St Louise de Marillac Primary School
Drumfinn Road, Ballyfermot
Dublin 10

MANAGING CHRONIC HEALTH CONDITIONS AT SCHOOL

EPILEPSY

What is epilepsy?

Epilepsy is a tendency to have seizures (sometimes called fits). A seizure is caused by a sudden burst of intense electrical activity in the brain. This causes a temporary disruption to the way that messages are passed between brain cells so the brain's messages briefly pause or become mixed up. There are many different kinds of epilepsy and about 40 different seizure types. Some of the common types of seizure are described in signs and symptoms. Epilepsy can affect anyone at any age. It can have an identifiable cause such as a blow to the head, meningitis or a brain tumour but for the majority of people there is no known cause. In some cases, the tendency to have seizures runs in families but having a parent with epilepsy does not necessarily mean a child will have the condition. There are approximately 1 in 200 children with epilepsy in Ireland.

Signs and symptoms

The brain is responsible for controlling the functions of our bodies. What a child or young person experiences during a seizure will depend on where in the brain the epileptic activity begins and how widely and rapidly it spreads. For this reason, there are many different types of seizure and each student with epilepsy will experience the condition in a way that is unique to them. Seizures can happen at any time and they generally only last a matter of seconds or minutes after which the brain usually returns to normal.

Seizures can be divided into two groups:

- Generalised
- Partial (sometimes called ‘focal’)normal.

Generalised seizures

Some seizures affect the whole or most of the brain and are called generalised seizures. These will always involve a loss of consciousness although the child or young person will not necessarily fall to the floor.

Absence seizures

In an absence seizure the person stops what they are doing and may stare, blink or look vague for just a few seconds. Absence seizures can sometimes be mistaken for daydreaming or inattention but in fact the person has lost consciousness. Absence seizures are one of the most common seizure types in children and young people and can occur several times a day. You may be able to help your students who have absence seizures by providing written information at the end of a lesson and helping them catch up on things they have missed.

Myoclonic seizure

These seizures involve sudden contractions of the muscles. The seizure can be a single movement or a series of jerks. Myoclonic seizures most commonly affect the arms and sometimes the head but can affect the whole body. Usually no first aid is needed unless the student has been injured.

Tonic-clonic seizures

Tonic-clonic seizures are the most widely recognised epileptic seizure. In a tonicclonic seizure, the student loses consciousness, the body stiffens and then they fall to the ground. This is followed by jerking movements sometimes called convulsions. Sometimes the student will be incontinent (lose control of their bladder or bowel). After a few minutes, the jerking movements usually stop. The student may be confused and need to sleep after the convulsive movements are over for minutes or even hours, until recovery is complete. However, some students will recover quickly.

Atonic seizures

In atonic seizures all muscle tone is lost and the person simply drops to the ground, hence the other name for this type of seizure: ‘drop attack’. When a student experiences an atonic seizure, the body goes limp and they usually fall forward – this can lead to them banging their head. Although they fall heavily, the student can usually get up again straight away.

Partial seizures

In some types of seizure, only part of the brain is affected: these are called partial seizures. Sometimes a partial seizure can turn into a generalised seizure and some types of partial seizure can act as a warning or ‘aura’ for a generalised seizure. Partial seizures can be either simple where consciousness is not impaired or complex where consciousness is impaired to some extent.

Simple partial seizures

The symptoms depend on the area of the brain affected. For example, a student experiencing a simple partial seizure may go pale and/or sweaty, may report tingling or a strange smell or taste or experience deja vu. During a simple partial seizure, the student remains fully conscious and the seizure is brief. Some students experience a simple partial seizure on its own or it may be a warning that the seizure may spread to other parts of the brain.

Complex partial seizures

The specific symptoms of a complex partial seizure depend on which area of the brain the seizure is happening in. In a complex partial seizure, it can appear that the person is fully aware of what they are doing but they may act strangely, for example: chewing, smacking their lips, plucking at their clothing or just wandering aimlessly. It is important to remember that a person experiencing a complex partial seizure cannot control their behaviour and that their consciousness is altered so they cannot follow instructions and may not respond at all.

