Inclusive schools
Your rights and responsibilities in education
A parent/guardian resource
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Epilepsy affects people of all ages

About **1 in 200** children live with epilepsy

Epilepsy is a neurological condition characterised by recurrent seizures due to abnormal electrical activity in the brain
Introduction

Feeling valued, being able to participate in school activities and being seen as ‘normal’ are things students with epilepsy consistently tell us are important.

Parents and guardians tell us that they want schools to understand that their child’s epilepsy is unique and that the impact of their epilepsy is often greater than the seizure itself. Impacts such as academic, social and psychological issues commonly influence their child’s education.

For students and their families; the challenges of a typical school day can seem overwhelming.

The Epilepsy Australia member organisations have supported many families who have felt overwhelmed, confused or discriminated against in their education. It is through these many calls to our organisations that the Epilepsy Foundation saw the need to provide better information to parents/guardians, so that they understand not just their rights but also their responsibilities.

We encourage parent/guardians to take a proactive approach by having frequent scheduled conversations with the school about their child’s progress. This will build a foundation where parents/guardians can ask questions or raise concerns early, rather than letting them build.

This resource is part of a suite of documents that have been updated for parents/guardians across Australia to assist you and your child in their education.

On the occasions where you need additional support, your Epilepsy Australia member organisations are just a phone call away.

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Throughout this resource you will see this icon – by clicking on it, you will be directed to additional resources. If you have printed this resource, the webpage addresses of these links are summarised on page 29.
What is an ‘Inclusive school’?

An inclusive school is a school where all students have the opportunity to participate in all aspects of their education. Children with epilepsy have a right to feel included, in the same way children who don’t have epilepsy do.

Inclusive education is about the way that schools are designed, teachers are trained, activities are developed and programs are implemented, so that all students learn and participate together and equally.

Inclusion as a principle in the education system is based on the right to education and the principle of free compulsory education. Compulsory education in Australia starts from the age of five or six years, with variations between states and territories, refer to your state website for further information. Refer Page 28 for government web details.

Inclusive school parameters are set out in the Disability Standards for Education which was developed by the Australian government under the Disability Discrimination Act. ¹

Disability – what does it mean?

Your child may have an epilepsy diagnosis but you may not consider that they have a disability. However, under the discrimination law framework the definition of disability is stated broadly. Having an epilepsy diagnosis would be considered a disability in the context of discrimination law, as would other medical conditions such as asthma, diabetes and arthritis.

Article 26 of the 1948 Universal Declaration of Human Rights provides the right to education. This principle has been re-stated in many international human rights treaties. This includes in Article 13 of the 1966 International Covenant on Economic, Social and Cultural Rights which reaffirms the right to education for all and highlights the principle of free compulsory education.

¹ Disability Standards for Education 2005 (Cth). – these standards are formulated under the Disability Discrimination Act 1992 (Cth) s. 31(1). (This is a piece of legislation which legislates the provision of disability services.)
The following standards reflect what an inclusive school would look like:

1. The school must take reasonable steps to make sure your child can enrol on the same basis as other children and do so without experiencing discrimination.

2. The school must take reasonable steps to make sure your child is able to participate in all aspects of their school experience on the same basis as other children, and without experiencing discrimination.

3. The school must take reasonable steps to make sure your child is able to participate in the school curriculum (including assessment and certification requirements) on the same basis as other children and without experiencing discrimination.

4. The school must take reasonable steps to make sure your child has access to the school’s support services on the same basis as other children and without experiencing discrimination.

5. The school must develop and use strategies and programs to prevent your child from experiencing harassment and victimisation.

Disability Standards for Education

Watch this short video where three students talk about their experiences of living with epilepsy.
Enrolment

Q: Do I have to tell the school that my child has epilepsy?

A: It is a reality that unfortunately some children may receive unfavourable treatment from their peers and possibly even from school staff as a result of their epilepsy diagnosis.\(^2\)

It is a personal choice whether you choose to tell the school and it may be best to disclose your child’s diagnosis only when you need to do so.

It is your responsibility to disclose your child’s epilepsy diagnosis where the epilepsy is likely to affect your child’s participation at school, specifically where it is necessary for your child’s health and safety or where you are seeking reasonable adjustments to be made for your child.\(^3\)

Q: My son only has seizures during his sleep and I am worried that he will be labelled and not be accepted into the school ...

A: If your child only has seizures during his sleep and this doesn’t affect his ability to attend school and participate fully, it may not be necessary to disclose that your child has epilepsy. However you have to keep in mind the unpredictable nature of epilepsy and certain types of activities, like school camps. The impact of epilepsy on your child is not limited to their seizure activity. There are also potential learning and behavioural considerations. If teachers are made aware of these they are better able to support your child in a way that is appropriate to his needs.

