

Tics and Tourette syndrome: What have you learnt today



Thank you for coming to one of our group sessions – we have put together this information sheet to remind you about what we talked about as well as give you some ideas for managing your tics in future.

Information for children and young people

Great Ormond Street Hospital for Children NHS Foundation Trust

What are tics?

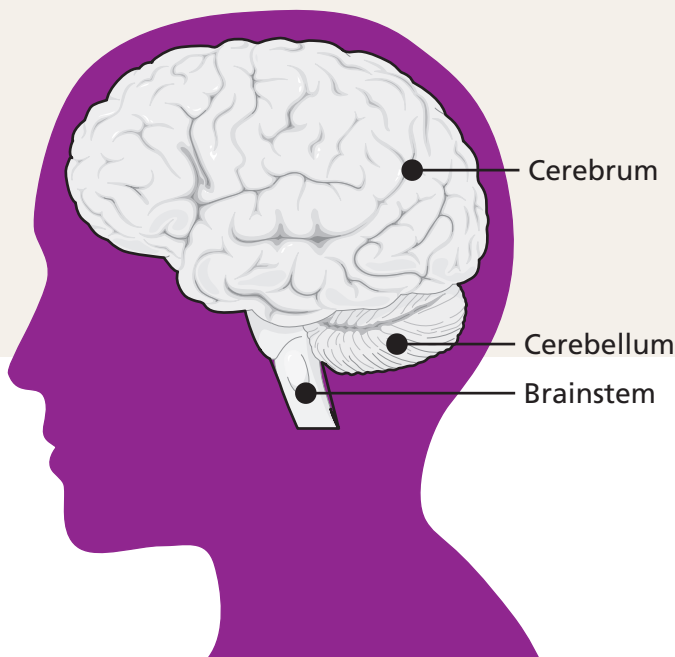
Tics are movements or sounds that you make without warning that you can only control to an extent.

- Movement or motor tics can be simple, such as shoulder shrugs or touching things.
- Complex movement tics affect more than one muscle group – for example if your arms and legs tense at the same time – or when several different tics happen together – such as twisting your body and slapping yourself.
- Simple sound or vocal tics can include repeated sounds, such as throat clearing or making a specific noise.
- Complex sound tics might involve making several sounds or sentences.

Where do the tics come from?

Tourette syndrome is caused by the way our brain is wired. Tourette syndrome is normally genetic and most people can identify someone in their extended family with tics or OCD, but not everyone

We know that a region in the brain, called the basal ganglia, is involved in Tourette syndrome. The basal ganglia sit deep inside the cerebrum and are responsible for movement.