Status epilepticus

Sometimes a student with epilepsy can experience a longer seizure or a series of seizures without regaining consciousness. The “five minute rule” is the cut off point at which either emergency medication should be administered or medical attention sought. If a seizure (or series of seizures) lasts 5 minutes without recovery it has the potential to become status epilepticus which is a medical emergency. Prompt intervention at 5 minutes is required to prevent this. Status epilepticus occurs when a seizure continues for more than 30 minutes and it is a medical emergency as the stress on the student's body may lead to brain damage. Some people are prescribed emergency medication such as rectal diazepam or buccal midazolam which aim to bring them out of the seizure before they enter 'status epilepticus'. These need to be administered by a properly trained member of staff. Training can usually be provided by the public health nurse in your area or contact your local Brainwave office for further information.

The effect of epilepsy on the student at school

There are various considerations for students with epilepsy especially if their seizures are not controlled. These might include safety in sports, activities and practical subjects. Storage and administration of medicines may also need to be planned for. Seizures are just one aspect of epilepsy that can affect education. A student with epilepsy may experience many seizures during a school day and this disruption can make learning a difficult process. Epilepsy can have other effects that are not easily observed during the school day such as night-time seizures that can leave a student exhausted and unable to concentrate and social or psychological effects.

Intellectual disabilities and other conditions

Most students with epilepsy are just as capable of learning as other students and some are high achievers. However, students with epilepsy can struggle academically in comparison to their intellectual level and some have problems with learning and attendance. Some students with epilepsy have intellectual disabilities and need a high level of support. Rates of epilepsy are higher among students with other conditions such as autism, cerebral palsy, hydrocephalus, acquired brain injury, ADHD and intellectual disability. Students with epilepsy can experience a range of difficulties at school. Some reasons why students with epilepsy can have difficulties at school are:

- Difficulty concentrating
- Working more slowly than others
- Being too tired

Epilepsy can lead to variation in a student's performance and may also be associated with developmental delay and learning difficulties. Students and their families may find these effects have an impact socially and sensitive input from school staff is needed to prevent damage to the student's self-esteem. Behavioural and learning difficulties in and outside school can be due to:

- Frequent and/or prolonged seizures
- Damage to the brain
- Side effects of epilepsy medication

They can also result from a low level of epileptic activity in the brain which can disturb brain function without causing a seizure. People with epilepsy often complain of a poor memory and the reasons for this may vary. Epileptic activity or underlying damage to the brain may cause memory problems. Some anti-epileptic drugs may cause side effects including memory problems, drowsiness, dizziness, headache or disturbances to vision. Having many seizures or severe seizures can cause damage to the brain and this can lead to learning disabilities. Epilepsy can occur in combination with other factors and sometimes epilepsy and learning disabilities can both be a part of a syndrome. (A syndrome is a group of signs and symptoms that, added together, indicate a particular medical condition).

Medicines and treatments

Regular medication

The majority of people with epilepsy take regular medication with the aim of controlling their seizures. Some students with difficult to control epilepsy may take several different types of medication. Generally, these can be taken outside school hours. Side effects can include drowsiness, poor memory and concentration, confusion, irritability, over-activity and weight gain.

At school

There may be some students who will require the administration of medication as part of their Healthcare Plan or Emergency Epilepsy Plan. Rescue medication such as buccal midazolam may be prescribed to some students to stop seizures that last over 5 minutes, the details of which should be included in the student's Emergency Plan. For further information on buccal midazolam please contact your local Brainwave office. You can also get more information on the Administration of Medication from the INTO and ASTI. It is important to remember that students with epilepsy may appear to display inappropriate behaviour or lack of concentration but these may be due to their medication and/or condition.

Epilepsy surgery

One alternative to long-term medication for a small number of children and young people is epilepsy surgery. This usually involves an operation to remove a small amount of brain tissue in the area involved in abnormal activity, with the aim of stopping or reducing seizures.

At school

When a child or young person is being considered for epilepsy surgery, they will have a series of tests to find out if they are suitable. This may be a long process and can be worrying and distressing. After the tests, the doctor will decide whether surgery is the best option and if so, the child or young person will have the surgery and may then gradually reduce their medication. The school may need to be aware that a student is likely to have several periods out of school before and after the surgery. School staff should also be aware of the psychological impact of the tests, surgery and coming to terms with the outcome of the surgery, whether or not this means being free from seizures.

Vagus nerve stimulation (VNS)

VNS is another treatment for epilepsy where a small electric impulse generator is implanted under the skin below the left collar bone in an operation. The generator sends electrical signals along electrodes that are attached to the vagus nerve in the neck to the brain. The signals aim to stop or prevent seizures.

At school

The surgery to implant the VNS generator is minor but the student will need some time away from school to recover. Using a VNS device can have side effects such as hoarseness, sore throat, coughing or shortness of breath.

