

They require one-to-one teaching in a highly structured environment, where each task is broken down into simple steps and instruction is given over and over again for short periods of time.

Obsessive behaviour or insistence on sameness is one of the autistic characteristics exhibited by some people with TS. Changes in routine or separation from a prized possession can lead to significant tantrums.

Lack of useful speech is a problem for about 80% of TS children severely affected by the condition. For those with a few words, language may begin with echolalia, but some TS children may never have any speech, since they are not motivated to communicate.

Hyperactivity is well-recognised in TS and varies in degree from a child who is unable to sit and concentrate for more than a few minutes at a time to a child who is constantly on the move, flapping his hands and jumping around, climbing wherever possible and frequently being destructive.

Because difficult behaviour can be a symptom of TS, it is easy to dismiss all behaviour problems as being just part of the condition. Parents and teachers alike should be aware of medical problems which might arise in TS which could lead to behaviour problems in a child, particularly a child who is unable to speak. Occasionally a child with TS develops a brain tumour and signs to look out for are headaches, vomiting, double vision and unsteadiness. If these symptoms occur a doctor should be notified straight away.

Kidney tumours, too, can sometimes cause symptoms of pain in the flank, blood in the urine and anaemia. Some children with these problems have started to self-mutilate and become aggressive and destructive, and quite out of character with their normal behaviour. Any such changes should be investigated to eliminate a medical cause.

Teachers should also be aware that children with the TS facial rash may be bullied by other children who call them names and make their lives miserable. Fortunately, treatment can be offered for the rash.

It is important that those who teach children with TS 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. Many children with normal IQ's will nevertheless require additional support in schools to help them achieve their full potential.

Prognosis

Contrary to what was frequently stated in the past, the prognosis for the majority of people with Tuberous Sclerosis is excellent and over half will lead normal lives. Whilst it is true that on rare occasions premature death results from brain tumours, kidney failure or (even more rarely) heart or lung involvement, for most people (including those with severe learning disability) life expectancy is good.

The Tuberous Sclerosis Association

The TSA was set up in 1977 to support people affected by TS and their families, to educate people about the condition, and to encourage research. The Association has a wide variety of literature available and for further details please contact us at the address below:

Further information on TS and the work of the TSA can be obtained from:

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Tuberous Sclerosis Association

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Registered in England No. 2900107. Registered Charity No. 1039549.

September.2006.



What the Teacher of a Child with Tuberous Sclerosis Should Know



This leaflet has been written to alert teachers to some of the problems which a child with Tuberous Sclerosis (TS) might have. Although some affected children will have significant problems such as epilepsy and severe learning disability, there are many mild cases where the symptoms may go unnoticed in the classroom yet which may have a significant effect upon the child's ability to learn, his behaviour or his relationships. A teacher who is aware of the nature of the condition is better able to help the child develop his skills to his maximum potential.

What is Tuberous Sclerosis

Tuberous Sclerosis is a complex genetic disorder affecting 1 in 7,000 newborn babies. It derives its name from the tuber-like growths on the brain which calcify and become hard or sclerotic.

These brain lesions are not only associated with epilepsy and learning disabilities but also with behavioural difficulties such as autism, hyperactivity, aggression and unpredictable temper tantrums. Almost any other organ in the body can be affected, notably the skin, eyes, heart, kidneys, bones and lung, although only rarely do they cause problems.

The severity of TS can vary enormously and around 60% of those affected are of normal intelligence. The remainder have some degree of learning disability, with a high proportion being severely affected. In this latter group, two thirds have autistic behaviour - i.e. poor social relationships, language difficulties and ritualistic or compulsive behaviours.

About 80% of people with TS will have epilepsy at some time during their lives. Although some will be well-controlled as a result of anti-epileptic drugs, many others will continue to have fits regardless of medication.

In addition to the above symptoms, there are a number of skin signs which are associated with TS: white skin patches, a facial rash around the nose and cheeks, and leathery patches of skin mainly on the lower back.

Possible Effects on Behaviour and Learning

Not all children with TS will actually have been diagnosed. For example, a child with the facial rash may have mistakenly been diagnosed as having acne; or a diagnosis of TS may have been missed in a child who has no obvious sign of the facial rash yet who has epilepsy, challenging behaviour and is severely affected by the disorder.

Children with TS and little or no problems associated with the condition will be in mainstream education. Others with mild learning disabilities may be integrated into mainstream schooling, requiring extra help in certain areas, specifically reading, writing, maths or language. Of the children with TS who are within the normal range of intelligence, many will have problems associated with specific language delays. Whilst 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 this, too, can cause learning problems in ordinary class work. From this it is easy to see how short-term memory problems and attention deficit could cause difficulties between the child and his parents or teacher.

The more severely affected children may be in special schools and the majority of these will suffer from epilepsy. Teachers in special schools are more used to coping with epilepsy than those in mainstream education. Virtually all seizure types are possible in TS and, whilst some forms of epilepsy (notably the generalised tonic-clonic or grand-mal seizures) are instantly recognisable, other seizures are far more subtle and may go unrecognised by teachers. Simple partial seizures are not dramatic to the onlooker, with the affected individual possibly

experiencing a tingling in part of their body or odd sensations such as fear, a rising feeling in their stomach, 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 this happens on a regular basis, the implications for learning are serious: this can be compared with listening to a radio programme with frequent interruptions as someone turns the radio on and off, making the entire programme disjointed and very difficult to follow. Teachers should be aware of the different seizure types and the possibility that learning might be interrupted by subtle seizure activity.

Anti-epileptic drugs can have side-effects, such as sedation or hyperactivity, which may affect the child's ability to learn. If teachers notice such side-effects, they should draw these to medical attention. Parents and their doctors need to decide the optimum solution for their child. Is it better to have a child whose fits are controlled but who is so sedated that he is unable to learn, or find a balance between acceptable fit control and a happier, more alert and responsive child?

Whilst some children with TS may be sociable, there are those both in mainstream and special education who experience poor social relationships and find it difficult to make friends with their peer group. They find it easier mixing with adults or with children younger than themselves.

Autistic behaviour is found in over 60% of TS children with severe learning disabilities. Severely autistic children do not relate to others and cannot be taught as part of a social group. They will not learn through play in the way other children do.