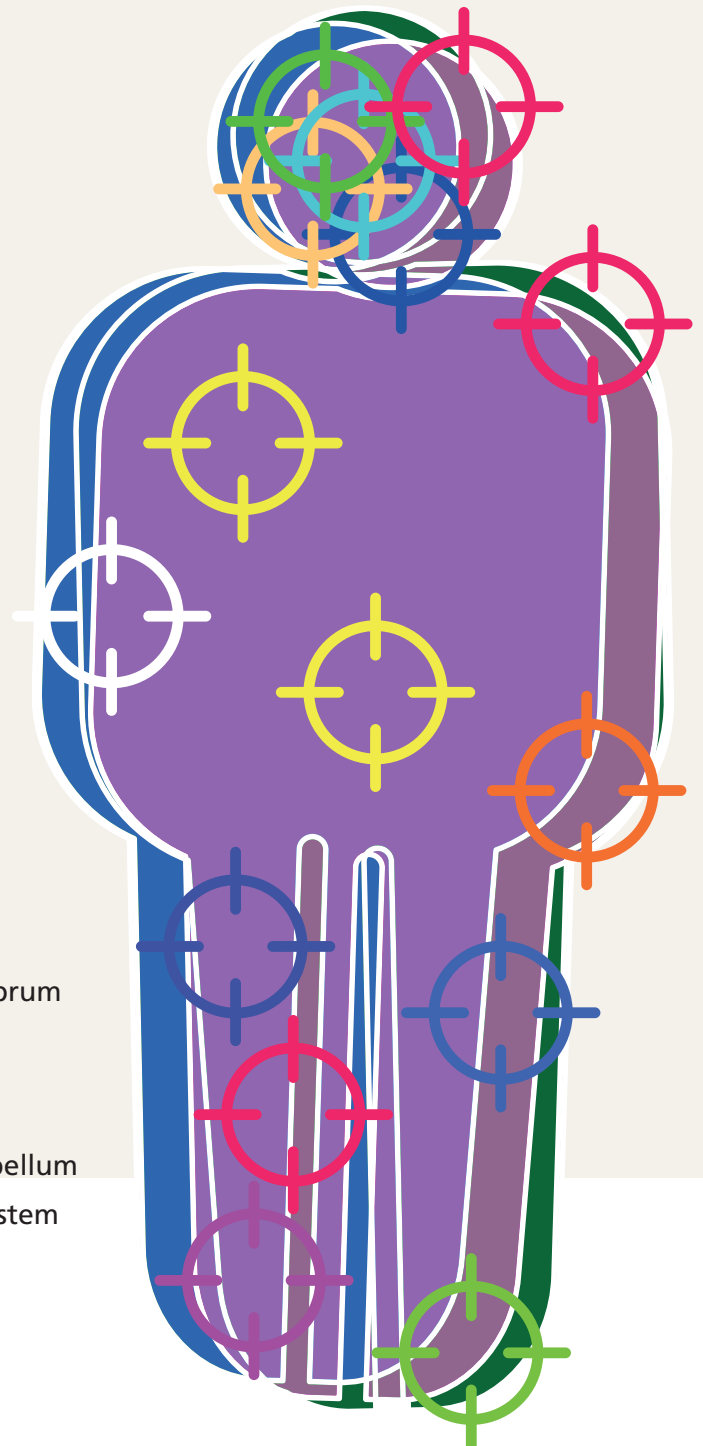


Which parts of the body can tics affect?

Tics can occur everywhere in our body. The first motor tics tend to be of the face, and as we get older, tics move to other areas such as neck, arms, legs and body.

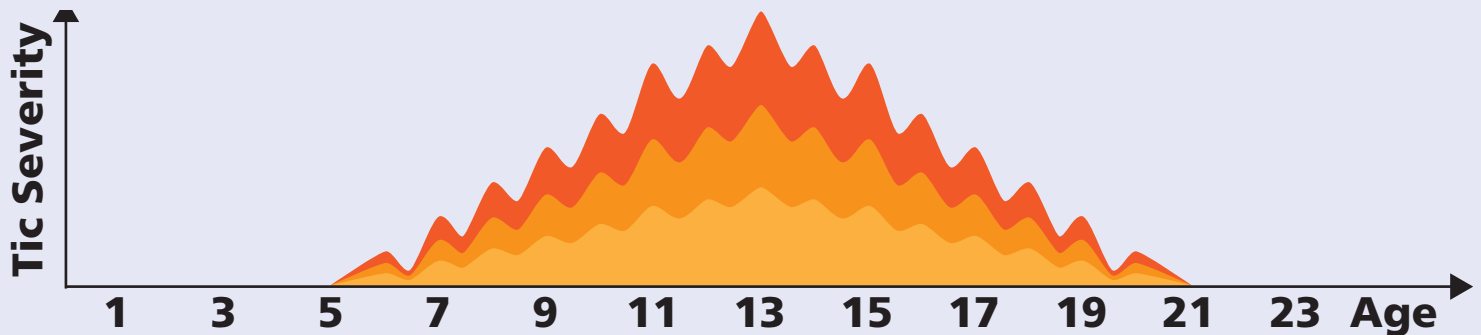
Sound (vocal) tics tend to start off as simple noises such as sniffing or one sound. They can later become more complex which include words or sentences.

Not everybody experiences these in the same order.



How Tourette syndrome changes as you grow older

Although everyone is different, we know that most children and young people have times when their tics are better or worse – as shown by the wavy line on the graph below.



For some people, their tics will get worse around the age of 13 and then will reduce.

For others, their tics will stay the same over time and there is not an age when their tics are at their worst.

For most people, Tourette syndrome starts between the age of 3 and 9 years, with tics generally peaking at around the ages of 10 to 13. Following this, tics tend to decrease.

For one in every three people with Tourette syndrome, tics will get better as they grow into adulthood.

