



EDUCATE ME
INCLUDE ME

Learning conversations about epilepsy

A parent and teacher's resource



The impact of epilepsy is variable – some children are greatly affected while others are not

Epilepsy and its possible impacts on learning

An **iceberg analogy** is a good way to show how the possible impacts of epilepsy can often be far greater than the seizure itself. Just as only the tip of an iceberg can be seen above the surface of the ocean, with epilepsy the actual seizure itself can often be easily

seen but many of the other possible impacts of the seizure may be hidden from view. These impacts are not necessarily present for all children, and indeed may change over the duration of a child's life.

This is what others usually see when a child has epilepsy

Seizures

These are some of the other possible impacts of epilepsy that children may experience because of their seizures and which can often impact a child more than the seizure itself

Memory

For some children with epilepsy, memory can be a significant challenge

Tiredness/fatigue

Due to seizure activity (including during sleep) children can be tired, find it difficult to concentrate and can feel ill post seizure

Medication

Side effects from medication may cause tiredness, difficulties with concentration or mood/behaviour changes

Stigma

A child can experience stigma due to a lack of community awareness and understanding of epilepsy

Self-esteem

The unpredictable nature of seizures can have a negative effect on a child's confidence and self-esteem

Depression and anxiety

Up to 50% of people living with epilepsy experience depression or other mental health illnesses

Use this checklist to identify areas of concern you may have in regard to your child

Read the indicators listed for each area and tick the box that you feel best describes your child. If your child never displays a behaviour just tick *not often*.

Do you have concerns about your child's:	How often do you notice the following about your child:	Not often	Sometimes	Often
Concentration	▪ is very tired			
	▪ does not appear to be listening			
	▪ is easily distracted			
	▪ is slow at finishing things			
Memory	▪ continually losing things			
	▪ has difficulty recalling events			
	▪ can have difficulty remembering directions			
	▪ can have difficulty following conversations			
Cognitive skills - these are the thinking skills that make learning possible	▪ slow response time when asked to do things			
	▪ difficulty following more than one instruction at a time			
	▪ slower to grasp new ideas and ways of doing things			
	▪ can become easily frustrated when completing a task			
Executive functions - these are the skills that a person uses to plan and organise	▪ avoids tasks that require effort			
	▪ has poor time management skills			
	▪ can act impulsively without first considering possible consequences			
	▪ can overreact emotionally to situations			
Confidence	▪ needs a lot of encouragement to participate in new activities			
	▪ often asks for help with things they are able to do themselves			
	▪ finds it difficult to make and/or maintain friendships			
	▪ appears anxious and/or withdrawn			
Other observations about your child				

After a discussion with the teacher/school it may be decided to set up a Student Support Group (SSG) to assist your child's additional learning needs

Student Support Groups

This group is a cooperative partnership between parent/guardian(s), school representatives and professionals to support a student with additional learning needs to achieve positive learning outcomes.

Members of the Student Support Group may include:

- the parent/guardian(s) of the child
- a parent/guardian(s) advocate (if parent/guardian(s) choose this option)
- the child's teacher or teacher nominated as having lead responsibility for the child
- the principal or their nominee
- the child (where appropriate)
- specialist advisors (as required)

It is the responsibility of this group to:

- identify the child's needs
- plan an appropriate educational program
- develop and monitor the child's Individual Learning Plan (ILP)
- plan for reasonable adjustments to be made to ensure the child's access to curricula and participation in school activities.

(Refer references: Student Support Guideline 2015)

Individual Learning Plans should be reviewed on a regular basis to make sure that current teaching strategies are effective and set goals are being achieved

Parents should be consulted in the development of their child's Individual Learning Plan and, where appropriate, the child should also have input

Parents' input plays a vital role in planning for reasonable adjustments to school programs to ensure their child's access to and participation in school activities

Individual Learning Plan

An Individual Learning Plan (ILP) is developed by the school to address the educational needs of a child. The plan is based on an assessment of a child's learning and sets out the child's strengths and needs.

Specifically an Individualised Learning Plan

- Identifies the child's areas of strength and preferred learning style, and accommodates their cultural identity
- Lists the skills the child has already gained in relation to a desired goal
- Lists short term goals that are both measurable and achievable in an agreed time frame
- Describes the teaching strategies which have been developed to support the child in achieving these goals

In the Victorian Government schools system a Student Support Group is mandatory for students who receive funding through the Program for Students with Disabilities, and is strongly encouraged for any students with additional learning needs. Similar processes also exist in Catholic and independent school sectors but may have an alternative title and operate under different guidelines from the government school sector.

