



Invisible Illness

—an online resource about children and young people with chronic conditions for school communities



EPILEPSY Entry

Organisations who wrote / approved the information

Epilepsy Victoria

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***Chronic Illness Alliance
www.chronicillness.org.au
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A: FACTS ON THE CONDITION

1. General description, including different types, causes, prevalence, signs and symptoms

Epilepsy is the most common serious brain disorder in the world. Current estimates suggest that over 142,000 Victorians will have epilepsy before the age of 70 (approximately 3% of the population).

Epilepsy is a tendency to have recurrent seizures. A seizure occurs as a result of a sudden, usually brief, excessive electrical discharge in a group of brain cells. Seizures can vary from person to person. A seizure can consist of any of the following: a blank stare, tremors or jerks, a convulsion with a total loss of consciousness, strange feelings and sensations, unusual tastes, lip-smacking and chewing, visual disturbances, aimless wandering, fiddling with clothes or objects. These behaviours and how they present all relate back to the area of the brain from which the seizure is originating. There are two main groups of seizures – partial and generalised. Partial seizures start in one part of the brain and what happens to someone during a partial seizure will depend on where the seizure occurs in the brain and what function that part of the brain controls. There are two types of partial seizures – simple partial & complex partial and the distinction between the two is important in a school setting.

Simple Partial Seizures:

During simple partial seizures the person remains fully aware. The seizure may involve involuntary movement or stiffening of a limb, feelings of de ja vu, an unpleasant smell or taste or sensations in the stomach such as ‘butterflies’ or nausea. The key feature about simple partial seizures is that full awareness is maintained throughout the seizure and injury is less likely to occur as a consequence. These seizures are usually brief, often lasting less than a minute.

Complex Partial Seizures:

Complex partial seizures are more serious because they involve impaired awareness. This means that the person doesn't know who they are, where they are or what they are doing for the duration of the seizure and therefore the potential for injury is much greater. The person may appear confused and dazed and may do strange and repetitive actions such as fiddling with clothing, making chewing or lip smacking movements or uttering unusual sounds. The seizure usually lasts for one or two minutes but the person may be confused and drowsy for sometime after the seizure ends and will need close supervision until they have regained full awareness.

Generalised Seizures:

Generalised seizures involve the whole brain at the outset and always involve unconsciousness or impaired awareness even though some of these seizures are very brief. There are a number of generalised seizures but the most relevant for a mainstream school setting are absence and tonic-clonic seizures. The Epilepsy Foundation of Victoria and other State epilepsy organisations can provide much more detailed information about the different types of seizures and epilepsy syndromes.

Absence: (previously called petit mal)

During this type of seizure the student will momentarily lose awareness of what is happening around them but they rarely fall to the ground. They simply stare and their eyes may roll back or their eyelids flutter. It can sometimes be difficult to tell the difference between absence seizures and daydreaming. Absence seizures begin suddenly, last only a few seconds and then stop suddenly usually with no confusion after the event. Although these seizures last only a few seconds, they can occur several times daily and can be very disruptive to learning. This type of epilepsy usually responds successfully to treatment. Early detection and treatment is essential to minimise disruption to educational progress.

Tonic-clonic: (previously called grand mal)

During the tonic phase of tonic-clonic seizures a person's body stiffens, air is forced past the vocal cords, which often causes a cry or groan, and they fall to the ground. This is followed by the clonic phase which involves jerking of their arms and legs in strong, symmetrical, rhythmic movements. The person

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may dribble from the mouth, go blue or red in the face and may lose control of their bladder and/or bowel as the body relaxes at the end of the seizure. As consciousness returns, the person may be confused, drowsy, agitated or depressed. They may have a headache and want to sleep. This drowsiness can last for a number of hours.

2. Treatments, including role of specialists, effects of treatments, use of devices, daily routines

A variety of anti epileptic drugs (AED) are available and used in the treatment of epilepsy. Up to 70% of people will achieve good seizure control with AED therapy. More complex management is required for some, and this often consists of multiple medications. Some people who do not respond well to AED therapies will be offered treatments such as surgery, a vagal nerve stimulator or the ketogenic diet.