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2 Victorian Equal Opportunity & Human Rights Commission. (2012). Participation. Held Back Report, chapter 4, 36-49. Page 70 – ‘Bullying is a significant and widespread problem for children with a disability’ and Page 48 – Parents suggested ‘information for staff as well as other parents about disabilities, particularly those that some may be fearful of, such as epilepsy’.

3 The Disability Standards for Education 2005 (Cth) sets out how a reasonable adjustment is defined and expectations of education providers Part 3. Pages 13-16, refer state and territory Equal Opportunity and Discrimination legislation for further information on state and territory application and guidelines.
Epilepsy Australia encourages all schools to be ‘epilepsy smart’ by ensuring:

- current Epilepsy Management Plans (EMP) are held for each student living with epilepsy. Additionally where emergency medication has been prescribed, a current Emergency Medication Management Plan (EMMP) is held.
- school staff are aware of the impact of epilepsy on the individual and their learning through participating in training. Where a student has an EMMP, all school staff with a duty of care responsibility for that student have received student specific epilepsy training.
- school staff educate students about epilepsy using resources from the Epilepsy Smart Schools website either through embedding education within curriculum or supporting an awareness raising campaign such as a purple day event.

Q: **My daughter has many seizures, and I am afraid her school will say they cannot support her ...**

A: **Your child should not be excluded from school because of their epilepsy diagnosis or because of her seizure activity.**

If your child were to be prevented from enrolling in a school on the basis of her seizure activity this would be direct discrimination and illegal under anti-discrimination law.

Under the Disability Standards for Education, students with disability\(^4\) have the right to seek admission or apply to enrol in a school on the same basis as prospective students without a disability and be able to do so without experiencing discrimination.\(^5\)

Under these Standards, schools must also make reasonable adjustments to ensure your child’s ability to seek admission is considered on the basis of those adjustments being made.

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4 An epilepsy diagnosis is sufficient to show that your child has a ‘disability’ under anti-discrimination law. Your child may have an epilepsy diagnosis but you may not consider they have a disability, and many people with epilepsy may not fit within the definition of having a ‘disability’ under their state or territory disability legislation e.g. Disability Act 2006 (Vic) (This is a piece of legislation which legislates the provision of disability services ). However, under the discrimination law framework the definition of disability is drawn very broadly. This is a reflection of the concern of the anti-discrimination law framework to avoid unfair and discriminatory treatment rather than with medical or technical accuracy.

5 Disability Standards for Education – Part 4.2 (1) – ‘The education provider must take reasonable steps to ensure that the prospective student is able to seek admission to, or apply for enrolment in, the institution on the same basis as a prospective student without a disability, and without experiencing discrimination.’
Q: My daughter has only had one seizure and the doctors are not sure whether she has epilepsy. Should I tell the school about her seizure when enrolling?

A: Epilepsy is a brain condition that causes recurrent unprovoked seizures. Epilepsy is usually diagnosed in children who have more than one seizure, but sometimes it is possible to diagnose epilepsy after only one unprovoked seizure if the EEG (brain wave test) suggests a high likelihood of further seizures.

Anyone can experience a seizure in his or her lifetime – it does not mean they necessarily have epilepsy.

Febrile seizures are seizures in infants and children that are provoked by a fever. Febrile seizures affect 4–5% of children aged 6 months to 6 years. Less than 5% of children who have febrile seizures go on to develop epilepsy.

Some parents are worried that by saying that their child has had a seizure, the school will identify their child as having epilepsy and either; treat their child differently, label them or insist on additional medical reports.

Your decision on whether to tell the school should be based on what is in the best interests of your child at that stage. Remember that this decision may change in the future based on the reoccurrence of seizure activity or other changes to your child’s condition.
It is best to disclose your child’s health support needs taking into account the following considerations:

- Was the seizure prolonged?
- Has the doctor prescribed the emergency medication midazolam for any future seizure?
- Did the doctor indicate that there was a likelihood of another seizure?
- Has the doctor recommended you disclose to the school?
- Would it be helpful to your child for school staff to document and report any symptoms that may assist with diagnosis?

If the answer to any of the questions above is ‘yes’ then parents may consider developing a Seizure Management Plan (SMP) with their doctor’s endorsement. This document will outline the emergency procedure for school staff, should another seizure occur.

If a diagnosis of epilepsy is later made, an EMP can then be developed. Your local Epilepsy Australia member organisation can support you in developing an SMP or an EMP. Refer Page 28 for member contact details.
Participation

Q: My son’s first camp is coming up and he is very excited. However his school has said to me that I either stay overnight in the same room, arrange accommodation for him off-site during the night, or fund an aide to “look after” him. My son understandably doesn’t want mum ‘hanging around’ and I can’t afford to pay for an aide. Can they exclude him on the camp if I don’t attend?

