

Tuberous Sclerosis Complex Information for Teachers

What is TSC?

Tuberous sclerosis complex (TSC) is a multi-system genetic disorder that can cause tumor growth in all of the vital 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, such as skin abnormalities, to severe, such as seizures, mental retardation or renal failure. Most individuals mildly affected by TSC lead active and productive lives.

The diagnosis of TSC and further evaluation of at-risk persons involve careful examination of the skin, heart, retinas, brain and kidneys. It is important to understand the manifestations and to follow the recommendations for screening and evaluating TSC. Genetic testing may now aid in making a diagnosis of TSC.

Population-based studies suggest TSC has a prevalence of 1 in 9,000 individuals, but its incidence has been estimated to be 1 in 6,000 live births. It is estimated that approximately 50,000 Americans and 1 million individuals worldwide have TSC. TSC occurs in all races and ethnic groups, and in both genders.

TSC and the Classroom

Although some affected children may have significant problems such as epilepsy and severe learning disabilities, many children who have TSC exhibit no symptoms in the classroom. The condition may impact the child's ability to learn, his or her behavior and relationships. A teacher who is aware of the nature of the condition is better able to help the child develop to maximum potential.

With the development of the child's Individual Education Plan (IEP), parents, teachers and other professionals will determine the child's classroom placement to each child's specific abilities in accordance with the *Individuals with Disabilities Education Act (IDEA)*. Under this law, students have the right to a free and appropriate education in schools receiving federal funding and educated in the least restrictive setting possible.

TSC presents itself in children on a wide spectrum. Children with TSC can have little or no educational difficulties associated with the condition. Others with mild learning disabilities may require extra help in certain areas, specifically reading, writing, math or language. Additionally, 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, and 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. Attention deficit disorders are common and these, too, can cause learning problems in ordinary class work.



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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.

Some children with TSC exhibit autistic behaviors, including difficulty in social relationships with peers, obsessive behavior, a need for structure and routine, and communication/ language delay.

Children with TSC may have difficulty with social relationships and need support to make friends with their peer group. Through careful observation and thoughtful recommendations during the special education evaluation process 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.

Obsessive behavior 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 demonstrated behavior. The demonstrated behavior is often 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.

Because difficult behavior may be part of TSC, it is easy to dismiss all behavior problems as being just part of the condition. Parents, teachers and other professionals should be aware of medical a problem that might arise in TSC that could lead to behavior problems in a child, particularly one who has communication difficulties.

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 behavior 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 disease 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 Alliance at 800-225-6872 or visit www.tsalliance.org.

***Tuberous Sclerosis Alliance Information Sheets are intended to provide basic information about TSC. They are not intended to, nor do they, constitute medical or other advice. Readers are warned not to take any action with regard to medical treatment without first consulting a physician. The TS Alliance does not promote or recommend any treatment, therapy, institution or health care plan.*

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