Education and TS: Advice for Parents

Tourette Syndrome is not a learning disability but some of the symptoms and co-occurring conditions can have a substantial impact on a child's ability to learn.

For example:

- Writing can be made difficult by movement tics, or obsessions relating to how things should be written
- Movement tics involving eyes can make reading tasks very difficult, while vocal tics can make reading aloud a source of anxiety and embarrassment.
- Concentrating on a lesson can be hard if a child is trying to suppress tics.
- Impulsive traits can manifest as calling out or speaking out of turn in class.

A minority of children with TS may need to attend SEN schools, usually if they have additional complex needs. However, if a mainstream school can effectively provide structured support and encourage knowledge and understanding of TS amongst pupils and staff, most children with TS will be capable of remaining in mainstream education.

Your child's diagnosis will be unique to them and will require support that is individually tailored to their needs.

Steps to take following a diagnosis

Don't assume that school will have prior experience and knowledge of teaching children with TS. Supporting your child through their education should be viewed as a working partnership between the family and school. Your child's symptoms may fluctuate over time, along with their thoughts and feelings towards their condition, which is why strong communication between the family and school is vital to ensuring that your child is effectively supported through their school experience.

It can be very common for children to suppress their tics in school, so teachers may not be aware that your child has any symptoms and potential barriers to learning. Even if the child is able to suppress tics and continue to learn without their school work suffering, it is important that the school are made aware of their diagnosis in case your child's circumstances change.

Several of these steps may already have been taken before your child received their diagnosis.

- Organise a meeting with the school, including the Special Education Needs Co-ordinator (SENCO) and/or your child's teacher to discuss your child's symptoms/diagnosis and how it affects them.
- Find out if the school have prior experience of teaching children with TS. Do they have a good understanding and working knowledge of TS?
- Find out what action the school intend to take to support your child.
- Provide information and resources to the school from Tourettes Action to help educate the teaching staff about the condition.
- Discuss the possibility of informing the rest of the class/school about TS to help reduce any misunderstanding, unwanted attention or bullying. Tourettes Action can provide power point presentations for primary and secondary schools.
- If your child has TS in combination with another condition such as Obsessive Compulsive Disorder (OCD), teaching staff may need extra information and suggestions of which difficulties are caused by which condition and how they should be treated.

- Share information about strategies you have found helpful at home to help create a more consistent approach to supporting your child.

- If your child is on medication, explain the possible side effects, and inform the school of any changes to medication.

Stay in communication with the school and meet with your child's class teacher and/or SENCO on a regular basis, keeping records of discussions about your child's progress. Don't wait until parent's evening to discuss any concerns you may be having, as they are often rushed and crowded.

Suppressing tics in school all day often leads to an explosion of tics at home once the school day is finished, and can leave the whole family feeling exhausted. There might be ways to better manage this, i.e. the child having the opportunity to release their tics over the course of the day, so it is worth exploring with the school how they might be able to accommodate this.

Current thinking suggests that the contrast in environment could trigger an increased activity of tics. For example, a structured school environment versus an unstructured home environment. Creating a structured transition between school and home may help ease the child from one environment to the next, with the view to reducing "tic explosions" after school.

Does my child have Special Educational Needs?

A pupil has SEN where their learning difficulty or disability calls for special educational provision, namely provision different from or additional to that normally available to pupils of the same age. Not every child with TS will be considered as having a disability because their symptoms may be mild to the degree where they don't impact in any way on the child's learning development. Typical TS and co-occurring symptoms which may impact on a child's learning development are physical and vocal tics which may make a student reluctant to read aloud, or ask/answer questions; motor tics of the head, eyes and neck which may interfere with reading; motor tics affecting handwriting or the ability to write for prolonged periods of time; "thought tics" which may inhibit auditory processing and Obsessive Compulsive Behaviours. There are many other activities which the relentless presence of TS may affect: communication, planning, time management, organisation and initiating tasks.

Who decides if my child has SEN?

Every school is required to identify and address the SEN of the pupils they support. The main criteria for considering whether a child has a special educational need, is whether they are "making expected progress." It is not based on their level of achievement within a key stage but on the tests that they will have at various stages of their school life.