A: Your child should have the opportunity to participate in the school camp to the same extent as any other student. It is not your responsibility as a parent to contribute to the cost of additional support for your child. By refusing to provide an aide, the school is imposing a requirement on all students that they attend the camp without an aide, and for your child, this will disadvantage him. If your child is unable to fully participate in the camp without an aide, the school’s refusal or failure to provide one could constitute indirect discrimination. Additionally, there is a positive requirement on the school to make reasonable adjustments to accommodate your child’s disability. In some cases having an aide may not be necessary; it may be a matter of having plans in place to help supervising staff to support your child if he was to have a seizure during the camp. This is similar to the plans that would need to be put in place for a child who had diabetes, anaphylaxis or asthma. A student may need extra support at certain times but as long as appropriate planning is put in place there may be no need for them to have a dedicated staff member, and indeed this may be upsetting for the child if unnecessary.

5 Different state and territory regulations or legislation may apply. e.g. this Victorian expectation is set out in Education and Training Reform Act 2006 (Vic), s. 2.2.6. 6 ‘Indirect Discrimination’ - This is where a standard or requirement is imposed on all people equally, but some people are unable or less able to comply with the requirement as a result of their disability. Disability Discrimination Act 1992 (Cth) State or territory Equal Opportunity or Discrimination legislation may also apply. 7 Disability Discrimination Act 1992 (Cth) ss. 5 and 6.
Q: My daughter has been told she must have a teacher with her during all recess and lunch breaks and cannot use the play equipment like the other children. If a teacher cannot be allocated, she has been told that she must stay in the library so that a teacher can observe her at all times. My daughter is feeling isolated from friends and feels ‘different’. Is this discrimination?

A: It is important that your child is able to participate fully in their school experience. This includes socialising with other students and getting full access to all available activities without feeling excluded. It is also important that the health and well-being of your child and other children are protected. If your child is treated less favourably than other students on the basis of their epilepsy diagnosis, their seizure activity, or any behaviour related to this then they may be experiencing direct discrimination. The school would be directly discriminating against your child by restricting her use of the play equipment because of her epilepsy.

Your child has a right to an inclusive education under the Disability Standards, hence excluding and separating your child from other students based on her epilepsy diagnosis is a breach of the Disability Standards.

However, where the right to an inclusive education may be in conflict with health and safety concerns, consultation is necessary between you and the school to identify probable risks and appropriate precautions based on the individual circumstances of your child.

It is important in this instance that you have an Epilepsy Management Plan (EMP) that is signed by your child’s doctor. Section 8 of the plan allows insertion of ‘risks/safety alerts’ and associated strategies to deal with this. This would be the appropriate section to list any risks that your child may have using the play equipment and how these risks could be avoided to ensure your child’s safety - whilst ensuring your child’s opportunity to participate and maintain a sense of independence.

Refer Page 16–17 for a suggested risk approach.

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8 Disability Standards for Education 2005 (Cth), part. 5.
9 ‘Direct Discrimination’ – Where someone treats or plans to treat someone less favourably because of their disability. Disability Discrimination Act 1992 (Cth) State or territory Equal Opportunity or Discrimination legislation may also apply.
10 Disability Standards for Education 2005 (Cth), part. 5.2. ‘The education provider must take reasonable steps to ensure that the student is able to participate in the courses or programs provided by the educational institution, and use the facilities and services provided by it, on the same basis as a student without a disability, and without experiencing discrimination.’
Q: My son has really bad epilepsy and needs constant supervision. I don’t think it is safe for him to attend school. Do I have to send him to school?

A: In recognition of the benefit of education, it is legally required under state and territory legislation that a child attend school. States and territories have slightly different expectations in this. E.g. in Victoria you must attend school until you are seventeen years of age either at a registered school or registered for home schooling.

There are guidelines set out by each state and territory Education Department as to the way home schooling should be conducted, including the obligations on parents who choose to home school their children. E.g. in Victoria there is a requirement that the child receives regular and efficient instruction following eight key learning areas.

The decision on whether it is appropriate to home school your child should be based on the best interest of the child involved and their particular needs. The decision should be made after seeking the opinion of your child’s doctor and other relevant professionals e.g. paediatrician, psychologist, occupational therapist.

It is important to note that the benefits of attending school go beyond the academic benefits. School gives a child the opportunity to socialise with other students, develop their communication skills, learn how to follow instructions and increase their independence. In addition, the choice to home school your child could have potential consequences for them entering into higher education programs or completing studies. The decision to withdraw a child from school should not be made lightly.