The thumbnail shows a document titled 'Student Individual Learning Plan' with the epilepsySMARTS logo. It includes a header with the text: 'This document outlines the process for developing an Individual Learning Plan (ILP) for students with additional learning needs. The ILP is developed by the school in consultation with the student and their family. It is a key document for the school to use to plan and deliver the student's learning program. The ILP should be reviewed regularly and updated as needed.' Below the header is a table with columns for 'Student Name', 'Year Level', 'Teacher', and 'Parent/Guardian'. The table is titled 'Step 1: Understanding your student' and has several rows for data entry.

Teachers can access an Epilepsy ILP template via epilepsysmartschools.org.au

Why are learning conversations important?

The impact of epilepsy on a child and their family is often far greater than the seizure itself. This resource aims to educate both parents and teachers about what the possible impacts may be and provides a practical way to start a learning conversation.

What are the benefits of understanding the impact epilepsy may have on a child's learning?

- If epilepsy is impacting a child's learning, strategies can be developed and put in place to support the child to achieve
- If there are learning difficulties, the sooner they are identified the better the chance of improving a child's learning outcomes
- If a child is constantly frustrated because they are not achieving success in a specific area, it can lead to a lack of motivation to learn, behavioural difficulties and may affect their self-esteem and social interactions

Myth: The impact on a child's learning is related to how many seizures they have

Truth: Children who only have occasional seizures or whose seizures occur while they are asleep can have their learning impacted

Truth: Sometimes a child may also have abnormal electrical activity that may not be noticed by the child or an observer, however it may influence the child's thinking, concentration, mood or behaviour

How can this learning conversations resource be used?

1. The parent/s should complete the checklist printed inside this resource using personal observations of their child in their home environment.
2. If the *often* response has been frequently ticked, this is an indicator that the child may be having difficulties in an area which could also be negatively impacting on their learning at school.
3. Parent/s should request an interview with their child's teacher and take the completed checklist along to assist in discussing their concerns.
4. An important outcome from this initial discussion will be to decide if further support needs to be put in place for the child.

Note: Just because the *often* response may be selected in the checklist, this does not necessarily mean there is a difficulty. This could simply reflect a developmental stage of the child and a conversation with the teacher may assist in better understanding expectations.

Myth: All children with epilepsy lose consciousness

Truth: Seizures can involve the child being fully aware, having altered awareness or being unconscious

Myth: Only children develop epilepsy

Truth: Anyone regardless of gender, race, age or intellectual ability can develop epilepsy. About 1 in 200 children will have epilepsy

Key professionals who can provide support in improving learning outcomes for students living with epilepsy:

Paediatric Epileptologists specialise in the diagnosis, treatment and management of epilepsy in children.

Psychologists provide assessment, intervention and counselling services to help young people with psychological or social issues.

Clinical Neuropsychologists have advanced skills in the assessment, diagnosis and treatment of a range of disorders. Their skills are underpinned by knowledge of brain structure, function and dysfunction, and the effects of multiple factors on cognitive, behavioural and emotional functioning. There are a limited number of specialist neuropsychologists that specialise in the area of paediatric epilepsy.

Occupational Therapists identify any safety risks in a child's environment and can also work with children to improve their sensory, physical, academic, social and emotional capabilities.

Speech Pathologists typically assess and treat people who have a communication difficulty. This includes all aspects of communication including speech, writing and reading (language disorders).



The Epilepsy Smart Schools Practical Guide and supporting resources provides information on how a school can embed inclusive, safe and educationally sound practices for students with epilepsy and in so doing become 'epilepsy smart'. The guide and supporting resources which can be accessed via www.epilepsysmartschools.org.au

References

1. Department of Education and Training: Student Support Group Guidelines 2015 [http://www.education.vic.gov.au/school/teachers/teaching resources/diversity/pages/handbook.aspx](http://www.education.vic.gov.au/school/teachers/teaching%20resources/diversity/pages/handbook.aspx)
2. *Victorian Equal Opportunity & Human Rights Commission: Held Back 2012* The experience of students with disabilities in Victorian schools

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The information contained in this publication provides general information about epilepsy. It does not provide specific advice. Specific health and medical advice should always be obtained from a qualified health professional.

The images in this publication show models who do not necessarily have an epilepsy diagnosis and are for illustrative purposes only.