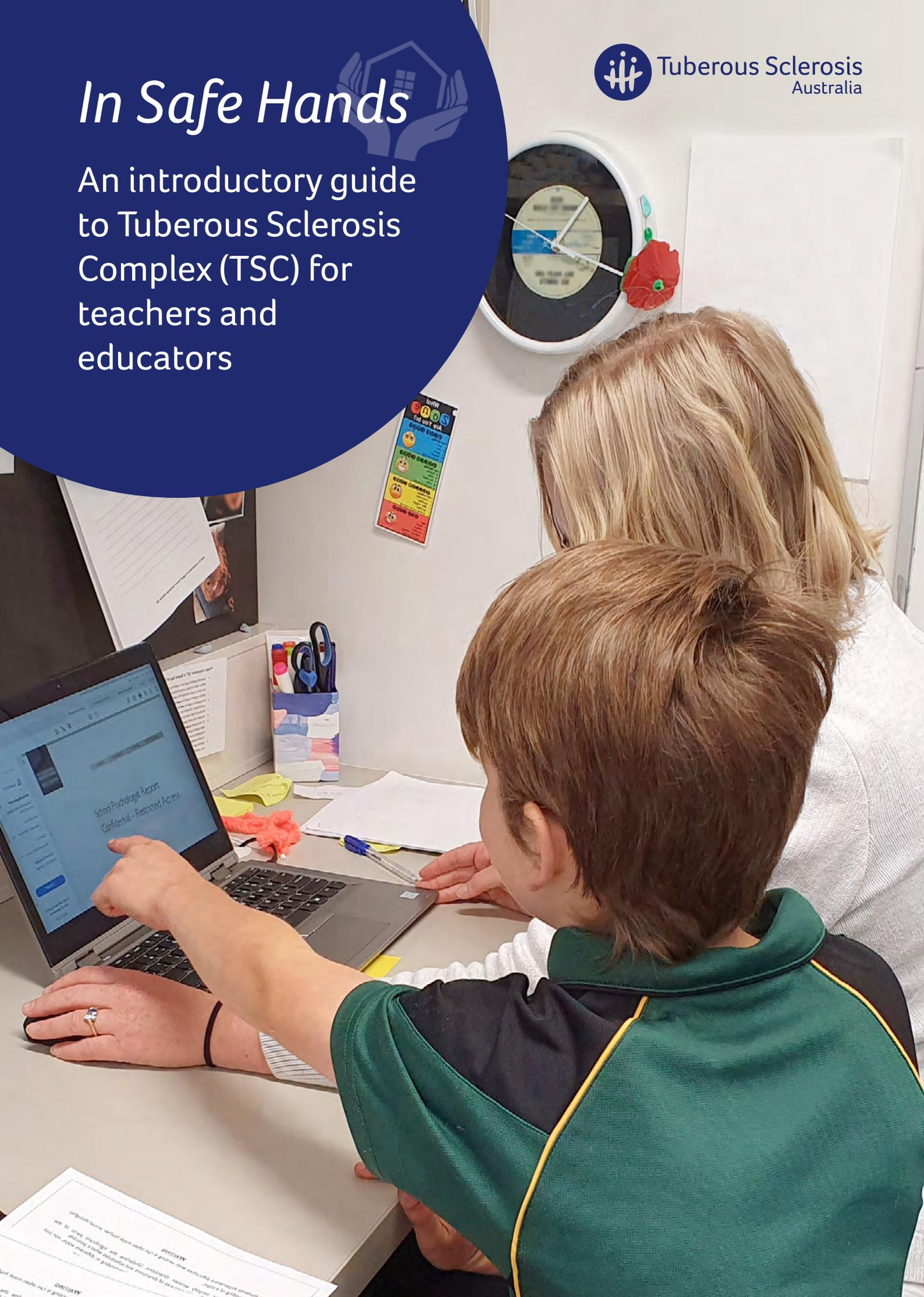




Tuberous Sclerosis  
Australia

# *In Safe Hands*

An introductory guide  
to Tuberous Sclerosis  
Complex (TSC) for  
teachers and  
educators



# Table of contents

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<b>Purpose of this guide</b> .....	<b>3</b>
<b>Part I: Understanding TSC</b> .....	<b>4</b>
What is TSC? .....	4
Treatment options .....	4
Infection prevention and control .....	4
TSC associated neuropsychiatric disorders (TAND) .....	5
Epilepsy and seizures .....	6
Epilepsy .....	6
Seizures .....	6
<b>Part II: The child with TSC in your classroom</b> .....	<b>8</b>
Individual education plans (IEPs) .....	8
Notice and discuss behaviour changes or concerns .....	9
Your relationship with a child affected by TSC .....	9
Your relationship with the family of a child affected by TSC .....	10
Teamwork .....	10
The transition to high school .....	10
Thank you for reading this guide .....	11
<b>Additional information</b> .....	<b>12</b>
<b>Acknowledgement</b> .....	<b>12</b>
<b>Disclaimer</b> .....	<b>12</b>

Front cover: Caleb Chalk with one of his teachers at Blackmans Bay Primary School, Tasmania.

