

Transport issues and Tourette Syndrome



Transport can prove to be challenging for some people with Tourette Syndrome. Some symptoms might compromise your safety on the road, or leave you feeling vulnerable and anxious about using public transport. This factsheet discusses what challenges may arise when using different modes of transport, and suggestions to help improve your travel experiences.

Flying with TS

Flying can be a stressful experience for anyone. Fear of flying and on-flight conditions such as tightly packed seats and spaces, tend to make people feel uncomfortable. Having TS can cause added stress; concerns about tics, people's reactions and the not knowing how you will be on the flight can sometimes feel overwhelming.

Preparation, organisation and communication are key points to planning your trip and ensuring that your flight is as stress free and comfortable as possible.

When booking your flights either with the airline directly or through a travel agent, think about seating arrangements on the plane. You might find it more preferable to be seated at the front where there is more room and easy access to toilets and flight attendants, should you need assistance.

If you feel it is necessary for the airline to know about your condition, inform them in advance of your flight. It is best to speak to them 48 hours before you fly, even if you have spoken to them previously – just to remind them.

Make sure you leave plenty of time to arrive at the airport. Once you have checked in you can take some time to relax, either in the seating areas provided, a café or perhaps some shopping. Allowing yourself enough time will also give you the opportunity to speak to airline staff if any issues arise.

If you are travelling light, you can check in online, avoid the check in queues and head straight to departures.

Make sure you have a Tourettes Action ID card with you. You can show this card at any point to support yourself in informing people about your TS.

Make sure that you have everything you need in your hand luggage including medications, Tourettes Action ID card and any items that will keep you occupied and help you relax on the flight – a book, magazines, music, puzzles etc. (don't forget you can only take small amounts of liquid)

Think about whether you'd like the passengers on the plane to be informed of your condition – this could be sensitively announced by the captain or a flight attendant. You may have particularly loud or suggestive vocal tics, and feel more comfortable knowing that people understand what the tics are about.

Driving with TS

How can I apply for a licence?

Application for a driving licence is made through the usual channels of the DVLA. You will need to notify the DVLA of your TS.

Are there any problems I could face whilst driving?

TS should not generally be seen to stop you being allowed to drive by the DVLA, but people who have more severe forms of Tourette's, and any associated disorders such as OCB, AD/HD, depression, mood swings,

behaviour disorders, Autism or Asperger's Syndrome, or learning disabilities must disclose this on their form and may be subject to assessment.

Tics whilst driving

Motor tics in particular can present a problem during driving. For example, a simple blinking tic means that you are taking your eyes off the road, even for only a split second, which could cause problems.

A leg or arm tic could cause you to either push down on the brake or accelerator at the wrong moment, or move the steering wheel in the wrong direction. Of course, this is totally dependent on the tics that manifest themselves at the time, due to the waxing and waning, and how confident you feel in your ability to deal with them.

Driving tests

The DVLA, or DVLNI must be informed of your TS before you take the test: mention it when you book it. However, the practical driving test is the same for everyone, no matter the disability. You may be allotted extra time for the test, but this is specifically for the examiner, so that they have time to talk to you about driving with your disability, and writing the report at the end of the test.

For the Theory test however, special measures can apply. The Driving Standards Agency (DSA) can provide facilities for those with special requirements. The difficulty most likely to affect people with TS are reading difficulties, due to ADHD and a lack of concentration; or OCD, perhaps having to read things in a particular manner.

You can ask for more time to do the multiple choice part of the theory test. If you do need more time, then you will need to send in evidence, maybe a letter from a teacher or a doctor, of your reading difficulty to the theory test booking customer services.

Driving and medication

If you are on medication, you need to check that it does not interfere with your ability to drive safely. It is against the law to be found driving under the influence of drink or drugs, and the law does not discriminate in favour of medicinal treatment for illness.

Below is the recommendation from Dr. Jeremy Stern, Medical Director of Tourettes Action:

“Most drugs that affect the brain are capable of causing drowsiness, including the ones commonly used for TS, for instance, neuroleptics (e.g. sulpiride, risperidone, aripiprazole), clonidine, SSRIs (e.g. fluoxetine, sertraline), clomipramine.

Whilst taking any drug, if that drug is causing drowsiness then you should not drive, in the same way that one

shouldn't drive if feeling drowsy in any case.

There is no ban on driving with any of these drugs, so that if a person is taking medication that is not making them drowsy then there shouldn't be a problem, as long as the DVLA and insurance company are aware of the medical condition.”