As TS does not affect intellect, most children will be able to access the curriculum in the same way as their peers.If a parent feels that their child is not attaining the grades of which they think they are capable, then they should discuss this with their child's tutor in the first instance and other subject teachers. A child may potentially also have SEN if they have particular physical difficulties which make it difficult to access the curriculum.

Another potential difficulty in identifying SEN, is that children tend to suppress their tics in school and teachers can be unaware of how a child's TS impacts on them. For example, a child may experience severe tics and behaviours at home which leave the child exhausted and can make homework and sleep difficult. However, especially at High School, homework is a vital part of succeeding and you should discuss with teachers whether homework can be done during the school day or some other arrangement made.

Also there can be "hidden features" of TS, such as "thought tics," "intrusive thoughts," "internal physical tics" and OCD which may not be apparent to a teacher, yet can severely impact a child's learning.

What are the implications of my child having SEN?

For the majority of children with SEN, most will have their needs met in mainstream schools and colleges from the resources ordinarily available in mainstream settings. If your child has been identified as having SEN, this decision should be recorded in the school records and the pupil's parents must be formally informed.

School based levels of support

"Assess, Plan, Do, Review" (APDR). This phrase, is central to the new system and refers to a "graduated response" which teachers should apply to a child who has been identified as having difficulties. This is an official record which covers:

"Assess" - Identifies what the problem is

"Plan" - An appropriate strategy, taking into account how the child learns best

“Do” - Carry out the plan

“Review” - How it’s working

A teacher may implement multiple APDR cycles before discussing with the SENCO what additional strategies could be employed and whether the intervention of an outside agency would benefit the child. It is essential that the SENCO is involved in the process at this stage as an assessment for an EHCP will fail if this process is not followed.

Since the SEN reform came into effect on the 1st September 2014, the APDR process has replaced School Action and School Action Plus and made Independent Education Plans (IEP’s) outmoded practice.
One of the key changes is that pupils and their parents MUST be involved in the planning and support for the interventions. Usually the parents will be invited to take part in review meetings termly and be involved in supporting the strategies, but other arrangements for involvement may be possible.

If after a period of time it looks like a child isn’t responding adequately to these increasing levels of intervention, a school or a parent can seek a Statutory Assessment of the child’s special educational needs. There are no set number of APDR cycles needed before it’s decided a statutory assessment for an Education, Health and Care Plan (EHCP) is required. This will only be considered if it is felt that school has done everything it can within its remit and applications may be referred back if this is not felt to be the case.

An EHCP may be indicated where the need and cost of support to ensure the child’s planned outcomes are achieved, can no longer be reasonably met by the school’s own resources.

The key need is that the child is not making expected educational progress.

What is an EHC Plan?

Since the SEN reform came into effect on 1st September 2014, Statements of Special Educational Needs and Learning Difficulty Assessments (LDA) have been replaced by Education Health Care Plans.
Local Authorities (LA) have a duty to assess a child or young person’s education, health and care needs where they may have SEN and may need special educational provision.

A school/college, parent or young person can request a “statutory assessment” also known as an EHC needs assessment. Once your Local Authority receives a request for an assessment, they have six weeks to decide whether to carry one out.

Once an LA agrees to carry out an EHC needs assesment, they must, by law, seek advice and information from a number of key professionals as part of the process. The LA will then decide whether an EHC plan should be issued based on the collective evidence they have acquired.

As part of the EHC needs assessment, the child’s parent or young person has the right to ask the LA to seek advice from anyone within education, health or social care, as long as it is seen as a reasonable request. This can include a speech and language therapist, occupational therapist, physiotherapist or a professional from CAMHS.

Depending on whether the child has already been assessed by CAMHS it may be that this would be an essential part of the process.

EHC assessment timetable

The LA has 20 weeks (formally 26 weeks with a Statement of SEN) from the initial request for an EHC needs assessment to issue a Final EHC Plan having first given the parents/young person at least 15 days to consider and comment upon a draft version.

If the LA decides that an EHC Plan is not needed, they must tell you within 16 weeks of the date they received a request for an assessment. If you disagree with your Local Authority’s decision on the following points:

- Not proceeding with an EHC needs assessment
- Not producing the EHC Plan, or
- The special educational support that is included in the EHC Plan

You have the right to challenge it. Your LA will tell you when and how you can challenge their decisions.