# Purpose of this guide

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You are probably reading this guide because you are a teacher or educator of a child affected by Tuberous Sclerosis Complex (TSC). Thank you for taking the time to find out more about this rare disease. This guide will help you in understanding TSC and will provide some insights into the learning challenges a child living with this condition might face. These challenges can include cognitive difficulties as well as behavioural, mental health and physical challenges.

TSC affects every child differently and the range of cognitive abilities in affected children is highly variable so not all the information in this guide may be relevant in understanding how TSC affects the child in your classroom.

Some children living with TSC may be in good general health, while others are severely limited by the disease and unable to attend school regularly. Even if you have had a child with TSC in your classroom in the past, do not assume you understand the needs of another child with TSC. There is nothing consistent about TSC except that it is inconsistent!

A team approach provides the best learning model for a child with TSC.

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TSC is a complex disease and it can be difficult for parents to explain it quickly to a teacher or educator. Teaching staff need to understand that while every child with TSC is different, they are at risk of having problems with executive functioning, sustaining attention and specific academic skills, even if they don't have a diagnosable intellectual disability. Helping teachers and educators to understand this as early as possible and become part of the support team for that child can make a real difference.



*Vanessa Sarkozy, Developmental Paediatrician at Sydney Children's Hospital, Randwick*

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# Part I: Understanding TSC

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## What is TSC?

TSC is a rare, non-contagious, genetic condition that can cause growths (non-malignant tumours) to develop in many organs of the body including the brain, skin, heart, lungs and kidneys. Any or all of these organs may be affected. TSC causes different signs and symptoms in each person who is affected and can range from treatable skin abnormalities to severe epilepsy, intellectual disability and autism.

TSC affects each person differently. There is no reliable way to predict how TSC will affect a particular child.

### **More information**

For more on the signs and symptoms of TSC see: <https://tsa.org.au/information/>

## Treatment options

There is no known cure for TSC but the good news is that over the last 10 years, research has changed the way we understand, manage and treat this complicated disease. This means a child can now benefit from new treatments and early interventions that may reduce the impact TSC will have on their life.

There are now several medications that can help with epilepsy management and tumour growth. Many children affected by TSC have to experiment with different medications and doses of those medications to hopefully get effective control of their symptoms.

Many children with TSC act differently when starting new medications or changing the dosage of medication. Medication may cause hyperactivity, aggressive behaviours or, conversely, cause a child to be sleepy and drowsy. Medications can also cause a change in appetite, alertness and moods.

### **Infection prevention and control**

Some children living with TSC are on medications that reduce their immunity. It is important that they avoid infections. Good hygiene practices should be implemented, such as:

- keeping a distance of 1.5 metres from people who have a cold, flu or an infection in all settings, especially indoors
- ensuring soap and water and alcohol-based hand gel is readily available in the classroom, as well as a ready supply of tissues
- encouraging everyone to wash their hands after using commonly shared items such as pencil sharpeners, lab equipment etc.
- encouraging children not to share personal items such as straws or eating utensils
- encouraging children to cover their coughs or sneezes with a tissue then throwing the tissue away immediately and washing or cleaning hands, or coughing or sneezing into their inner elbow if a tissue is not available.

## TSC associated neuropsychiatric disorders (TAND)

Almost 90% of people affected by TSC will suffer from one or more TSC associated neuropsychiatric disorders (TAND) over their lifetime. The level of severity varies widely. TAND can affect a child's quality of life and their education and learning. The TAND Checklist is a helpful screening tool.