Some children who have severe disabilities which make attending school every day too difficult, participate in a combination of home schooling and part time enrolment either in a special school or a mainstream school. This enables the child to continue to receive some benefit from a school environment in a way that is suitable to their needs. Open communication with the school is recommended.

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12 Education and Training Reform Act 2006 (Vic). s. 2.1.1.

13 Education and Training Reform Regulations 2007 (Vic). reg. 68.
“It’s a matter of supporting each other, and these children will blossom. They don’t need to be fearful because you’ve got the support of the teacher and the school and the parent” Molly’s mum

KidsMatter is an Australian mental health and well-being initiative set in primary schools and early childhood education and care services. The website has information and links to many resources.

Your local Epilepsy Australia member organisation can support you in developing an EMP and an EMMP. Refer Page 28 for member contact details.
Q: The school has organised an excursion and I was told in relation to my daughter that I would have to attend ‘in case she has a seizure’. Isn’t this unlawful discrimination? Parents of students with other conditions such as diabetes or anaphylaxis were not required to attend.

A: It is important that your child is able to attend excursions as all other students do without you being there; this will build their sense of independence and confidence.

If your child is being prevented from participating in the excursion because of their epilepsy then this could be direct discrimination.

A student with epilepsy usually has the same capacity to participate in school activities as any other child who may or may not have a health condition. When your child is having a seizure they are likely to require extra support. This is consistent with the specific support needs of other children with diabetes, anaphylaxis or asthma.

It may be that the reason that the school does not want your child to take part in the excursion is that they do not feel prepared to support your child if they have a seizure. This indicates that there may need to be increased education and training provided to the school so that they are better equipped to support your child. Your child needs to have an Epilepsy Management Plan (EMP) and Emergency Medication Management Plan (EMMP) – if emergency medication is prescribed. Only staff who have received recognised training specific to your child should administer this prescribed medication.

“…in case she has a seizure.”

“I have epilepsy and severe allergies so school often doesn’t want me to attend excursions.”

“When thinking about sports days, swimming and different excursions, it’s important to remember that someone like Chris, with epilepsy, can participate in those things and it’s up to us to accommodate his needs.”

Chris’ teacher

Curriculum development and assessment

Q: My daughter is studying VCE (Victorian Student) and because of her seizures and medication, she gets tired quickly and it is difficult for her to concentrate for long stretches. Can special accommodations be made for her during the examinations?

A: VCE, like all senior years programs, is a very important part of a child’s education; it can also be extremely stressful. It is important to ensure that your child does not have any additional stress placed on her.

If your child’s ability to complete their VCE exams is impacted due to her epilepsy then changes to the manner of undertaking the examination should be made to accommodate your child. It is important to identify and advise as early as possible what reasonable adjustments your child would need.

VCAA\textsuperscript{14} guidelines state “VCAA examination rules shall apply with appropriate and reasonable modifications to students who have disabilities or other impairments.”\textsuperscript{15} The most common adjustments for students with epilepsy include: extended reading time; breaks; separate examination room and extended examination time.

In Victoria, application for special adjustments during VCE exams is determined by VCAA. It is the school’s responsibility to make the application to VCAA on behalf of your child and this application must be endorsed by the school’s principal.

Documentation will be required to support the application, such as medical and educational assessments.\textsuperscript{16} In this case decisions made by VCAA, which involve refusing or limiting adjustments, may contravene anti-discrimination legislation. You should get legal advice as soon as possible.

NOTE: VCAA adopts the same definition of disability as under discrimination law.\textsuperscript{17} In addition, VCAA states that people with ‘illnesses or other circumstances’ may be eligible for Special Examination Arrangements. There is broad potential for special accommodation based on individual needs. However, a disability or illness will not automatically entitle someone to Special Examination Arrangements; this decision will be made on a case-by-case basis.

Different states and territories may not respond in the same way. Please refer to your state or territory government website for further information on senior years and health related adjustments for exams.

It is important that you seek legal advice where you are unable to reach an agreement with your school or where you believe your child’s rights under the Disability Standards for Education 2005 (Cth) are being compromised.

\textsuperscript{14} Victorian Curriculum and Assessment Authority – This is the body responsible for developing and implementing the Victorian Certificate of Education (VCE).


Support services

Q: My son has brief non-convulsive seizures (stiffening arms, staring and dribbling for a minute) and he requires a rest afterwards. The school insists that he needs to leave school on every occasion and calls me to collect him, however a thirty minute rest is usually sufficient for him to then resume his school work. Is this discrimination?

A: It is important that your child does not miss out on school unless it is absolutely necessary. Missing out on school could lead to your child falling behind academically. In addition, the benefits of attending school go beyond the academic benefits. Attending school gives a child the opportunity to socialise with other students, develop their communication skills, learn how to follow instructions and increase their independence. The decision of the school to exclude your child for the remainder of the day following a seizure should not be made lightly, and should be made on medical advice in consultation with you.