Most children are referred to a paediatrician for diagnosis & treatment by their local general practitioner. Children with more complex epilepsy will often be referred by the paediatrician to a paediatric neurologist. If this happens the paediatrician usually maintains an active role in the medical management of the child's epilepsy.

B: THE CONDITION'S EFFECT ON THE CHILD/YOUNG PERSON

1. Effects on the individual

Epilepsy and young people

Being 'different from the other kids' is something all students, whether well or ill, prefer to avoid. In adolescence, the need to fit in and be part of a group may assume even greater importance, than in childhood. Students who have epilepsy and ongoing seizures have strong fears of having a seizure at school. Students with epilepsy are often afraid of being bullied, teased, and excluded from activities by their peers. They may also be afraid that teachers and parents will limit their participation in the full curriculum due to over-protectiveness. Without adequate support, a student with epilepsy may adopt strategies that ultimately have an adverse impact on their health, education and social life. Such strategies may include staying away from school, avoiding social occasions, avoiding friendships, not taking medication, drinking alcohol and being chronically sleep deprived from staying up too late.

Epilepsy is the most common neurological condition in adolescence. The need to adopt some strategies to ensure one's own safety and the safety of others may, at times, seem burdensome to young people. However, most young people diagnosed with epilepsy ultimately achieve excellent seizure control and are able to participate with their peers in most activities and experiences. Managing daily medication and avoiding seizure triggers, such as lack of sleep, are an important part of living well with the condition. Convincing young people of the need to continue daily medication and avoid seizure triggers when they have had excellent seizure control for an extended period of time can be difficult. The impact of epilepsy can be experienced in many ways:

1. Disruption to Learning Opportunities:

- Ongoing seizures and unrecognised seizures may interfere with learning
- Fear and anxiety about having seizures in public can disrupt the students ability to attend in class
- Medication side-effects can be detrimental to optimum learning. Common side-effects include – fatigue, dizziness, irritability (& aggression less frequently), double vision, nausea and tremors.
- Students may miss learning opportunities during seizures and the recovery phase
- Students experiencing nocturnal seizures may be tired and drowsy during the day at school
- Missed school due to: seizures, medical appointments and tests, medication side effects, avoiding situations or activities where the student might need to explain why they couldn't participate, parental overprotection.

2. Social Implications:

Coping with a disorder characterised by unpredictable and irregular seizure activity can create situations that lead to:

- Embarrassment
- Rejection
- Isolation
- Guilt
- Diminishing Self-esteem
- Reluctance to join in and unwillingness to take risks due to fear of having a seizure
- Risk-taking behaviour to remain part of a group.

2. Effects on those close to the child/young person

The experience of caring for someone with epilepsy including children is not easy, especially if the seizures are not controlled. Carers of someone newly diagnosed with epilepsy may be frightened of the seizures. Sometimes carers become upset when they observe unusual reactions and behaviours. It is necessary to distinguish whether these are side-effects of medication or whether they are part of an emotional reaction. If a young person feels isolated and angry or is being bullied at school it is important that the carer is able to step in and offer some help. Talking about the issues to the person with epilepsy may help but sometimes it is necessary to adopt an advocacy role and enlist the help of the school, or professional counsellors.

Siblings of a child with epilepsy can feel anxious and fearful for their brother or sister. They may take on a caring role and feel a responsibility to protect their sibling, especially in the school environment. They may also feel that they aren't getting the same amount of parental attention as their sibling with epilepsy, which can lead to resentment and disruptive attention seeking behaviours.

Because epilepsy can be a confronting disorder, carers themselves may experience isolation. The Epilepsy Foundation of Victoria provides a range of services to assist parents & carers make a healthy and positive adjustment to having a child with epilepsy.

3. "In Their Shoes" - stories from children/young people with the condition

"When I was doing my VCE I asked for special consideration for my exams. My teacher said that I didn't need it, I should just study hard and I would be OK. I got tired and anxious and I had a seizure during the first exam. I didn't sit any more (exams) and didn't complete my VCE that year. Later I had neurosurgery and I no longer have seizures but it was a long time before I got to uni."