### TAND can impact six areas

#### **Behaviour**

Children with TSC may have some of the following behaviours of concern:

- Aggression
- Explosive behaviour
- Inattention
- Self-injury
- Anxiety
- Extreme shyness
- Poor eye contact
- Sleep-related issues
- Depressed mood
- Hyperactivity
- Repetitive behaviours

#### **Psychiatric**

Examples of psychiatric disorders children with TSC may be affected by include:

- Anxiety disorder
- Depressive disorder
- Attention Deficit Hyper-activity Disorder (ADHD)
- Autism Spectrum Disorder (ASD)

#### **Intellectual**

Learning problems in children with TSC may include:

- Intellectual disability
- Language disorders
- Uneven intellectual profiles

#### **Academic**

Children with TSC struggle most commonly in the following academic areas:

- Mathematics
- Writing
- Reading
- Spelling

#### **Neuropsychological**

Some children with TSC may struggle with one or more of the following neuropsychological issues:

- Attentional switching
- Memory recall
- Cognitive flexibility
- Spatial working memory
- Dual tasking
- Sustained attention

#### **Psychosocial**

Children with TSC may have difficulties dealing with:

- Parental stress
- Self-esteem
- Relationship difficulties
- Self-efficacy

#### **More information**

For more on TAND see: <https://tsa.org.au/information/tand>



One thing I did at Caleb's initial learning plan meeting was to look at the TSA website with his teacher and the support teacher. A lot of questions and discussion arose from looking at the website together. I found the TAND questionnaire to be a very useful resource. It explains the importance of monitoring children with TSC and how things can change.

*Miriam Chalk, mother of Caleb, who is now in Year 5*



## Epilepsy and seizures

Epilepsy that causes seizure activity is very common in children with TSC.

### *Epilepsy*

Epilepsy may affect a child's learning and development, and this may be due to seizures, sleep quality or side effects of medications such as sleepiness or hyperactivity. This may cause impacts on memory, concentration, mood and behaviour. In addition to medical treatment to manage seizures, children may benefit from early intervention and additional supports in school.

**All children with epilepsy must have a Seizure Management Plan, which their medical team will be happy to provide and update. It provides management strategies and guidance on supervision and safety.**

Having an epilepsy educated staff team as well as an individualised Seizure Management Plan for each child with epilepsy underpins a safe and nurturing environment.

### *Seizures*

Seizures occur when there is a disruption to the normal electrical activity of the brain. There are many different types of seizures depending on where in the brain the abnormal electrical activity occurs. Most seizures fall into two categories:

- **Focal**, which involve one small area of the brain, or
- **Generalised**, which involve the whole brain.

In TSC focal seizures are the most common, but virtually all seizure types are possible (there are over 40 and in some cases these can be frequent and/or severe). While some seizure types are instantly recognisable, others are far less obvious and present as staring episodes, subtle jerks or movements, which often go unrecognised. Some children will have seizures during sleep and/or at the time of awakening which may leave them sleepy and lethargic throughout the day

**Focal seizures** are different depending on which part of the brain is affected. They can be quite subtle and difficult to recognise in some cases. Symptoms of focal seizures can include:

- a feeling of déjà vu
- numbness or tingling
- single sided body movement
- unusual or repetitive behaviours.

The child may maintain awareness and consciousness – this is known as a **focal with awareness seizure**.

In some cases, the child may lose awareness and not be able to respond, or their response may be confused, and after the seizure they may have no memory of the seizure – this is known as a **focal with impaired awareness seizure**.

In generalised seizures, there can sometimes be a loss of consciousness. Some of the different types of generalised seizures and their associated symptoms include:

- **Tonic clonic** – body stiffening and jerking
- **Absence** – a brief lack of awareness
- **Atonic** – sudden loss of muscle tone that may cause the person to fall to the ground or a sudden head nod
- **Myoclonic** – sudden single jerks of limb/s, trunk.

There are also many others.

Many children have identified triggers that make their seizures more likely to occur.

Whenever there is seizure activity you should refer to the child's Seizure Management Plan. In general, if a convulsive seizure lasts longer than 5 minutes, or you are very worried, you should call an ambulance. There are also instances when an ambulance should be called sooner than this general rule eg, if this is a new presentation, an injury occurs, there are difficulties breathing or the seizure occurs in water.

It is important to have ongoing communication with a child's parents about seizure activity. The child's medical team will be working to reduce seizures and the information you provide can be very helpful in understanding the impact of medication changes. There might be times when you will be asked to help the parents and doctors by monitoring and documenting seizure activity including the date and time, what occurred before, during and after the seizure, the duration and a detailed description of the event. This information can assist in developing effective treatment plans in addition to identifying triggers and improving overall seizure control.

### *Training*

If you would like to learn more about seizures the epilepsy nurse/educator from your local hospital or a representative from a national or state-based epilepsy organisation such as Epilepsy Australia (<http://epilepsyaustralia.net/epilepsy-training/>) or Epilepsy Action Australia (<https://epilepsy.org.au/education-training/>) can provide professional education.

