

TRANSITIONING WITHIN THE EDUCATION SYSTEM WITH TOURETTE SYNDROME

A PARENT/CARERS GUIDE

W

hat is meant by the word transition? It means the process of change from one period to another. Changes that a child or young person (YP) may go through in life could include things such as:

- House moves
- Change in family arrangements such as parent divorce/separation
- Medical issues
- Big life events such as birth of siblings or family bereavement
- Special events such as visitors, visits and celebrations
- Changes in school staff, temporary or permanent

In the world of education, a transition means a movement or change in the environment, either physically or with relationships, behaviours, routines, roles, rules or expectations. We expect our children to manage transitions constantly through situations including:

- Room to room during the day
- Lesson to lesson/activity to activity
- Break to lesson
- Moves from structured and unstructured times
- Year group to year group/new teachers
- School and home
- A move to a new school

Starting secondary school is one of the biggest transitions a child can take in life, and for those with special educational needs or disabilities (SEND), it can be an even greater challenge, and they may experience lots of difficulties with this transition. As a parent, it's very important to raise your biggest concerns about your child's transition, you'll want to make sure that the new school knows how to meet your child's needs.

Regardless of the type of school, by law, they must have a special educational needs policy, which must be available for parents to look at. These policies apply to academies and free schools as well as maintained schools. They set out the school's approach to SEND and reading them through is a good place to start when you're choosing a school. Familiarise yourself with both the school's SEND and behaviour policies. It's important that the school understands if your child has SEND or behavioural difficulties and makes allowances for these where appropriate.

You may be reading this at the end of the school year when you might start to think about transition to new classes or new schools, what this can look like and how to best support your child through this process. Or, if you are a teacher then you may be looking at supporting a specific student in your class. We hope this factsheet can guide you through this process and give you some ideas and effective strategies to support this alongside Tourette syndrome.



WHAT ARE THE CHALLENGES A STUDENT MAY EXPERIENCE DURING TRANSITION

Transition isn't easy and our children can often find change tricky. It is normal for our children to experience a sense of anxiety, confusion and fear at this time. There are many challenges specifically to transition from Primary to Secondary school with TS, such as:

- Challenges to sense of security, confidence and sense of belonging (leaving that primary bubble)
- New pupils/peers/friends
- New teachers
- New, larger buildings
- New experiences/subjects
- New routines/timetables
- Longer lessons
- Less visual support
- Less consistency in general support or this may look very different
- Increase in independence
- Increase in assessments, tests and exams
- Expectation to manage own time for homework and study skills
- Strong sense of being controlled/meeting demands/conforming

- Strong sensory processing needs, creating challenges to triggers for tics
- Further struggles with executive functioning – organisational skills, starting and finishing tasks, memory, moving from one task to another, concentration and focus
- Managing co-occurring needs
- Managing pain and fatigue – coping and explaining
- General school anxieties
- With tics specifically, we can sometimes fall into a vicious cycle of anxiety – tics cause attention from others, which causes anxiety, which causes us to tic!

If a school transition isn't successful then we know this can lead to anxiety, worry, sleep issues, school refusal/attendance difficulties, friendship issues, falling behind in school and this can all escalate very quickly.

We have lots of tips for aiding a smooth and successful transition and how we can get this right. Our main focus in this factsheet will be on primary to secondary/college transition but it's easy to adapt for younger and older students. Please see our separate factsheet for transitioning onto higher education.

www.tourettes-action.org.uk/storage/downloads/1724928030_factsheet-transitioning-to-higher-education-student.pdf

WHAT PRIMARY SCHOOL SHOULD DO

A successful transition from primary to secondary school involves both schools working together. It's important that your child's primary school shares as much information as possible with their new school. This will help the secondary school plan how it will meet your child's needs. It's helpful if your child's primary school compiles a profile of your child which can be passed on to the secondary school. This could include details of:

- Your child's particular difficulties, such as with mobility, communication or concentration
- The special measures that support their learning, like extra time for tasks, one-to-one support, visual timetables, handwriting aids and any exam access arrangements currently in place
- Strategies that help them cope with school life, such as movement breaks, time outs, or a buddy system in the playground

WHAT SECONDARY SCHOOL AND COLLEGE SHOULD DO

To help your child settle into secondary school or college, the school should make sure they are proactive in planning for their admission, rather than waiting to see what their needs are after they start. They should:

- Consider how they can make the school/college accessible to your child, for example by timetabling classes on the ground floor if they have mobility problems
- Inform themselves about your child's needs by reading their EHCP or statement, and/or any materials supplied by you, their current school, or other professionals involved in their care
- Meet with you and your child to get to know them better and discuss their needs and how they can be catered for
- Prepare all staff who will be involved with your child so they understand their needs and can make them feel welcome and included
- Observe your child on induction days to see how they cope with the new environment and teaching practices and feedback to parents where possible

There are lots of other ways for secondary schools/colleges to help your child. Some, for example, use pupil premium money to fund support staff to work with small groups of students as they transition from primary to secondary. Some offer interventions your child can take part in once they start at the school/college to aid any specific needs they may have such as art or Lego therapy, forest school or nurture programs to aid social and emotional intelligence.

TIPS AND STRATEGIES TO AID A SMOOTH TRANSITION

Most of these should already be supported by a student's current education provision and if not, then don't be afraid to ask.

- Acknowledge their worries
- Adopt a 'worry is normal' philosophy and that everyone experiences worry

- Identify the specific worry trigger and make a plan
- Set a time limit on conversations about worry
- Recognise strengths and skills/self-esteem boosting
- Focus on positives – new friends, new subjects etc.
- Take transitional objects/physical reminders with you to create comfort, familiarity and reassure that all are ok, e.g. teddy
- Transition scenarios – Encourage questions that seek solutions, e.g. 'What if'. This helps to build confidence and have a plan
- Use of social stories/social scripts
- Discuss what will be same v's different – there will be more similarities than they think
- Challenge the negative thought process (what would I say to someone else that thought this? What could I think instead?) Great for intrusive thoughts
- Provide structure and routine (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 school layout to familiarise yourself where everything is
- Take photos or make a booklet of the new school/class/teachers/toilet/locker
- Ask for any additional resources in advance to help support in class such as a laptop, task planners, alternative texts, sentence starters, graphic organisers, concept maps, access to new vocabulary, PowerPoints, notes or instructions
- Get an equipment checklist
- Label uniform and equipment
- Think about and plan for emotional dis-regulation and how to re-regulate (exercise, fun, distraction)
- TA Passport – great to go through at home and with new teachers
- Ask about a buddy mentoring scheme
- Meet/identify sensory needs as soon as possible as these can be massive triggers to tics
- Teach self-advocacy and revisit diagnosis with family if needed (we are all at different stages in diagnosis and understanding)
- Offer the new school/college information on TS
- Offer the new school/college training for staff and peers
- Meet with new SENCo/ALNCo prior to starting to ensure continuity from previous provision and arrange extra transition meetings and visits outside school hours if needed (to get familiar with buildings and people)



SOME USEFUL TIPS/THINGS TO ASK FOR IN NEW PROVISION ONCE STARTED

- Ask for visuals to help follow instructions ahead of lessons and to help your child to remember, e.g. lists if worried about forgetting something
- Use of 'now and next cards' to help ease any concerns over any unexpected change
- The 'oops' card is a way of marking and explaining unexpected change and that the change is safe and manageable
- Use of 'task boards' outlining all steps involved in a situation or activity – helps to break down the tasks expected within a lesson and can tick off when done, giving sense of achievement
- Regular movement breaks and sensory circuits

EXECUTIVE FUNCTIONING

Many of the issues that can arise in secondary school and colleges for SEND students are typically around executive functioning difficulties. As we get older, our levels of expected understanding increases, language gets more complex, and we are expected to be a lot more independent in our learning and organisational skills. This can be tricky if your child experiences difficulties in areas 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 in executive dysfunction.