What special educational provision can an EHC Plan provide?

An EHC assessment will set out the necessary special educational provision to be made for a child or your person. This could be teaching assistant support or funding a child’s education in a specific school. It may also say that the child’s needs can be met with no additional funding.

The SEN Code of Practice sets out various considerations for LA to take into account when reaching a decision regarding the EHC Plan, but if the child/young persons needs cannot be met within the resources ordinarily available in a mainstream setting, an EHC Plan should be issued.

Who has a duty to deliver what is in an EHC Plan?

It is the LA's legal duty to ensure that the educational provision of a child/young person's EHCP is made. The duty cannot be delegated to a school or a college whatever funding arrangements are in place. Where additional resource is provided it is the schools decision how to deploy that resource, e.g. 15 hours of teaching assistant time or an additional 3 hours of specialist teacher time.

For further information on EHC Plans please visit the IPSEA (Independent Parental Special Educational Advice) website, a national chairty providing free, legally based advice for families who have children with special educational needs.

Home Education: Teaching your child at home

Sometimes parents may choose to home educate their child if they feel that attending school is too challenging. The following organisations can provide further information on Home Education. www.ipsea.org.uk/what-you-need-to-know/ehc-plans

Home education UK
Provides information, resources and support to people home educating or considering home educating in the UK www.home-education.org.uk/index.htm

Home Education UK special hosts the HE-Special-UK mailing list: a group of families who Home Educate children with Special Educational Needs www.he-special.org.uk

The Advisory Centre for Education (ACE)
Produces a fact sheet on home education
www.ace-ed.org.uk

GOV UK
Contains useful advice on parent's rights and obligations with regards to home education www.gov.uk

The Home Education Advisory Service
A UK home education charity dedicated to the provision of advice and practical support for families who wish to educate their children at home www.heas.org.uk

Changing Schools

Changing school is something that all pupils have to go through at least once. Pupils and parents alike would probably rather avoid it, but most children will have to attend secondary school eventually. Some children may find that the school they are currently in is not the right environment for them to be at their best, maybe because of bullying by other children, or because the school is unable to adequately provide for the needs of a child with TS. In either circumstance, changing school can be an exciting but anxious experience. In both cases, there is information below which may help the process.

How to choose the right school?

Choosing the right school can be a stressful experience. The last thing you want is for your child to dislike it, or if they're moving, for them to have the same problems as before. Here are some suggestions about what you might want to do when looking at a new school:

Talk to people: Ask as many people as you know with children what their school is like, and ask the children as well. These will be the people, more than the council, or even the school, who can give you an honest and accurate picture of what things are like at the school. The more people you ask, the more you can build up a picture of what the school is like and whether your child will fit into it or not.

Visit the open days: All schools will have open days, and going to as many as you can could help you get a feel for the school. This might also be a good chance to talk to the teaching staff and see the grounds. Still, don't take everything at face value – the school is trying to attract pupils, so they are probably presenting you with the most positive view.

Observe some lessons: Even better than just going to the open day is going to see the school in action. Arrange with the head teacher or head of year to see some of the lessons. That way, you might see how the school functions on an ordinary day.

Meet with the teachers: It might be a good idea to have a sit down with the head teacher, head of year, or any other relevant teacher, such as the school's SENCO. You could discuss the problems that your child has been having and ask how they propose to deal with the problem should it arise at the new school. Talking about your child's strengths is useful too: you can ask how the teachers plan to get the most out of their skills. Be wary though if the school says, for example, that bullying doesn't take place. Bullies are unfortunately in every school: what is important is how the school deals with it.

Ask about support: It might be worth making a point of asking what the support structures are, how discipline works, whether there is a counsellor etc. That way you can assess whether it's good enough for your child.

Think carefully about what your child needs: There are lots of schools in the UK that might specialise in children with behavioural problems, and it might be recommended that your child attends one of these schools. However, it might be that your child needs emotional, rather than behavioural support: there is a crucial difference between the two. You will know best what your child needs. Check to see if the school caters to the specific needs of your child.