Ketogenic diet

The ketogenic diet is a treatment for students with difficult to control epilepsy. The diet uses high fat and low carbohydrate levels to mimic the effect of starvation on the body. The diet must be carried out under close medical supervision. The Ketogenic Diet is a special diet, high in fat, which can have an antiepileptic effect. The reason for this is not clearly understood. This diet is not suitable for every student. Students who are on this diet must be carefully monitored by hospital doctors and a specially trained dietician. Parents need to be aware that it can be particularly unpleasant and difficult. There are several issues to be considered before commencing the diet to ensure safety, optimal growth and development.

At school

A student who is on the ketogenic diet will usually bring their own food to school and may need supervision at school breaks and meal times. It is very important that students on the ketogenic diet do not eat or drink anything that is not part of their diet as this could lead to seizures. It would be helpful for other students to be aware of the reason for the student's diet.

Managing the condition

Individualised Healthcare Plans

As epilepsy affects individuals differently, any policies or health care plans need to reflect the student's individual needs. Schools need to agree an individualised Healthcare Plan for each student. This should be done in consultation with the student, their parents/guardians and where appropriate should incorporate guidelines from the hospital team. The Healthcare Plan should address issues such as:

- The types of seizures the student is likely to experience
- How to recognise the specific seizures that apply to the student
- What to do- a detailed explanation of appropriate first aid for each type of seizure that the student may have
- Define what is an emergency in the case of the individual student and what action is to be taken and when. This section should be clear about issues such as: the typical duration of seizures, the typical recovery period, the point at which seizures are considered prolonged, any potential complicating factors (e.g. other health issues), other indicators of emergencies (e.g. injury) administration of emergency medication and contacting emergency services
- Additional relevant educational information, learning difficulties or disability, comprehension and memory issues
- Interruptions to school attendance and learning and any measures that may be availed of to support the student in the respect of same e.g. learning support, resource, home tuition
- Reasonable accommodations to permit the student to participate in activities such as swimming or practical classes requiring supervision
- Any relevant information that is pertinent to best practice in providing care to the student

Disability and Education Legislation

In terms of the legislation, epilepsy is considered to be a disability under the term physical disability. Current legislation requires that reasonable accommodations are made to prevent issues of discrimination regarding access issues. Examples of reasonable accommodations may include the provision of an LCD or TFT monitor for a student with photosensitive epilepsy. Other accommodations may extend to providing a quiet place for the student to recover from their seizure rather than sending them home.

Psychological and social factors

As with any student, those with epilepsy may experience psychological and social factors which can affect their behaviour and learning. These may range from issues of stigma and exclusion to issues of confidence, fear and anxiety, self esteem, memory and concentration. Social Personal and Health Education (SPHE) classes, science projects and a school talk from Brainwave, The Irish Epilepsy Association are all among the potential opportunities for raising awareness of epilepsy among other students. Such learning opportunities do not need to identify any individual student as having epilepsy unless they are happy to disclose it but can serve to create a climate of understanding among the school body generally.

Triggers

In many students with epilepsy, seizures happen without warning but in some people certain triggers can be identified. Some examples are given below.

Stress, anxiety or excitement can cause some students with epilepsy to experience more seizures and the seizures can occur before or after the feelings.

In school, factors might include:

- Worrying about their epilepsy and how it might affect their school life
- Worrying about exams
- Excitement/worry about being able to take part in school activities or events
- Stress caused by being bullied or teased

There may also be factors outside school that cause stress (for example, a difficult home life or bereavement).

Hormonal changes can affect a student's epilepsy. This could include the onset of puberty (in either sex) or seizures associated with menstruation (sometimes referred to as catamenial epilepsy).

Not taking medication as prescribed can lead to changes in a student's epilepsy such as the pattern or severity of their seizures.

Unbalanced diets and skipping meals can lead to low blood sugar levels that in some students with epilepsy, may be a seizure trigger. There is no evidence to suggest that specific foods can trigger seizures. A regular intake of balanced meals is advised. Energy drinks containing caffeine and other stimulating substances can lower seizure threshold and are best avoided.

Late nights, broken sleep or irregular sleep patterns can trigger seizures. Establishing a regular sleep pattern may help.

Alcohol and recreational drugs are increasingly part of many young people's lives. Alcohol can make seizures more likely and worsen the side effects of anti-epileptic medication. Recreational drugs can trigger seizures in students whether or not they have epilepsy. In students with epilepsy they can affect seizure patterns and are often associated with other possible trigger factors.