If your child were to be excluded from school because they have epilepsy then this could be direct discrimination.

The decision as to whether your child needs to be sent home should be made based on what is in his best interests rather than a general rule that he be sent home after every seizure. The school should make a decision based on how your son is feeling after a thirty-minute rest and as outlined in his Epilepsy Management Plan. It is important to remember that a seizure has many effects on a student’s learning that may not be obvious. These include effects on concentration, memory and behaviour. It is necessary for your child’s school to make a determination as to whether your child should remain at school for the remainder of the day based on the consideration of his well-being, as well as causing unjustifiable hardship to the school.

Where your child does remain at school, some adjustments to the rest of his day may need to be made based on his energy levels, ability to concentrate and behaviour. For example if a new and particularly difficult maths topic is being taught in the afternoon, the child may need some extra assistance in the class, or need to have the topic covered again in a future lesson.

There is an obligation on the school to make reasonable adjustments to accommodate your child. Simplicy because your child may require extra assistance to access their education following a seizure does not mean he should be sent home.

Refer Page 16-17 for a suggested risk approach.
Q: Our doctor and family are trying to monitor how frequent our son’s seizures are occurring as this will help with his treatment plan. I set up a communication book to go between home and school each day, however the teacher says she doesn’t have time to complete it. Is this reasonable?

A: It is important that you are able to monitor your child’s seizures in order to create the most effective treatment plan possible. Given that your child spends about thirty hours a week at school, information on his seizure activity while at school is vital to obtaining an accurate understanding of your child’s seizure activity.

The school has a duty of care to all students which includes an obligation to report important or critical events that occur.

Making note of your child’s seizures is unlikely to place a very large burden on the teacher. However, remember that your child’s teacher is responsible for a large group of students and may often have limited time.

It is important that you make the teacher’s task of filling in the communication book as quick and simple as possible whilst still recording the key information necessary to monitor your child’s seizure activity. Clearly explain to the teacher what information you need and why you need it, to ensure they understand how important the communication book is without them feeling overwhelmed by having to fill it out.

Your local Epilepsy Australia member organisation may have a seizure record form which allows for the details of seizure activity to be recorded briefly whilst ensuring all necessary information is collected. Alternatively, an app such as MyEpilepsyDiary could be used by the student.
RISK – a balanced approach

Everyone, not just those with epilepsy, face risks in the community. This includes the school environment. Unfortunately, some schools may think that all seizures are the same and that all seizures constitute an emergency and require an ambulance to be called. Some schools may try to restrict or exclude a student with epilepsy from some activities based on these assumptions. Every child’s epilepsy is unique, and no assumptions should be made about the risks that may or may not be relevant to your child until you are consulted.

A useful way to have a risk conversation with your school is:

1. Have an **Epilepsy Management Plan** (and when indicated, an Emergency Medication Management Plan) endorsed by your doctor which clearly outlines any risks and accompanying strategies. In some instances, you may find it necessary to review the EMP because a new activity (for example swimming) was not considered at the original time of endorsement.

2. **Think about risk in terms of a balance** as illustrated in the diagram above. You cannot reduce all risk to zero. However, together with the school, your child’s safety and inclusion can be discussed. Your child’s individual epilepsy, what’s important to them and strategies that your doctor has recommended should be the basis of this discussion.

Schools will have students at the centre of their focus. Most will readily talk about this in their school’s mission and documents.
What’s important to your child and you as a parent/guardian should be discussed – this is called being consulted. When a conversation wholly focuses on what is perceived to be important for your child (for example their perceived safety, perceived impact on other students, perceived impact on staff) then the conversation could become unbalanced.

3. When having a risk conversation, the following questions should be included:

- What sort of seizures does the student have?
- Do they lose consciousness during the seizure?
- Do they get a warning before a seizure?

- How well controlled are the seizures (frequency)?
- Are there any known seizure triggers?
- How do the student and parent/guardian feel about the proposed activity?
- What are the particulars around the activity (supervision, where it’s held, access to medical support etc.)?

Risk assessments include thinking about what harm a seizure may do to your child, their classmates or staff in the event of a seizure. Given that the inherent nature of seizures is that they are unpredictable, risk assessments will be different for various activities (eg. swimming; camps; school practical classes).

Assessing a risk involves weighing up:

- How likely a seizure may occur (triggers, current seizure frequency, specifics around the activity undertaken)?
- What are the possible outcomes if a seizure were to occur (no injury, minor or serious injury)?
- What least restrictive strategies may reduce the risk, based on the likelihood of a seizure and it’s possible outcome if a seizure was to occur?