Be guided by your child: It may be obvious, but however good a school looks on paper, if a child doesn't like it, then they probably won't be happy there.

Ask to see the special needs policy: it might be worth asking for a written document or meeting with the head teacher or relevant teacher, to determine what your child will and will not be entitled to at the school.

School transfers

Changing schools can be a major disruption to a child's education and should not be taken lightly. Sometimes however, parents feel it is the only choice they have if the school repeatedly fail in their efforts to support their child and resolve problems. Before you make the decision about your child's future, make sure you have discussed the matter fully with the head teacher, and if necessary, officers from the Local Authority.

How to change schools

There are two options that you can choose from:

- Contact your local county council: If you ask the council for help, then they will guide you through the procedure, as the process varies from county to county.
- Approach the school yourself: If you decide to initiate the process yourself, then you call the admissions desk directly, and see if they have places. If they do, then set up a meeting with the head of year or head teacher, to talk about your child and the school.

Some people find switching school easy. For others it is harder, especially if places are unavailable, or the school is far away. As difficult as it may be at times, don't give up.

A good resource to use if you are trying to find a school with adequate facilities to cope with your child's specific needs is the Good School's Guide www.goodschoolsguide.co.uk

New SEN system Vs old SEN system

Useful facts

The views, wishes and feelings of children, young people and their parents and also their participation, must be central to every decision the LA makes in regard to assessing a child or young person's SEN and how to support them.

If a child has SEN under the old process, they may not under the new law as some areas such as behaviour have disappeared from the new criteria.

Statements of SEN no longer exist and all new provision will be through EHC Plans.

The threshold for EHC Plan is not higher than for statements - the legal threshold for when an LA has to carry out an assessment and issue a plan is the same as was previously.

An EHC Plan can be maintained for a young person up to the age of 25 if they remain in education or training and it remains necessary.

Depending on their age, if a child has a statement of SEN, they must be reviewed to evaluate if they need an EHCP.

The government has provided guidance setting out transition arrangements from the old system to the new to be completed by April 2018.

Useful organisations

The Independent Parental Special Education Advice (IPSEA)
A national charity providing free legally based, independent advice and support to families who have children with special educational needs.

How they can help: Problems with schools; requesting statutory assessment; proposed statements; annual reviews; disability discrimination; exclusion, etc.

Contact: www.ipsea.org.uk

ACE Education Advice
A charity offering a comprehensive range of advice and information on education issues. Their information is based on current education law and guidance and covers state funded education for children aged 5-16 years in England only.

How they can help: offer support and advice on Special Education Needs; anti-bullying; exclusion.

Contact: www.ace-ed.org.uk

Information, Advice and Support Services Network (IASSN)
Provide training to local information Advice and Support services (IAS) across the UK. IAS Services have a duty to provide information, advice and support to disabled children and young people and, those with SEN and their parents. There should be an IAS Service in every local authority.

Contact: cyp.iassnetwork.org.uk

SOS!SEN
The Independant Helpline for Special Educational Needs. They offer a free, friendly, independent and confidential telephone helpline for parents and others looking for information and advice on Special Educational Needs (SEN).

How they can help: specialise in helping people to find their way through the legal and procedural maze which is so daunting to so many who try to obtain satisfactory provision for a child's special needs.

Contact: www.sossen.org.uk

Tourettes Action Support

Tourettes Action has a range of resources for families and teachers with advice on supporting children with TS in school:

- Key facts for teachers leaflet - an easy-to-read leaflet that outlines the main facts that all teachers need to know when supporting a child with TS
- Power point presentations that can be used in primary and secondary schools to provide greater understanding of TS
- What Makes Us Tic leaflet – an introduction to TS
- A guidance booklet for teachers on education issues and TS

Recent media articles about education articles

TA can also arrange to speak to schools to help explain TS and offer support for children with TS. If you are a parent or teacher of a school who is struggling to understand and support a child with TS, TA can provide telephone and face to face advocacy support in England, Wales and Northern Ireland.

Please contact our Helpdesk to speak to us about this service by emailing help@tourettes-action.org.uk

TA also has factsheets with advice for young people with TS in higher and further education. You can download them from the website

www.tourettes-action.org.uk