Some over-the-counter and prescription medicines may make a student more likely to have seizures – always check with the pharmacist.

Illness can make seizures more likely especially when associated with a high temperature. Using measures to lower a high temperature is important for this reason. For some people pain, when severe, can be a trigger also.

Photosensitive epilepsy is the name given to a form of epilepsy in which seizures are triggered by flickering or flashing light, glare and certain patterns. It is often assumed that everybody with epilepsy is photosensitive but only around five per cent of people with epilepsy are. People are typically screened for this when they are being diagnosed and would be advised that they have this form of the condition. Photosensitive epilepsy is most common between the age of 9 and 15 years. High contrast, for example, black and white stripes, grids, swirls, patterned clothing, blocks of intense red colour, wallpaper patterns, fireworks and sunlight through blinds may also trigger seizures for some students with photosensitive epilepsy.

Flickering from television screens can sometimes trigger seizures for some children and young people with photosensitive epilepsy. Some TV and computer screens such as plasma and LCD are flicker free (but not glare free). The larger the screen the greater portion of the visual field it fills so distance from the screen required is relative to its size. A smaller screen viewed at the recommended distance (8-10 feet) will pose less risk overall.

Unless they are displaying high contrast patterns or material that is flickering or flashing, computers and interactive whiteboards themselves should not trigger seizures for most students with photosensitive epilepsy. This is because they usually either flicker at a rate that is too fast to trigger seizures or do not flicker at all.

In the case of TV, the risk can also be minimised by viewing the screen from at least 2.5 metres (8 feet) away so distancing the student from the whiteboard may also help reduce the risk from any problem image. With computers where close work is necessary and distancing is not feasible, the student should where possible, use a monitor that is flicker free, has an anti-glare screen and is in a well lit area. Web content can now be screened similar to TV but again it has not been universally adopted so caution is advised and it may be wise to stick to trusted sites that have not caused previous problems. Wearing polarised sunglasses outdoors on sunny days can help to remove flickering reflection (e.g. from water). This will help to minimise the risk of seizures occurring although it will not remove it entirely.

Experts in the field of photosensitivity have responded to concerns raised about the use of CFL bulbs and have stated they should not pose a risk. Individual sensitivities however can vary and should be assessed on this basis.

Guidelines for reducing risk to students with photosensitive epilepsy include distance from screen, having good background lighting to offset contrast and using glare reduction screens (although most newer equipment has this feature built in). As other factors are naturally occurring and are hard to control, good guidance is for the student to place one hand over one eye in the event of exposure to an image that can provoke this kind of seizure.

Most people with epilepsy should be aware of possible triggers and know which activities or equipment to avoid. Drawing up a Healthcare Plan in consultation with the student and their parents, can help the school and relevant staff to clarify possible triggers and how to avoid them.

Exercise and physical activity

Exercise and physical activity is good for every student including those with epilepsy. Some students with epilepsy are advised against taking part in some activities when this is not necessary. With the relevant safety precautions (including qualified supervision where appropriate) students with epilepsy can take part in most, if not all, school activities including sport. Many students with epilepsy have their seizures completely controlled by medicines and do not need to take any greater safety precautions than anyone else.

Indeed, when a child or young person with epilepsy is active they are less likely to have seizures. So, for most people with epilepsy, exercise can be of real benefit. However, a very small number of people with epilepsy find that exercise increases their likelihood of having a seizure. This is usually due to over-exertion. Also, taking up exercise or a sporting activity for the first time or after a long period of inactivity, could affect a student's body weight and metabolism, which in turn could have an effect on their seizure control.

Students with epilepsy may need to speak to their doctor before taking up a new sport or leisure activity, particularly if their seizures are not fully controlled. Things to take into account are the type, severity and frequency of the seizures and known triggers such as stress and excitement. Good communication between schools and young people and their families is important for ensuring that students with epilepsy are fully included in school activities.

