If you start taking medication then your professional should suggest that you start taking a low dose and keep track of both how well the medication is working and any side effects.

There are two types of medication that are usually used to help with Tourette's syndrome:

- Antipsychotic medication
- Noradrenergic medication

#### Antipsychotic medication

There are several different types of antipsychotic medications used to manage tics in Tourette's syndrome. They are called antipsychotic medications because they were developed to treat psychosis, but they can be helpful for Tourette's syndrome too. Your professional is most likely to offer you a medication called aripiprazole, but in some circumstances they might suggest that you take a different type of antipsychotic medication.

#### Noradrenergic medication

Clonidine and guanfacine are types of noradrenergic medications (which means they act on a chemical messenger in the body called noradrenaline). They were originally developed as blood pressure medication but are also effective for ADHD and to treat tics.

Research has shown that noradrenergic medications can be as effective as antipsychotic medication to reduce tics for some children and young people. These medications do still have side effects including feeling drowsy, headaches and a drop in blood pressure. Because of this, your blood pressure will need to be monitored while you take noradrenergic medication and your professional will explain that stopping taking the medication suddenly can cause a rise in blood pressure.

#### What type of medication will I be prescribed?

Choosing the right medication will be different for each person because Tourette's syndrome can involve a wide range and severity of symptoms. Any other mental or physical health conditions that you might have (such as ADHD, obsessive compulsive disorder or depression) can also affect which medication might work best for you.

Your professional will work with you to decide whether taking medication is the best option for you. This might depend on:

- the severity of your tics
- how much distress they cause you
- how much they interfere with your life

- whether the medication would help with your tics or another mental health condition such as ADHD or OCD
- whether you might need a combination of medications to treat your different symptoms.

If you decide to take medication then your professional is most likely to suggest an antipsychotic medication called aripiprazole. However, if you also have ADHD then your professional might recommend guanfacine or clonidine instead.

If you don't find aripiprazole helpful or you can't take it then your professional might suggest another type of medication. This might be another type of antipsychotic medication such as risperidone or a noradrenergic drug such as guanfacine or clonidine.

You might need to try several different medications before you find one that suits you. As tics can naturally come and go, it can be hard to figure out which type of medication has worked best. To help with this, it can be useful to keep a diary of how you feel while taking each type and dose of medication. This means that you can look back and work out which medication worked best for you with the fewest side-effects.

Occasionally, your professional might suggest that you try a combination of medications. For example, your professional might recommend this option if your tics are very severe, they are causing you problems in everyday life and single medications haven't helped very much.

### Exercise



# Emerging evidence

There is some research evidence that exercise can help with symptoms of Tourette's syndrome as well as anxiety and mood. Exercise is also important for good general health. Some people with Tourette's syndrome find that exercise improves their tics, although other people experience the opposite.

#### Botulinum toxin



# Insufficient evidence

Botulinum toxin is a chemical which is injected and causes temporary muscle paralysis. There is some evidence that botulinum toxin injections can help with persistent and well-localized motor and, sometimes, vocal tics by temporarily weakening the specific muscles involved. The effect of the injection usually lasts 3 to 4 months, but can last up to 6 months. Some people also experience reactions including temporary soreness and mild muscle weakness.

This treatment can only be offered by a neurologist who specialises in treatment with botulinum toxin. It is not usually offered as a treatment for tics in Tourette's syndrome and would not be suggested for young children.

# Relaxation training



# 🕜 Insufficient evidence

Relaxation training involves learning techniques that can help you feel calmer and more aware of your body, such as deep breathing exercises and muscle relaxation techniques.

There isn't much evidence to suggest that relaxation training can help with Tourette's syndrome.

# Dietary interventions



# 🕜 Insufficient evidence

There is no evidence that specific diets or supplements help with Tourette's syndrome, although many people notice that their tics get worse when they eat foods that contain additives, artificial colourings or high levels of sugar.

A healthy balanced diet is good for your general health. It's also important to let your doctor know if you are following a special diet or taking supplements.

# Deep brain stimulation



# Insufficient evidence

Deep brain stimulation (DBS) is a type of neurosurgery that involves placing electrodes at certain points in the brain. DBS has only been used as an experimental treatment for adults with very severe Tourette's syndrome that has not improved after other types of treatment. Although the results have been hopeful, the research is still in its early stages and it is still not clear whether this will become an available treatment option.

It is an invasive treatment which carries the risks of surgery (e.g. bleeding and infection) and there are potential side-effects related to the stimulation (e.g.

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sedation, anxiety, altered mood, changes in sexual function). It is not offered as a treatment for children and young people.