

Tourette's Syndrome

What is Tourette Syndrome?

Tourette Syndrome is a neuro-developmental disorder which begins between the ages of 2 and 21 and lasts throughout a person's life.

What are the common features of Tourette Syndrome?

- Rapid, repetitive and involuntary muscle movements and vocalisations called 'tics'.
- Often involves behavioural difficulties.

Types of Tics

Tics are experienced as a build up of tension, are irresistible and eventually must be performed. Typically tics increase as a result of tension or stress and decrease with relaxation or concentration on an absorbing task.

Simple Tics

- *Motor - blinking, head jerking, shoulder shrugging, facial grimaces, nose twitching.*
- *Vocal - throat clearing, barking noises, squealing, grunting, gulping, sniffing, tongue clicking.*

Complex Tics

- *Motor - jumping, touching other people or things, twirling, repetitive movements of the torso or limbs, pulling at clothes, self-injurious actions*

including hitting and biting.

- Vocal - uttering words or phrases, swearing, echolalia (i.e. repeating a sound, word or phrase just heard), repeating own phrases.

Common difficulties often (but not always) experienced by the child with Tourette Syndrome:

- Obsessive Compulsive Disorder (OCD)
- Attention Deficit &/or Hyperactive Disorder (ADD/ADHD)
- Attention difficulties
- Sleep difficulties
- Depression
- Low self-esteem
- Learning difficulties, such as dyslexia, arithmetic or perceptual difficulties, handwriting difficulties.
- Social isolation
- Poor academic performance
- Anxiety
- Aggression
- Oppositional Defiant Disorder (ODD)

Management strategies that support the child with Tourette Syndrome (at preschool, school and/or home):

- Medication can be used to decrease the effects of 'tics'.
- Psychologists can provide support to families for behaviour management and educating those involved in the care of the child about Tourette Syndrome.
- Psychology can also help a person to manage the social and emotional problems that can occur with Tourette Syndrome.
- Behavioural Treatments, such as Cognitive Behavioural Intervention for Tics (CBIT) can be used to help reduce the effects of tics - these treatments may help a person to develop better awareness and learn to control their tics better. However, the tics are not eliminated but may reduce in severity.

- Development of a sensory diet.
- Improving reading and writing difficulties.

Occupational Therapy approaches and activities that can support the child with Tourette Syndrome and/or their carers include:

- **Expanding abilities:** Developing a gradually broadening range of skill areas.
- **Social stories:** Providing ideas and education around social story development.
- **School transition:** Advocating and professionally supporting the transition to school, and liaising with teachers, as required.
- **Visual cues** can be used to support routine and to introduce new activities, or a change in, tasks.
- **Gross and fine motor skills:** Determining the current age level of a child's gross and fine motor abilities.
- **Devise goals:** Setting functional and achievable goals in collaboration with the child, parents and teachers so that therapy has a common focus beneficial to everyone involved.
- **Educating** parents, carers, teachers and others involved in the child's care about Tourette Syndrome and the age appropriate skills a child should be demonstrating.
- **Direct skill teaching** through a task based approach.
- **Management strategies:** Providing management strategies/ideas to assist the child in the home, at school, and the community.
- **Task engagement:** Providing alternative ways to encourage task engagement.
- **Developing underlying skills** necessary to support whole body (gross motor) and hand dexterity (fine motor) skills, such as providing activities to support:
 - balance and coordination
 - strength and endurance
 - attention and alertness
 - body awareness
 - movement planning

Speech Therapy approaches and activities that can support the child with Tourette Syndrome and/or their carers include:

- **Speech and language assessment** to help the family to understand how the child is processing, understanding, learning and using language and communication.
- **Communication strategies:** Providing the family with strategies and techniques to increase and enhance communication with the child.
- **Daily activities:** Helping the child to understand the environment, routines and language.
- **Developing language:** Helping the child to understand and use richer language and to use language more spontaneously.
- **Conversation skills:** Developing conversation skills (e.g. back and forth exchange, turn taking).
- **Concept skills:** Developing concept skills, especially abstract concepts, such as time (e.g. yesterday, before, after).
- **Visuals** can be used to help with understanding and the child's ability to express their needs, wants, thoughts and ideas.
- **Social skills:** Development of social skills (i.e. knowing when, how to use language in social situations).
- **Enhancing verbal and non-verbal communication** including natural gestures, speech, signs, pictures and written words.
- **Visual strategies:** Using visual information to help understand, organise and plan the routine for the day.
- **Liaising with educational staff** regarding nature of the difficulties and ways to help the child to access the curriculum.

Why should I seek therapy for my child with Tourette Syndrome?

Diagnosis alone is NOT the solution. It simply opens the door to getting the help that is needed by arming all involved with the relevant information.

The 'help' still needs to be provided. The help that is provided (at least from a therapy perspective) will reflect:

- First and foremost what medical intervention is needed.
- What the parents/teachers/carers biggest concerns are for the child (i.e. what are the most significant functional challenges).
- The specific areas that are problematic to the child (which will vary even within children with the same diagnosis).
- The capacity of the child's environments to meet the child's needs.

If left untreated, the child with Tourette Syndrome may have difficulties with:

- Following instructions within the home, kindergarten or school environment.
- Vocabulary whereby a child cannot clearly get their message across due to limited word knowledge.
- Understanding jokes and figurative language during interactions with others, and when watching TV shows and movies and reading books.
- Learning to talk, speech intelligibility and clarity.
- Managing a full school day due to poor strength and endurance.
- Participating in sporting activities leading to an inactive lifestyle, increasing the risks of other health related issues such as obesity, diabetes, cardiovascular disease or similar conditions.
- Self esteem and confidence when they realise their skills do not match their peers.
- Fine motor skills (e.g. writing, drawing and cutting) due to poor core stability, meaning they do not have a strong base to support the use of their arms and hands.
- Completing self-care tasks (e.g. doing up shoelaces, buttons, zips, using cutlery).
- Self regulation and behaviour as the child is unable to regulate themselves appropriately to settle and attend to a task for extended periods of time.
- Sleep habits, impacting upon skill development due to fatigue.
- Accessing the curriculum because they are unable to attend to tasks long enough to complete assessment criteria.
- Anxiety and stress in a variety of situations leading to difficulty reaching their academic potential.

- Reading/understanding social situations and being perceived as 'rude' by others.
- Social isolation because they are unable to cope in group situations or busy environments, impacting on their ability to form and maintain friendships.
- Social communication, such as eye contact, appropriate distance when talking to someone, turn-taking within a conversation.
- Academic performance: Developing literacy skills such as reading and writing and coping in the academic environment.
- Academic assessment: Completing tests, exams and academic tasks in higher education.

More specific implications of not seeking treatment will be influenced by the common difficulties that are most influencing your individual child.

For more information see the relevant fact sheets under areas of concern or refer to the other relevant resources section below.

What does the diagnosis of Tourette Syndrome really mean for the child?

Diagnoses are used to label a specific set of symptoms that are being experienced by a child. This label then helps to narrow down and specifically tailor what:

- Other issues commonly occur simultaneously.
- Medication might be appropriate.
- Therapies might help the child (e.g. Medical, Occupational Therapy, Speech Therapy, Psychology).
- Course of intervention (medical and/or allied health) might be and what outcome might be expected (prognosis).
- Can be done to help the child.

A diagnosis helps the child and their carers (parents, teachers, health professionals, carers) to:

- Access information about the relevant cluster of symptoms.
- Communicate the salient features of the child's challenges to all people

involved in the child's care.

- Possibly interpret certain behaviours differently in light of the diagnosis.
- Obtain information about what can be done to help the child.
- Determine specifically where and how to help the child.
- Access funding or services that might not otherwise be accessible.

Contact us today to make an initial enquiry or book an assessment for your child
on 1800 KID SENSE (1800 543 736)