Young woman aged 22, (personal communication in 2000).

C: STRATEGIES FOR SCHOOLS/TEACHERS

1. Overview of strategies for schools.

Epilepsy Education for Students, School Staff and Community

A student or teacher faced with a young person having a seizure may experience fear, embarrassment and a feeling of inadequacy. The teacher has a vital role to play in ensuring the student with epilepsy is safely managed within the school environment. In addition, teachers have an important role in encouraging the student with epilepsy to develop a healthy, positive adjustment to living with the disorder. Teachers can also model appropriate attitudes and behaviours about epilepsy, which can be a powerful means of ensuring the student's acceptance by his or her peers. It is vital for the school community that teachers and students develop an awareness of epilepsy, first aid knowledge, and strategies to support and assist all students to reach their full potential academically, socially and emotionally. Starting from a basis of inclusion rather than exclusion for students with epilepsy in a school setting is very helpful. Understanding the individual student's unique set of epilepsy circumstances, planning and supervision are key strategies adopted by schools dedicated to best practice.

Epilepsy Education for School Staff:

An epilepsy management and action plan should be developed for all students with epilepsy. A good plan should be concise, and easy to understand with the key information about the particular student's unique epilepsy circumstances, including emergency contact numbers, seizure type/s with a detailed description of the episodes, triggers, medication, and specific instructions of what to do when the student has a seizure and when to call an ambulance. The Epilepsy Foundation of Victoria and other State epilepsy organisations have epilepsy management plans available and can assist with writing the plan and training the teaching staff to implement the plan. It is important to discuss issues of confidentiality and disclosure with the parents and student. If the student hasn't had a seizure at school and is unlikely to have a seizure at school, the student and parents may not want this information disclosed to other students.

Epilepsy Education for Students:

Young people may feel afraid for the welfare of a person having a seizure or they may feel vulnerable themselves. If all students are given factual information, the likelihood of a young person with epilepsy being teased and excluded is reduced and inclusion and support are the more likely outcomes. Open explanations, discussions and questions are to be encouraged. A helpful strategy is to incorporate epilepsy education into the health curriculum, especially if the student or family hasn't consented to disclosure. The young person with epilepsy should be allowed to decide if they want to be part of the discussion or not. It can be a powerful and very positive experience for classmates when a student with epilepsy talks openly about their disorder. If a student has a seizure in the classroom or school grounds, the incident affects the student with epilepsy and the students who witnessed the seizure. Seeking permission from the student (& for a younger child, the parents) to provide specific epilepsy information about the student's particular epilepsy is essential. Establishing and maintaining excellent communication between the school and the student's family is also very important.

An excellent way for students to gain knowledge about epilepsy and first aid as part of the school curriculum is through Trivia Challenge (Victoria, Tasmania, Queensland, ACT). Students participate in a quiz of 100 general knowledge questions, 10 of which are about epilepsy. Information about epilepsy is provided for each student to research. Call 1300 852 853 for further details.

- Avoid an over-protective attitude

A student may feel that they are being singled out even though the teacher only feels concerned for their welfare and this may create problems for them with their peers. It is better to assume that a student will undertake all the activities on a curriculum, unless they or their parents indicate concern. Students can contribute to creating their own positive environment by listing what they can do or what they aspire to do. Concentrating on aspirations and achievements rather than on the limitations imposed by their health will foster a student's self-esteem and undermine misconceptions among some members of the school community.

- Consider the words

It is preferable to use the term “person with epilepsy” and not “epileptic”. Others should also be discouraged from using this term by politely explaining to them that the person with epilepsy is first and foremost a person with diverse interests and roles. Their health is only one aspect of their whole life.

- Consider other explanations

If a student appears drowsy or lacking in concentration do not assume this is due to their condition or their medication. As with other students, if the behaviour continues, the matter must be explored. It may be due to the epilepsy itself, or the medication, but it may also be due to other reasons, and these will require attention.