For another one of the three people with Tourette syndrome, tics will become much less severe.

The last one of the three people with Tourette syndrome will continue to have tics into adulthood.

Tics tend to wax and wane – there will be times when there are lots of tics and times when they decrease. This can happen in a day, a week, or a month.

Some people get a big increase in their tics as they reach adolescence, whereas others have a much smaller change.

Types of tic disorders

Although Tourette syndrome is the best known type of tic disorder, there are other sorts too:



Probable Tic Disorder/Transient Tic Disorder

– when someone has motor and/or vocal tics for less than 12 months



Chronic Tic Disorder (Motor or Vocal)

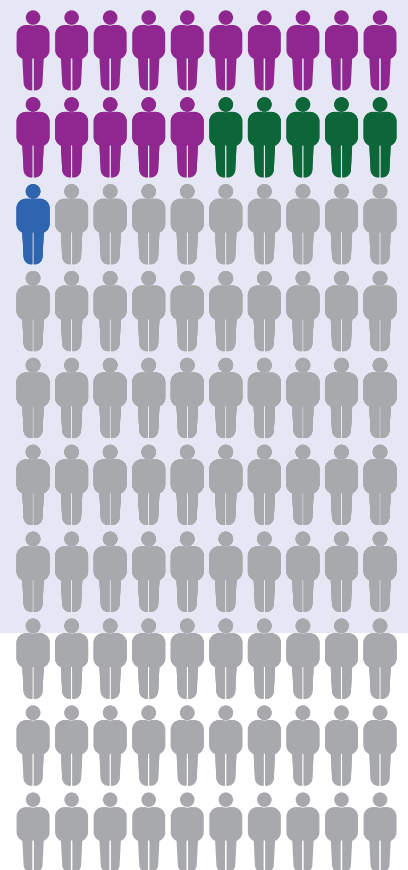
– when someone has either motor tics or vocal tics for more than 12 months.



Tourette syndrome

– when someone has at least two motor tics and at least one vocal tic for more than 12 months.

The diagram on the right shows how many people have each type of tic disorder out of 100 people

