



The Tuberos Sclerosis Association

TSC Information for Teachers

What is TSC?

Tuberous sclerosis complex (TSC) is a multi-system genetic disorder that can cause growths (sometimes called tubers or lesions) in many organs including the skin, kidney, brain, heart, eyes and lungs. Presenting features may be in any or all of these organs and can be difficult to predict. The severity of TSC can range from mild to severe in all systems, such as only having a few skin abnormalities or having very prominent skin features; from a total absence of seizures to treatment resistant epilepsy; from very high intelligence to profound intellectual disability.

At least two children born each day will have TSC. Current estimates place TSC affected births at one in 6,000. Nearly 1 million people worldwide are known to have TSC, with approximately 8,000 people in the UK. There are many undiagnosed cases due to unfamiliarity with TSC and the mild form symptoms may take in some people.

Most people with TSC will live a normal life span. There can be complications in some organs such as the kidneys and brain that can lead to severe difficulties and even death if left untreated. To reduce these dangers, people with TSC should be monitored throughout their life by their physician for potential complications. Thanks to research findings and improved medical therapies, people with tuberous sclerosis can expect improved health care.

TSC and the Classroom

Many factors may influence how well a child with TSC may do in a classroom or educational setting. Children with TSC will have a huge range of presentations. It will be important to consider where every child falls in terms of their own strengths and weaknesses. Here we list some of the common factors to consider:

Intelligence and Intellectual Disability.

About 50% of children with TSC will have normal intellectual abilities and some may be intellectually gifted. About 30% of children with TSC will however have profound intellectual disability and will need special schooling and will have high levels of care needs. Some children have better verbal (auditory) skills; others will be better at non-verbal (visual and spatial skills). It will be important to determine where every child is at.

Scholastic difficulties

Many children with TSC have additional educational needs. Even children with normal intelligence often have specific problems with reading, maths, writing and language-based tasks. These children may require extra help in a classroom setting.

A teacher who is aware of the nature of the condition is better able to help the child develop to maximum potential.

Language and Communication Difficulties:

Some children with TSC will have problems associated with specific language delays. While receptive language is usually good, some children may have impaired use of interactive language for social communication. Extreme word retrieval difficulties can be a problem in expressive language.

Abstract language and concepts can be difficult to grasp and metaphorical expressions may be rarely used or understood. As far as auditory language is concerned, instructions may be heard but not retained long enough for action.

ADHD and Attentional difficulties

Many children with TSC have trouble focusing, concentrating and may display many of the features of ADHD (Attention Deficit Hyperactivity Disorder). Even in children who don't appear overactive or impulsive, attention difficulties are common and these, too, can cause learning problems in ordinary class work. Many children struggle with 'multi-tasking', when they have to do two things at the same time. Attention and language problems can also interfere with memory and other skills in the classroom.

Autism Spectrum Disorders and Social Interaction:

About half of children with TSC will have an autism spectrum disorder (ASD). This may present with behaviours such as difficulty in social relationships, obsessional behaviours, a need for structure and routine and communication/ language difficulties.

Even children with TSC who don't have ASD may have difficulty with social relationships and need support to make friends with their peer group. Through careful observation teachers, parents and other professionals can work together to develop strategies to help the affected child obtain a level of comfort with peers within the classroom.

Obsessional behaviour or insistence on sameness is one of the autistic characteristics exhibited by some children with TSC. Changes in routine or separation from a prized possession can lead to significant disruptive behaviours. These challenging behaviours are often the child's method of communication due to a developmental delay in speech and language. A technique to consider when supporting a child with autism in learning includes one-to-one teaching in a highly structured environment, where each task is broken down into simple steps and instruction is repeated over a short period.

Many other challenging behaviours are seen in TSC. These include aggressive outbursts, temper tantrums and difficulty regulating their own emotions. It is easy to dismiss such behavioural problems as either being just part of the condition or as deliberately willful or stubborn. Parents, teachers and other professionals should be encouraged to make a careful assessment of such behaviours and to be aware of the range of medical conditions that might arise in TSC that could lead to behaviour problems in a child, particularly a child who has communication difficulties.

Epilepsy:

Another manifestation of TSC is the high incidence of epilepsy that causes seizure activity in children. Virtually all seizure types are possible in TSC. While some seizure types are instantly recognizable, other seizures are far less obvious and may go unrecognized by teachers. Simple partial seizures are not dramatic to the onlooker. The individual may experience a tingling in part of the body or odd sensations such as fear, recall of past memories or strange sounds, tastes and smells. In a complex partial seizure, the person may exhibit '*automatisms*', consisting of repeated motor actions such as lip smacking, fiddling with objects or walking about. In an absence seizure, a person may just go blank for a few seconds, after which they will continue with whatever they were saying or doing.

If seizures occur on a regular basis the implications for learning are serious. Teachers should be aware of the different seizure types and the possibility that learning might be interrupted by subtle seizure activity. Anti-epileptic medications may have side effects, such as sedation or hyperactivity, which may affect the ability to learn.

Other Health Concerns:

Occasionally a child with TSC can develop a type of brain tumor called a Subependymal Giant Cell Astrocytoma (SEGA). Signs of this include headaches, vomiting, double vision and imbalance. Kidney tumors can sometimes cause pain, blood in the urine and anemia. Some children with these problems may begin to self-mutilate and become aggressive, destructive and act out of character. It is crucial to note that any such behaviour changes should be investigated to eliminate a medical cause.

It is important that those who teach children with TSC are aware of the possibility of epilepsy, specific learning problems, attention deficit and poor concentration, together with the possibility of certain language and communication difficulties. By being aware of the condition and its manifestations, teachers, parents and other professionals can work in partnership to create an environment that allows the child with TSC to reach full potential.

For more information on tuberous sclerosis complex, contact the Tuberous Sclerosis Association on 0121 4456970 or view other areas at www.tuberous-sclerosis.org