

TRANSITIONING TO HIGHER EDUCATION WITH TOURETTE SYNDROME

A STUDENT'S GUIDE

As we enter the world of adulthood, we are expected to be so much more independent, however many adult learners with SEND (Special Educational Needs and Disabilities) find this a challenge. Much of the support we were used to in school and college disappears, especially if a students' EHCP (Educational Health and Care Plan) does not continue into higher education. Other challenges we may experience could be understanding finances with getting paid employment, taking care of our own health, moving to independent living and the challenges that living with other people may bring.

We hope this factsheet provides you with all the advice you may need to aid a smooth transition from further to higher education.

EXECUTIVE FUNCTIONING

Many of the issues that can arise in higher education for adult learners with SEND typically revolve around executive functioning difficulties. As we get older, our levels of expected understanding increases, language gets more complex, and we are expected to become more independent in our learning and organisational skills. This can be tricky if you experience difficulties in aspects such as working memory, flexible thinking, self-control, organisational skills, starting and finishing tasks, completing tasks, following instructions and focus/concentration. Remember, it's ok to not understand

everything but also important to ask for clarification if you don't. Please see link below to our factsheet all about Executive Functioning with some great in class strategies to support difficulties with executive dysfunction.

www.tourettes-action.org.uk/storage/downloads/1605794292_Factsheet--Executive-Funtioning.pdf

TRANSITION TIPS

- Acknowledge your worries as these are valid and reach out to the student well-being team for support
- Know that you are not alone, as everyone else will have very similar concerns as you
- Recognise your strengths and skills
- Try to focus on the positives, meeting new friends and experiencing new learning opportunities
- Challenge the negative thought process (what would I say to someone else who thought this? What could I think instead?) Great for intrusive thoughts
- Get support to provide yourself with some structure and routine as soon as you can (knowing what to expect is key to being able to manage it)
- Ask for a sample timetable to see what the flow of the day looks like
- Ask for a map of the campus to familiarise yourself of where everything is before you get there
- Arrange extra transition meetings/visits to ease worries and concerns



WHO CAN SUPPORT ME?

Every University will have a **student well-being department with a disability advisor or learning support co-ordinator** who will be able to assist you with any additional support you feel you may need, or even just to answer any concerns or questions you may have about the support you may be eligible to receive at university. Reach out to them before you start your course to have all your worries and questions answered.

If you do need extra support on a day-to-day basis, then the well-being team should offer to meet with you before your course starts to work with you in putting together an individual support plan (ISP). This may be called by different names in different universities. This document should clearly set out any support you may need and then can then be shared with all staff so that everyone you work with will have a clear understanding of your needs and how best to support you. Examples of the kind of support you could ask for and that may be included in this could be:

- Attend fresher's week and join clubs to make new friends if you feel comfortable enough to do this. Having a trusted group of people around you can really help
- Meet/identify sensory needs as soon as possible as these can be massive triggers to tics
- Meet with the well-being team to ensure continuity from your previous provision and arrange extra transition meetings and visits if needed (to get familiar with buildings and people)
- Consider whether you would like to disclose to friends and tutors about your SEND or any disabilities you may have. This is completely your choice, and you do not have to do this, but you may gain extra support and understanding from people around you if they can learn how to best support you

Once you arrive don't be afraid to ask for any additional resources in advance to help support you in class such as a laptop, task planners, alternative texts, sentence starters, graphic organisers, concept maps, access to new vocabulary, PowerPoints, notes or instructions.

The evidence suggests that transition programmes for young adult learners with SEND can have a significant and observable impact on behaviour, attainment and progression. Your new education provision should provide you with a transition program whereby they offer you some extra visits, either in person or virtually, to give you the chance to meet the tutors you will be working with and a chance to become familiar with the buildings and timetables and routines of university life.

- Weekly check-ins to aid anxiety and task management
- Note takers/scribes
- Notes and PowerPoints in advance of lectures
- Extra time for assignments
- Extra time/rest breaks/separate room for exams or assessments
- Extra breaks for movement or sensory needs/re-regulation during lectures
- Recognised quiet area for tic release or individual learning
- Regular talking therapy/counselling sessions
- Discuss possible tic triggers and ways to support you to avoid these
- Include any other reasonable adjustments that you feel would support you
- Recognised need for awareness training for staff and peers

Make sure to apply for **Disabled Students' Allowance (DSA)**. This can be up to £26,948 per year. This support is designed to cover the study-related costs you have because of a mental health problem, long-term illness or any other disability. This can be on its own or in addition to any student finance you get. The type of support and how much you get depends on your individual needs – not your household income. This means you can apply for specialist equipment such as laptops/computers, non-medical helpers to aid with note taking or travel costs etc. www.gov.uk/disabled-students-allowance-dsa

As part of the DSA process, once they have confirmed you are eligible, you will be contacted by a company called **Study Tech** who will contact you to arrange a study needs assessment to decide exactly what you need.

www.study.tech

THINGS TO REMEMBER

- You know your limits and challenges best
- Don't be afraid to have a voice and be your own advocate or take a family member/friend advocate with you to meetings
- Don't be afraid to be specific about your needs
- Knowledge is power (the more they know, the more they can do to meet your needs more successfully)
- Solutions help your brain to move on
- Nothing lasts forever/negative feelings will pass
- Know that you are not the only one transitioning! Everyone will be feeling the same!
- Above all, make sure you keep communicating – with your university and tutors as they are there to help

FURTHER SUPPORT

You can get TS ID cards here to help you explain your conditions to new friends and tutors: www.tourettes-action.org.uk/12-ta-id-cards.html

TA Passport – a great document to help others to understand your needs: www.tourettes-action.org.uk/105-ta-passport.html

Training opportunities to offer your peers and tutors: www.tourettes-action.org.uk/155-elearning.html and www.tourettes-action.org.uk/160-our-training-offer.html

Adult with TS support groups: www.tourettes-action.org.uk/146-online-support-groups.html and www.tourettes-action.org.uk/174-in-person-support-groups.html

Information on employment support: www.tourettes-action.org.uk/77-employment.html

Apply for our TA grant: www.tourettes-action.org.uk/79-ta-grants.html

Find out what benefits you may be eligible for including Personal Independent Payments to help with living costs: www.tourettes-action.org.uk/103-benefits.html

Further support for adults with TS: www.tourettes-action.org.uk/11-adults-with-ts.html

Please visit our helpdesk for any further help, advice or support you may need: www.tourettes-action.org.uk/9-helpdesk.html

You can find out here how universities can support learners with SEND: www.ucas.com/undergraduate/applying-university/individual-needs/disabled-students

You can find out here how accessible Universities are for learners with SEND: www.ucas.com/connect/blogs/how-accessible-university-learners-send

LAWS TO BE AWARE OF

'Human rights' are the rights and freedoms that belong to every person in the world. These are based on principles such as dignity, fairness, equality, respect and autonomy. The 1998 Human Rights Act brought human rights into UK law. One of these is: *'Everybody has the right to an effective education.'*

In 2009, the UK ratified the **UN Convention on the rights of people with disabilities**. This means that the UK government agreed that they would work to: *'...ensure the education system at all levels is inclusive and geared towards supporting disabled people to achieve their full potential and participate equally in society.'*