**Remember:** Managing risk is always about balance. If you are not consulted and risk assessments are made on assumptions, there could be potential for your child to be discriminated against in terms of their inclusion and access to educational activities.
Q: I applied for additional support for an aide (Victorian school); however we were not successful as I was told the seizures were episodic and not frequent ‘enough’. But that’s the nature of epilepsy! Isn’t this discriminating?

A: Funding for your child to have an aide is subject to state or territory guidelines e.g. Victoria’s Program for Students with Disabilities. The criteria for eligibility varies and may not always be reflective of the accepted definitions of disability. For students living with epilepsy matching specific funding criteria to their diagnosis or seizure activity can be a challenge.

Government schools are expected to support all students with disabilities through either specific funding for students with special needs or their global funding. Students with a disability have the right to access specialised services they need to participate in their education regardless of available school funds. The failure or refusal to provide an aide to assist your child if they require one to access education could be indirect or direct discrimination.

The school’s responsibility to provide an aide is limited to whether this is a reasonable adjustment for the school to make for your child. This will take into account a number of factors including the individual needs of the child, the effect the adjustment would have on your child and the financial circumstances of the education provider.

The exception to whether there is an obligation to make reasonable adjustments is where these adjustments are either unreasonable or would cause unjustifiable hardship. This will be based on a consideration of the benefits of making the adjustment relative to the burden of making the adjustments.

It is reported that there is significant unmet need for one-to-one assistance in the education system, with the major reason for this being identified as a lack of funding. It is doubtful that a lack of funding will be a consideration in determining the hardship imposed on a government school in providing you with one-to-one assistance as the responsibility is one owned by, in this example, the Department of Education and Training, being the State of Victoria.

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20 Disability Standards For Education 2005 (Cth) s 7.1.


However it is important to note that regardless of each school system’s individual funding regime, the overriding obligation of schools is to comply with the law, not internal procedure.

Q: My son is prescribed the emergency medication midazolam. The school has told me that he can’t come to school until staff are trained in administering the midazolam, however the plans have not been completed and signed yet by the doctor, this could be several weeks off – isn’t this discrimination?

A: It would generally be considered reasonable for the child to continue to attend school while the training is being organised, with the default position being that the school provide basic first aid and ring for an ambulance if a seizure were to occur. Refer to your state or territory government policy on health related matters and required first aid response. Refer Page 28 for Government website details.
It is a requirement that an Epilepsy Management Plan (EMP) and Emergency Medication Management Plan (EMMP) have been completed and signed by the doctor before the midazolam administration training can take place. This is to ensure that the training is tailored to the specific needs of your child as approved by their doctor. This also ensures that everyone involved in supporting your child has the same information. School staff may not administer emergency medication such as midazolam without parental consent. Only staff who have received recognised training specific to your child should administer emergency medication. It is not appropriate or sufficient for a parent to instruct staff on the administration of any emergency medication, including midazolam.

The use of emergency medication is not a substitute for calling an ambulance or providing first aid. It is in addition to calling an ambulance and providing a first aid response. Most typically, the EMMP will state that an ambulance needs to be called prior to or immediately following administration of the emergency medication.

It is important for your child’s teachers to have access to his emergency medication when required. Therefore the most important thing you can do is to encourage your doctor to complete and sign the plan as soon as possible so that training can be organised for the school.

If your school refuses school access to your child, always ask for them to put it in writing and state what support the school will provide to maintain your child’s education. Seek legal advice as needed.

EMP and EMMP templates are available from your local Epilepsy Australia member organisation. Refer Page 28 for contact details.

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<th>Description of seizure</th>
<th>Typical duration of seizure (seconds/minutes)</th>
<th>Usual frequency of seizure (state in terms of seizures per month, per year or per day)</th>
<th>Is emergency medication prescribed for this type of seizure?</th>
<th>When to call an ambulance</th>
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![Epilepsy Smart](image)
Harassment and victimisation

Q: My daughter has told me that on several occasions other children are teasing her by calling her ‘fitty girl’. I have spoken to the teacher, however it is still happening. Isn’t this bullying?

A: Students with disabilities have the right to education in an environment that is free from discrimination caused by harassment or victimisation based on their disabilities. Teasing someone based on their disability is clearly bullying and your child has a right to attend school without experiencing this behaviour. The school’s responsibility to your child is set out under the Disability Standards for Education.25 The school is responsible for having strategies and policies in place to avoid this bullying behaviour, and to implement these in practice. While the school may not be able to eliminate all bullying behaviour of students, there are significant measures that the school has a responsibility to put in place.

“...you don’t need to be nasty, don’t need to be a bully, just need to be a friend”

Molly

Great resources on bullying can be accessed via: bullyingnoway.gov.au

Q: The school posted a copy of my daughter’s management plan and a first aid poster in the classroom where other students can see it. Isn’t this breaching her privacy?