First Aid:

Always follow the student’s Epilepsy Management Plan and ensure that the plan is kept up to date. Regularly review the plan to ensure all teachers understand what needs to be done if the student has a seizure. Work out strategies for managing seizures in various settings in the school environment. Determine who will take responsibility for which aspect of the plan and practice implementation of the plan. Ensure relief teachers are aware of the student’s epilepsy and the plan. Special consideration needs to be given for the swimming program, excursions and school camps. One to one supervision is strongly recommended for all students with epilepsy participating in swimming lessons. Most students with epilepsy can successfully participate in school excursions and camps with careful planning before the events and appropriate supervision during activities.

Medication:

Most students take antiepileptic medication twice daily and are unlikely to need to bring medication to school. Some students require emergency medication for prolonged seizures and staff can only administer this medication if there is a clear, detailed order from the prescribing doctor and those responsible at the school for administering the medication have been trained by a registered nurse.

Behaviour:

In general, students with epilepsy don’t have specific behaviour problems unique to their condition and most will respond to appropriate discipline in the classroom. Sometimes a student with epilepsy can have behaviour problems due to seizure activity, or side effects from their medication. In addition, the student’s own anxiety and low self-esteem or parental overprotection or overindulgence may also contribute to behaviour problems. Epilepsy often occurs in children and young people with other conditions such as an intellectual disability, autism, an acquired brain injury, or a physical disability. Sometimes behaviour problems are more likely to be caused by the other co-existing conditions.

Learning Difficulties:

Some students with epilepsy can have learning difficulties, which can result from any one of a number of factors such as the disruption to learning from ongoing seizures, underlying brain damage which may have caused the epilepsy and either a cognitive impairment or an intellectual disability. The anti-epileptic medication can also contribute to a disruption to the student’s optimum learning in some circumstances.

Program Support Groups and Recruiting external professional assistance often helps the school improve outcomes for a student with epilepsy.

Link(s) to other useful online resources for schools on strategies in responding to a child/young person with this condition

Contact the Epilepsy Foundation of Victoria (www.epinet.org.au) or your State epilepsy organisation for multiple copies of the following resources :

- Epilepsy Foundation Services
- Seizures and Epilepsy & First Aid
- Epilepsy Management Plan
- When an ambulance is called in an emergency situation for Epilepsy
- Seizure observation sheet
- A4 First Aid Poster

D: FURTHER INFORMATION

1. Organisations, including services and resources available

The Epilepsy Foundation of Victoria

The Epilepsy Foundation of Victoria (EFV) is a member of Epilepsy Australia and aims to provide information, education, and support to people living with or affected by epilepsy.

The EFV provides services to metropolitan and regional Victoria. Contact us at our:

Melbourne Office

818 Burke Road
Camberwell VIC 3124

Phone: (03) 9805 9111

Fax: (03) 9882 7159

1300 852 853

Email: epilepsy@epilepsy.asn.au

Web: www.epinet.org.au

Regional Offices

Grampian Region

The Cooina Centre
10 Learmonth Road
Wendouree VIC 3355

Phone: (03) 5320 7416

Barwon South West Region

Barwon Design Park
400 Pakington Street
Newtown VIC 3220

Phone: (03) 5223 1645

The services from EFV include:

Information & resources including DVD's. We have an extensive library of books and journals about epilepsy and related issues, which members can access.

Counsellors are available 9-5 pm Monday to Friday.

Community education, including for schools, is available throughout Victoria.

An annual camp for families of children with epilepsy under the age of 18.

Advocacy of issues individuals identify as important.

Support for research.

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2. Further reading/viewing:

Epifile: an epilepsy management manual, 2002, edited Russell Pollard and Denise Chapman, Epilepsy Australia.

Epilepsy: a resource for teachers, 2002, Anne Little, Epilepsy Qld Inc

Epilepsy and behaviour: a guide for parents, 2002, Epilepsy Qld Inc

Challenging behaviour in children with epilepsy, 2002, Epilepsy Qld Inc