Schools can be accredited for accessing training and resources in epilepsy – see: <https://epilepsy.org.au/education-training/seizure-smart-schools/>

### **More information**

For more on epilepsy see:

<https://tsa.org.au/information/epilepsy/>

<https://epilepsy.org.au/about-epilepsy/factsheets-and-brochures/>

<https://epilepsy.org.au/schools/>

<https://epilepsy.org.au/about-epilepsy/living-with-epilepsy/information-for-teachers/>

<http://pennsw.com.au/> (although this is a NSW-based resource, the information is universal)

For more on seizure first aid and seizure management plans see:

<https://epilepsy.org.au/about-epilepsy/first-aid/>

## Part II: The child with TSC in your classroom

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Many children who are affected by TSC will exhibit no symptoms in the classroom and can participate in mainstream schooling in the same way as a child without TSC.

Other children may require extra help in certain areas, specifically reading, writing, maths or language. These children may have normal (average) cognitive skills (so average learning potential) but struggle to learn due to Specific Learning Disorders. These children have a capacity to learn and need specialist learning support. This is a common issue in children with TSC. Additionally, children with TSC can have some very specific deficits often with visuospatial and fluid reasoning components of learning which need specialist neuropsychology assessment and can lead to unusual patterns of strength and difficulties which could be misinterpreted as behavioural – eg, the child is seen as not interested or lazy as they only struggle in really specific aspects of learning.

Children with TSC who have significant problems, such as severe epilepsy and/or intellectual disabilities who struggle to learn due to cognitive issues will learn more slowly and have difficulties with abstract concepts. These children will need additional and individualised support.

Families of children with TSC are often anxious about whether a school, day care facility or preschool can accommodate their child's needs. As a teacher or educator, you can provide considerable reassurance to both the child and their family by working with them and other professionals to ensure a positive learning experience. Meet with the family to find out about their child's TSC and how it affects them. If possible, ask them to complete a summary particular to their child using a personal information form like the template found on our website. Work together to determine the best way to support and meet their child's needs as they progress through school.

A child who is affected by TSC may worry about being different from their peers and the condition may impact their behaviour and/or relationships. A teacher or educator who is aware of the nature of the condition is better able to help them get the most out of school and develop to their maximum potential.

### Individual education plans (IEPs)

Individual education plans (IEPs), or individual learning plans/learning improvement plans assist children who need a range of supports with their education, including children affected by TSC. They are written statements that describe the adjustments, goals and strategies to meet a child's unique learning needs. The best plan starts with and builds on the child's strengths and interests.

It is important to have a good baseline of the child's abilities and understand how they learn. TSC experts recommend all children diagnosed with TSC have a thorough developmental and behaviour evaluation at the time of diagnosis so that early intervention can be implemented.

An evaluation may also be useful at times of transition such as from primary to secondary school or when the child does not seem to be coping.

An educational evaluation assesses specific cognitive abilities affected by any TSC lesions in the brain. It provides valuable information about a child's development in areas such as language, memory, attention, perception, coordination and personality.

Many parents of children with TSC will already be working with a neuropsychologist, psychologist and/or paediatrician and have current assessments. The recommendations in these evaluations include

valuable information that will support the development of an IEP that best supports the needs of the child.

School counsellors are also an important resource to support families and educators to understand each child's strengths, difficulties and specific needs.

The needs of a child with TSC may change over time and the IEP may need to be modified more than once during a school year.

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Liam has an IEP and we have met with his teacher, the principal or deputy, the support coordinator and the school's psychologist at the start of each year. This meeting has provided a good opportunity to talk about Liam's TSC diagnosis, his particular individual needs and set up a plan for the year ahead. Throughout the year any concerns we've had have usually been addressed via email. At the end of each year we have discussed who his teacher will be and which supportive friends he might share a class with in the following year.



*Steve Walker, father of Liam, who is now in Year 7*

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## Notice and discuss behaviour changes or concerns

Because of the negative impact behavioural issues can have on children affected by TSC, early identification and interventions are recommended. Communicating and working with the child, their family and health professionals will help support their educational success.

If you notice any type of change in a child's social interaction, behaviour, learning and/or energy levels (eg they are more aggressive or more tired) you should contact the child's parents to discuss your concerns.

You may be the first person to notice a behaviour change. Changes could be a side effect of medications they are taking or a warning sign that medical intervention is required, particularly in a child who has communication issues. For example, occasionally a child with TSC can develop a type of brain tumour called a SEGA. Signs of this include changes in behaviour, headaches, nausea and vomiting, double vision and imbalance.