A: Your child has a right to privacy and should not have to disclose her medical condition to her peers if she doesn’t want to. If the school has done this without consultation this appears to be a serious breach of your child’s privacy.

The key question is – what is the purpose of having these documents on the wall? If the plans are only to be implemented by teachers then these documents should be kept in a location where students do not have access to them. On the other hand, having your child’s peers educated about epilepsy and learning how they can support your child if they have a seizure could be beneficial to your child.

If the plans are to be implemented by students, then this could be the basis of private discussions as opposed to displaying personal information about your child in a place where even visitors to the school may occasionally have access to such information.

There can often be a stigma around epilepsy that may not exist around other chronic conditions. If your child does decide to disclose her condition then the education of her peers about epilepsy and how your child wants to be supported needs to be done in a positive way. You and your child should be involved in a discussion with the school about what information is disclosed to the other students.

We encourage all schools to become “Epilepsy Smart Schools”. A suite of resources are freely available to support the student and educate the school community about epilepsy. Visit www.epilepsysmartschools.org.au.

“Some people used to tease me but they don’t do that anymore, because they kind of get that like – well if he has seizure, what if I had them, I wouldn’t like it”

Lachlan, Year 7
Student support groups and individual learning plans

Q: The school (Victorian school) has said they have established a Student Support Group however I wasn’t consulted. Is this reasonable?

A: School based supports such as the Victorian Student Support Groups (SSGs) are a cooperative partnership between parents, school representatives and professionals to support a student with additional learning needs to achieve positive learning outcomes. In Victoria the SSG is funded through the Program for Students with Disabilities. It is a funding program which is designed to add to existing global funding of schools by providing additional resources for some students with disabilities with moderate to severe needs.\(^{26}\)

Support for your student such as provided through a SSG is an important means of developing a shared understanding between parents and those people supporting the student about what the student needs to achieve the best possible educational outcome. There is a consultation requirement in the Disability Standards for Education, so it would be unreasonable if you were not consulted about the establishment of a SSG or any support group developed for your child.\(^{27}\)

The ‘Learning Conversations’ resource helps parents/guardians start a conversation with their teacher around the child’s education needs.

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\(^{27}\) Disability Standards for Education 2005 (Cth). parts 3, 4, 5, 6 & 7
Q: I asked for my son to have an Individual Learning Plan and was told that he didn’t need one as he did not have a disability. That’s not fair is it?

A: An Individual Learning Plan (ILP) is developed to address a specific educational or social need of a student. It is a mandatory requirement for some students who receive additional funding in school. The ILP is based on an assessment of a student’s learning and sets out the student’s capabilities and needs, in regard to explicit academic, social or behavioural learning outcomes. ILPs establish short-term goals that will lead sequentially to the achievement of desired long-term goals through explicit learning strategies and the identification of measurable outcomes.

The use of an Individual Learning Plan for a student is not just based on whether the child has a disability. Different schools use different criteria to determine whether an ILP is appropriate for the student.

Many schools also have a requirement that an ILP be used where a student is either 12 months above or 12 months below the expected level. However this is not applicable to all schools. It is simply good practice.

The fact that your child has epilepsy does not necessarily mean he will receive an Individual Learning Plan. The decision will be based on the above requirements and also on the current educational performance of your child. If you believe your child requires an ILP to address his educational needs then you should certainly discuss this option with your child’s school to convey your concerns and recommendations.
Complaints

Q: I want to make a complaint to the school as I feel my daughter is being discriminated against. I am fearful that I will be perceived as ‘troublesome’ and my daughter will be disadvantaged. What recourse is available to me?

A: The first step is to approach the school and let them know what you are concerned about and what you would like to see done to resolve the issue. If there is already a support process in place then this might be a good forum to raise your concerns.

Your child has many legal rights as set out under state and federal anti-discrimination law. However, hopefully most complaints can be resolved before having to resort to making a formal legal complaint. Therefore, it is important to use available internal processes to resolve a complaint first.

If you feel that your child’s rights are not being upheld you can write a letter to the school setting out:

- the alleged discrimination experienced by your child
- the effect that the discrimination is having on your child
- who you have spoken with at the school, what was said, any actions that were promised and that were/were not put in place, and what impact they had
- what you would like the school to do now
- time-frame of when you want a response.

If you are unable to make any progress with your child’s school, ask for a copy of the complaints procedure and either continue to follow that procedure, or obtain legal advice about making a legal complaint.

Depending on whether you are in a government or non-government school, you can progress your complaint through their regional offices.

Your school’s Principal should be able to provide you with a complaints/grievance process which outlines the policy.
If you are still unable to resolve your issue, then you may seek legal advice about whether you should bring a complaint to your state or territory Equal Opportunity and Human Rights Commission or the Australian Human Rights Commission (AHRC).