Driving insurance

You do have to disclose TS when you get insured, otherwise you could leave your policy invalid. Disclosing your TS does not necessarily mean that you will be charged higher premiums.

Advice from the DVLA

Dr K Watts, Medical Adviser to the Driver and Vehicle Licensing Agency (DVLA), February 2010.

“Medical Advisers at DVLA understand that the condition ranges from very mild to very severe and we always consider individual circumstances before making a medical licensing decision. We would normally seek information about the condition from the individual and if necessary from their general practitioner or specialist. With Tourette Syndrome, as with other medical conditions, it is only where there are symptoms likely to affect safe driving that notification to DVLA is required. This applies equally to other conditions associated with Tourette Syndrome such as Attention Deficit Hyperactivity Disorder.

In considering driving safety we are concerned with functional abilities and not with diagnostic labels. Where an individual experiences day-to-day variation in symptoms, we are happy that they self-regulate by adjusting their driving patterns accordingly.

We recommend that individuals who are concerned or uncertain about the need to notify DVLA should discuss this with their doctor who may then decide to contact one of the Agency's Medical Advisers for further advice, if required. Advice can be provided on an anonymous basis.

We recognise the importance of independent mobility to the individual and our aim is always to preserve this while maintaining our primary remit of supporting road safety for all road users”.

Using Public Transport

As a person with TS, you should be able to use public transport just like anybody else. Of course, it's not always so simple...

Many find using trains and buses a bit daunting and stressful, from being with lots of people in an enclosed (and, if you're on the Tube, cramped) space, having to really try hard to suppress tics, or even having to put up with people staring at you because you are ticcing. Having your ID card in situations like this can be very useful.

Shamefully, some people with TS have even been removed from buses or trains because the drivers thought that they were simply badly behaved. This is something that should not be happening. Transport infrastructure, services and certain specified vehicles have an obligation under the Equality Act 2010 to outlaw discrimination.

So if you are asked to get off a bus or train because of your TS, you have the right to complain, and should go straight to the Rail, Bus or taxi company to do so.

Aside from the worry of being thrown off, it can be a bit intimidating to take public transport. We have compiled some tips that we hope will make your journeys more pleasant:

- Listen to music. Using a portable music player may help you to block out the outside noises, phase out anything else that might be going on, and help the journey to pass far more quickly. It might also help to disguise your tics: you could make it look like you are simply tapping along to the beat.
- Reading material may also help you to block out what is going on around and give you something to focus on.
- Avoid rush hour. Making a journey might be a bit more bearable when there are fewer people. If you've got to get to work, then maybe ask the office if you can change your working hours.
- Plan your route. Sounds obvious, but sometimes the quickest way that websites give you isn't always the most comfortable. E.g. the Tube is a quick way around London, but there are overground trains to a lot of stations that are less crowded.
- Have the Tourettes Action ID card, or something similar, that you can show to a driver or member of staff, so that they know that your tics are not voluntary.

- Call ahead. If you are going to be travelling by train for a long time and find that crowded stations exacerbate your tics, you might be able to call the rail service provider in advance and arrange to have someone accompany you on the journey.

Who can help?

The following organisations may be able to offer you useful information on driving and using public transport.

Please note that Tourettes Action cannot guarantee the accuracy of information offered by external agencies.

- The Access to Work programme can provide help with the additional costs of travel to work for people who are unable to use public transport.
www.gov.uk/access-to-work
- The Blue Badge Scheme helps you park closer to your destination if you are disabled. For further information, see the government website: www.gov.uk/blue-badge-scheme-information-council
- The Citizen's Advice Bureau has a wealth of information on transport options and rights for disabled people on its Advice Guide website at www.adviceguide.org.uk/index/your_world/travel/transport_options_for_disabled_people
- For more information on the Disabled Person's Railcard (which allows you - and an adult companion with you - to get a 1/3 off most fares throughout the UK), visit www.disabledpersons-railcard.co.uk
- DVLA: www.dft.gov.uk/dvla
- The government website has information and guidance on medical conditions, disabilities and driving: www.gov.uk/driving-medical-conditions
- The Motability Scheme enables disabled people to use their government funded mobility allowance to lease a new car, scooter or powered wheelchair: www.motability.co.uk
- Travel Training provides tailored and practical help with travelling by public transport, on foot or by bicycle: www.gov.uk/government/uploads/system/uploads/attachment_data/file/4482/guidance.pdf

If you make a complaint and are unhappy with the response, the following organisations may be able to help:

- For rail: www.passengerfocus.org.uk
- For buses: www.busappealsbody.co.uk