It is crucial to discuss with the family any behaviour changes in a child with TSC to eliminate a medical cause.

Even if the behaviour can be linked to the child's TSC, it still needs monitoring and management. A child's needs will change depending on their health and medication and it may be necessary to adapt and modify their IEP.

## Your relationship with a child affected by TSC

All teacher/child relationships involve trust and understanding. The strategies you use to help build trust and understanding with a child affected by TSC will depend upon the individual child and their particular abilities and challenges. Some common strategies include:

- getting to understand their unique likes, dislikes and interests
- being very specific in what you are asking them to do
- letting them know they can count on you NOT to put them in an embarrassing situation such as asking them to perform a task that they are not good at doing in front of the class
- writing directions on the board, verbally going over directions and giving examples
- ensuring that classroom rules are understood and visible in the classroom.



What I have learnt from my journey with Max through school is that some teachers are naturals at working with kids with 'issues' and others can learn...Max and I have been lucky in finding people both at primary school and high school who really connected with him and had a genuine interest in helping his education. Persistence is the key.

*Brigitte Mansour, mother of Max, who is now in Year 12*



## Your relationship with the family of a child affected by TSC

A parent of a child with TSC often has an extra layer of anxiety in sending their child to school. They may worry about how teachers and school staff will understand and help manage their child's condition. They will want to know that their child is being adequately supported to do well at school and reach both their academic and social potential, particularly if they learn differently. Parents want to know that their child is 'in safe hands'.

**Your relationship with the parents of a child affected by TSC is just as important as your relationship with the child themselves. Parents are usually the best source of information about their child's TSC.** Through necessity, many have become experts about the disease. You can gain a lot of information about TSC and how it affects a particular child by talking to the parents and asking questions.

TSC is a very complicated condition and can change very quickly. Seizures, heart issues, lung issues, brain surgery and medication changes are just a few of the issues some families deal with on a day-to-day basis. Parental stress is common. If you are struggling in your dealings with the parents of a child living with TSC, please remember what is going on in their lives and try to be empathetic and continue to work with them as they do know their child best.

## Teamwork

A team approach provides the very best learning model for a child with TSC. Communicating well and often, working in partnership with the child, the child's parents and other professionals involved in their care, will help create a positive environment that allows the child to reach their full potential and have their very best learning experience.

## The transition to high school

The high/secondary school environment can pose fresh challenges for a child with TSC because of having multiple teachers and moving from one classroom to another.

Adolescence is also a time which can cause changes to TSC-related symptoms. As the child's body adapts to 'growing up' changes, symptoms or their severity may change. For example, a child whose TSC seizures were well controlled during primary school may find that this changes in adolescence. They may, for instance, need additional medication.

## Thank you for reading this guide

Even though some of the information in this guide may not be relevant to the child affected by TSC in your classroom or in your particular education setting, it is important that you have an understanding of TSC, what it is and the ways it can affect a child. Thank you for taking the time to read this guide.

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Liam enjoys school. He likes his teachers and routines. He has struggled with anxiety at times (particularly on stormy days) and making connections with his own peer group (he'll tend to gravitate to the sandpit with the younger kids). Even though he enjoys choir and drama group, often he chooses not to go. Despite the occasional challenges, being able to stay in a familiar environment at the same school has been a great benefit to Liam.

*Steve Walker, father of Liam, who is now in Year 7*



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## Additional information

The online version of this resource provides a template for a personal information form for a child with TSC and a sample IEP. It also provides more detail with respect to a number of possible learning disabilities that a child with TSC may exhibit and includes possible warning signs and strategies teachers and educators may use to assist children.

For more information on TSC, visit TSA's website at <https://tsa.org.au>

You may also like to call TSA's Nurse Service on 1300 733 435 (Australia only) or email [nurse@tsa.org.au](mailto:nurse@tsa.org.au)

## Acknowledgement

TSA would like to acknowledge that much of the material used within this resource is adapted from and used by permission of the Tuberous Sclerosis Alliance, USA. We would like to thank the US Alliance for its generosity in sharing its expertise and knowledge with us.

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TSA would also like to acknowledge that publication of this material would not have been possible without the financial support of our TSC community, the Disabled Children's Foundation (DCF) and Universal Charitable Fund (UCF).



### Disclaimer

This publication provides basic information about Tuberous Sclerosis Complex (TSC). It is not intended to, nor does it, constitute medical or other advice. Readers are warned not to take any action with regard to medical treatment without first consulting a health care provider.

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