Complaints to either commissions must be done within 12 months of the discriminatory conduct taking place. When you make a complaint, you are lodging it on behalf of your child. After you have lodged a complaint, a conciliation meeting will be arranged between yourself and the respondent. Neither commission has the power to force the participation of the other side. At conciliation meetings, the school’s lawyers may also be present. For many parents/guardians this can be overwhelming.

The four key elements that must be set out in the complaint are:

1. What is the basis of discrimination? (eg. race, age, disability etc.)
2. Describe the discrimination
3. Describe the effect or impact of the discrimination
4. What outcome do you want to resolve your dispute?

At this initial stage you do not need to provide a lot of evidence. After you have lodged your complaint either commissions may contact you for further information. If you are not able to settle the claim at the conciliation stage or you decide not to go to conciliation, then you still have the option of taking your claim further under a range of state/territory or federal legislations. You cannot bring your complaint under state and federal law at the same time.

Your child does not need to participate in the conciliation or court/tribunal proceedings.

Your local Epilepsy Australia member organisation can support families get the best outcomes for their child. However Epilepsy Australia member organisations do not offer legal services, we recommend that you contact your state legal aid service as a first point of call.

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28 These parties do have the discretion to accept complaints outside this time frame but it is advisable to file claims as soon as possible. Australian Human Rights Commission Act 1986 (Cth) s. 20(2)(c)(i).

29 This is the body that you are making your discrimination claim against. E.g. if your child goes to a government run school in Victoria then this will be the Department of Education and Training (DET), if your child goes to a catholic school then this will be the Catholic Education Office and if your child attends an independent school then it will be the school itself.
Conclusion

We hope you found this resource on epilepsy and inclusion for children in schools helpful. Contact your local Epilepsy Australia member organisation for more information about other epilepsy-related topics. Refer Page 28 for contact details.
Contacts

**Australian Human Rights Commission**
A: Level 3, 175 Pitt Street, Sydney NSW 2000
P: (02) 9284 9600
National Information Service:
1300 656 419
General enquiries and publications:
1300 369 711
TTY: 1800 620 241
W: www.humanrights.gov.au

**Federal Circuit Court of Australia**
www.federalcircuitcourt.gov.au

**Epilepsy Australia National Office**
A: 587 Canterbury Road, Surrey Hills Vic 3127
P: (03) 8809 0600
E: epilepsy@epilepsyaustralia.net
W: www.epilepsyaustralia.net

**Epilepsy Australia member organisations**

**Epilepsy Foundation** (NSW and Vic)
P: (03) 8809 0600 or 1300 761 587
E: epilepsy@epilepsyfoundation.org.au
W: www.epilepsyfoundation.org.au

**Epilepsy ACT**
P: (02) 6287 4555
E: epilepsy@epilepsyact.org.au
W: www.epilepsyact.org.au

**Epilepsy Queensland**
P: (07) 3435 5000
E: epilepsy@epilepsyqueensland.com.au
W: www.epilepsyqueensland.com.au

**Epilepsy WA**
P: (08) 6457 7699
E: epilepsy@epilepsywa.asn.au
W: www.epilepsywa.asn.au

**Epilepsy Centre** (SA and NT)
P: 1300 850 081
E: enquiries@epilepsycentre.org.au
W: www.epilepsycentre.org.au

**Epilepsy Tasmania**
P: (03) 6344 6881
E: epilepsy@epilepsytasmania.org.au
W: www.epilepsytasmania.org.au

**Government Departments - Education**

**VIC** www.education.vic.gov.au
**NSW** www.dec.nsw.gov.au
**ACT** www.det.act.gov.au
**QLD** www.education.qld.gov.au
**WA** www.education.wa.edu.au
**SA** www.decd.sa.gov.au
**NT** www.education.nt.gov.au
**TAS** www.education.tas.gov.au

**Non-Government Schools**

**National Catholic Education Commission**
www.ncec.catholic.edu.au

**Indepandant Schools Council of Australia**
www.isca.edu.au
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We wish to greatly acknowledge the work of the Disability Discrimination Legal Service in providing input into the original Victoria parents/guardian suite of resources from which this has been adapted.

For Victorian parents/guardians seeking legal advice and support please contact:
Disability Discrimination Legal Service
2nd Floor, 247–251 Flinders Lane,
Melbourne, VIC 3000
Telephone: (03) 9654 8644
Email: info@ddls.org.au www.ddls.org.au

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

Readers should not act on the basis of any material in the book without obtaining advice relevant to their own particular situations. The authors, editor and publisher expressly disclaim any liability to any person in respect of any action taken or not taken in reliance on the contents of this publication.
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