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

FRIENDSHIPS AND SOCIAL COMMUNICATION DIFFICULTIES

Many children with SEND may have social communication difficulties which can make it difficult to make friends. Many secondary aged children and young people in college develop their own lingo or banter and can use non-verbal communication and body language to communicate with peers. This can often be something SEND children and YP can struggle with. The school or college may need to support them in initiating and maintaining conversations and friendships.

Social skills are very complex in secondary school and college and involve lots of sophisticated language skills such as persuasion, negotiation, listening and code switching to keep up with different groups of people. Social scripts and social stories are a great way to build upon these skills using breaking down and visual prompts. Encourage your child/YP to join clubs and make friends and don't be afraid to ask for the school/college to assist and support with this.

THINGS TO REMEMBER

- You know your child best
- Don't be afraid to be your child's advocate
- Don't be afraid to be specific
- Knowledge is power (the more they know, the more they can do to meet your child's need more successfully)
- Solutions help your brain to move on
- Nothing lasts forever/negative feelings will pass
- Know that your child is not the only one transitioning! Everyone will be feeling the same!
- Above all, make sure you keep communicating – with your child, their teachers and their SENCO/ALNCO

RESOURCES

Please also see below links to some of the specific resources mentioned in the above tips and strategies, provided to us by specialist teacher Katie Skinner, who kindly volunteers her time to work with our charity.

www.tourettes-action.org.uk/storage/downloads/1567358145_About-me-leaflet-example.jpg

www.youtube.com/watch?v=P9mMZC9T8dl

www.tourettes-action.org.uk/storage/downloads/1588603656_Managing-my-worries.pdf

www.youtube.com/watch?v=rvvQ9dYLEAw

www.tourettes-action.org.uk/storage/downloads/1572276335_Reframing-my-thoughts.pdf

www.tourettes-action.org.uk/storage/downloads/1572276905_STAR-chart.pdf

www.tourettes-action.org.uk/storage/downloads/1572276987_Using-Apps.pdf

www.tourettes-action.org.uk/storage/downloads/1567358044_What-if-board.jpg

www.tourettes-action.org.uk/storage/downloads/1567358300_What-if-board-2.jpg

SIGNPOSTING/USEFUL LINKS

SEND Code of Practice: www.gov.uk/government/publications/send-code-of-practice-0-to-25

Equality Act 2010: www.legislation.gov.uk/ukpga/2010/15/contents

The Children and Families Act 2014:
www.legislation.gov.uk/ukpga/2014/6/contents

FURTHER SUPPORT

For parents and carers, please visit our education page on our website below where we have lots of great factsheets about all things school for both parents: www.tourettes-action.org.uk/76-education.html

A parent's guide to support in school: www.tourettes-action.org.uk/storage/downloads/1600265722_ta-factsheet-ts-in-school-v3.pdf

See link below further information on TS and EHCP's: www.tourettes-action.org.uk/storage/downloads/1692794013_Factsheet--Education,-health-and-care-plans.pdf

See link below to information on Exam Access Arrangements: www.tourettes-action.org.uk/storage/downloads/1640011040_Factsheet--Exam-Access-Arrangements.pdf

For teachers, please visit our education professionals page on our website below where we have lots of free resources on how to best support a student with TS: www.tourettes-action.org.uk/62-education-professionals.html

Please also see below our link all about our teacher training we can provide: www.tourettes-action.org.uk/160-our-training-offer.html

Our Key Facts for Teachers Leaflet: www.tourettes-action.org.uk/storage/downloads/1583409432_tourettes-action-key-facts-for-teachers_Feb2020.pdf

For students, please see below our Tourettes Action Passport which is a really useful document for you to use in school or college: www.tourettes-action.org.uk/105-ts-passport.html