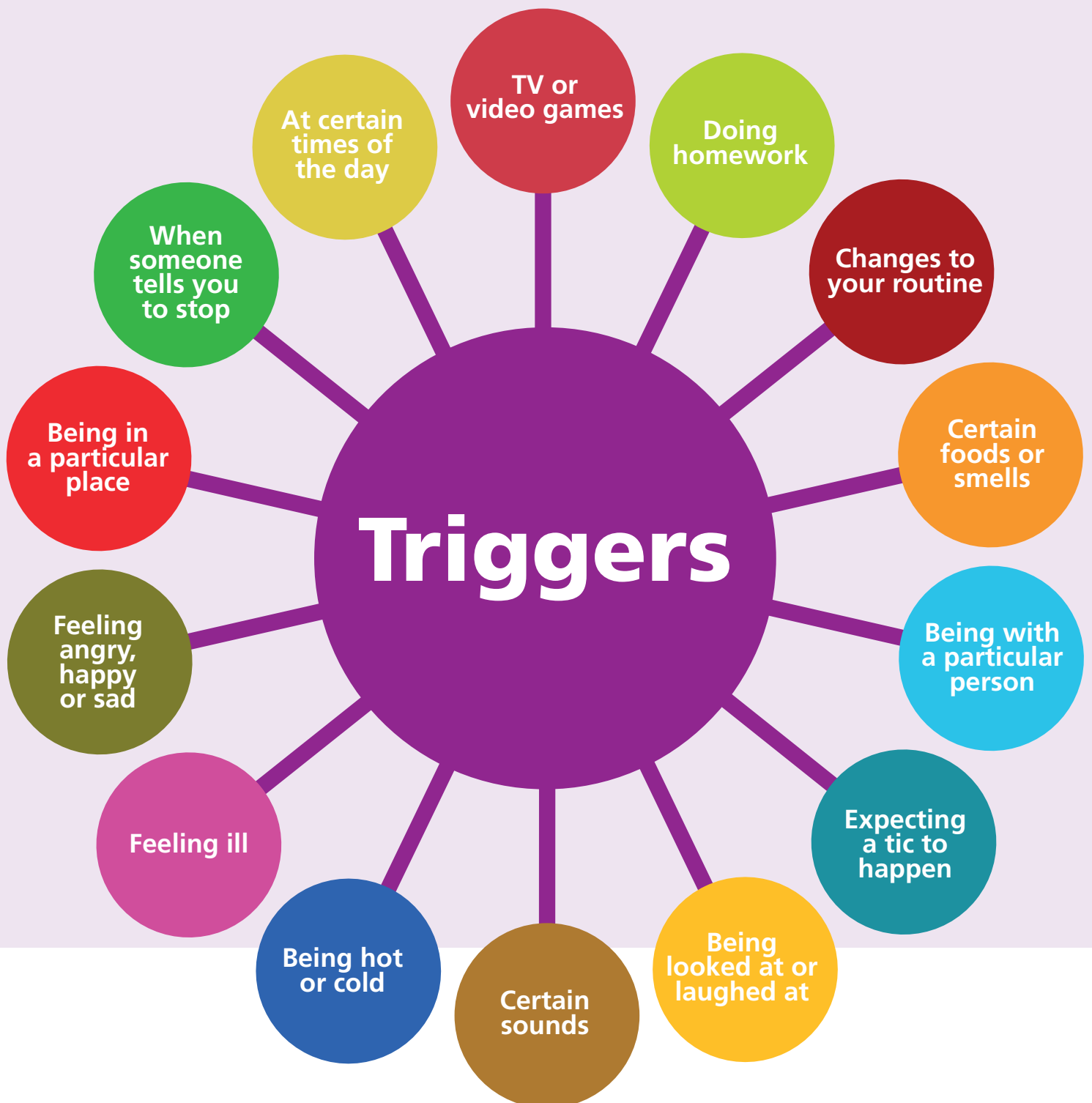


Things that often go with tics

ADHD or Attention Deficit Hyperactivity Disorder – this means you have difficulties concentrating and organising yourself.

ASD or Autism Spectrum Disorder – this means that you find it difficult being with other people, recognising and understanding what they are feeling.

What can set off a tic?



OCD or Obsessive Compulsive Disorder – this means you may feel like you have to do certain behaviours to stop something bad from happening. It also means that you may have lots of thoughts that you might not want to have.

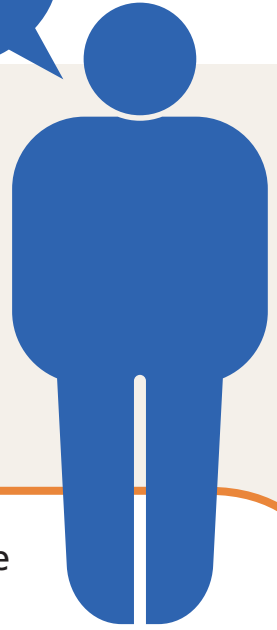
Anxiety – this means you feel scared or worried in certain situations or about lots of different things.
Finding learning hard so you may need more help in the classroom or at home.

What helps?

What helps our tics can be very different for each person.

Write down some of the things that help your tics in the empty circles below.





Describing your tics to someone else

Sometimes people might ask you about your tics.

It can be nice to have a few things you can say back to them.

You could say

"It's called Tourette syndrome and it means that I can't help it."

"They are tics, it is something my brain does and I can't control."

Why don't you write down what you might say to someone if they ask you to stop or ask you why you are doing that?

Section for grown ups

Describing your child's tics to others

Sometimes people might ask you about your child's tics. It can be helpful to have a few things you can say back to them.

You could say:

"My child has Tourette syndrome, which is a neurodevelopmental disorder that causes my child to have sounds or movements that they can't control. The best thing to do is to ignore them."

"I am sorry if my child's tics have offended you, they have a neurodevelopmental disorder which means that they have involuntary movements or sounds that they can't control. The best thing to do is to ignore them"

How you can help to support your child with their tics?

Talking to school and helping them understand the needs of your child.

Some people may find relaxation techniques helpful.

There are many resources and helpful information on Tourette Action (<https://www.tourettes-action.org.uk/>) where you can also access groups in your local area.

Treatments for tics:

- Medication management
- Habit Reversal Therapy (HRT)
- Exposure and Response Prevention (ERP)

It may be helpful to have a sentence that you can say if someone asks or comments on your child's tics...



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