School Policy

The Board of Management have responsibility to:

- Promote a supportive learning environment for students with epilepsy. This includes understanding of the potential cognitive impacts of epilepsy and its treatment on learning. Also, it includes extending support to the student to minimise disruption to learning from the seizures and from missed schooling
- Develop school guidelines for epilepsy management during school and school outings
- Allocate sufficient resources to manage students with epilepsy
- Meet annually with the school team to arrange and attend a meeting with the student, family, teacher(s) and other staff members who have primary responsibility for the student
- Identify all staff members who have responsibility for the student with epilepsy
- Delegate a staff member to ensure medication is stored safely, check the expiry date of epilepsy medicines kept at school and maintain the school chronic conditions register

- Allow adequate time for epilepsy management training for staff with responsibility for students with epilepsy
- Alert all school-related staff members who teach or supervise a student with epilepsy. Ensure that they, including the bus driver and substitute personnel are familiar with emergency procedures
- Include epilepsy awareness as part of health education
- Support and implement the Emergency Epilepsy Plan agreed by the school and the student's parents
- Advise the student and their parents of the Reasonable Accommodations provision in State examinations and of the arrangements in the event of seizures during in-house examinations

The teachers and SNAs have responsibility to:

- Participate in the school meeting with the parent(s) and the principal. The teacher(s) and SNA(s) who have the main responsibility for the student should participate in the meeting(s)
- Work with the school team and the parents to develop a written Healthcare plan including the Epilepsy Emergency Plan specific for the student
- Be prepared to recognize the triggers, signs and symptoms of seizures and know what to do in an emergency
- Maintain effective communication with parents including informing them if their child has become unwell at school
- Provide a supportive environment for the student to manage their epilepsy effectively and safely at school
- Provide alternative options for vigorous physical activity
- Promote inclusion of the student with epilepsy in all school activities that are appropriate and safe to participate in, including sports, extracurricular activities and school trips in accordance with the guidance of the student's medical team
- Ensure that emergency medication such as buccal midazolam is stored in a safe place in the school and readily available in the event of a seizure
- Ensure that the student has the right to privacy when recovering from a seizure if this is needed. However the student should be checked on at regular intervals

- Provide information for substitute teachers that communicates the day-to-day needs of the student with epilepsy and the Epilepsy Emergency Plan
- Attend Epilepsy management training if deemed necessary
- Be aware of the potential impact of seizures and medication on a student's memory and overall school performance

The parents/guardians of a student with epilepsy have responsibility to:

- Inform the school principal and their child's teacher that their child has epilepsy
- Attend and participate in the school meetings and provide specific information about their child's epilepsy including seizure type, pattern, triggers, management and drug regime
- Provide accurate emergency contact details and an up-to-date Healthcare Plan and Emergency Plan for their child including details of the GP, and local A&E service and conditions under which an ambulance is to be called
- Inform school staff of any changes in their child's health status
- Provide the school with the necessary information and emergency medication to meet the student's needs within school. Replenish supplies of emergency medication as needed. A ventilated pillow may be supplied in the case of a student who may need to sleep after a seizure
- Ensure their child's medication and any spare medication provided is labelled with their full name and is within the expiry date
- Provide information about their child's triggers which are relevant to the daily schedule e.g. impact of skipped meals. These can be tailored to fit into the daily school timetable
- Agree that the student with epilepsy will take part in all school activities, e.g. swimming, outings and extracurricular activities that are safe and appropriate for them to do. If there are concerns as to safety of a specific activity it is best to be guided by the student's neurology team
- Where the student is on a special diet for epilepsy such as the Ketogenic or Modified Atkins/Low GI Diet, provide the school with appropriate treats for their child for special events such as parties

Sample Epilepsy Emergency Plan

(This will be adapted from p.73 of the Resource Pack for Management of Chronic Conditions)

First aid for seizures is quite simple and can help prevent a student from being harmed by a seizure.

PLEASE NOTE THAT SOME STUDENTS MAY BE PRESCRIBED EMERGENCY MEDICATION AND PLEASE

REFER TO THEIR HEALTHCARE PLAN FOR DETAILS.

TONIC-CLONIC SEIZURES

DO

- Note the time
- Protect the student from injury (remove any harmful objects nearby)
- Cushion the head
- Wipe away excess saliva
- Gently put the student in the recovery position when the seizure has ended
- Stay with them until recovery is complete
- Calmly reassure the student

DON'T

- Restrain the student
- Put anything in their mouth
- Try to move them unless they are in danger
- Give the student anything to eat or drink until they are fully recovered

SEIZURES INVOLVING ALTERED CONSCIOUSNESS OR BEHAVIOUR

DO

- Guide the student from danger
- Stay with the student until recovery is complete
- Calmly reassure
- Explain anything that they may have missed

DON'T

- Restrain the student
- Panic
- Assume the student is aware of what is happening or what has happened
- Give the student anything to eat or drink until they are fully recovered

First Aid for Seizures

FIRST AID WILL DEPEND ON THE INDIVIDUAL STUDENT'S EPILEPSY AND THE TYPE OF SEIZURE THEY ARE HAVING.

Some general guidance is given on this page . This is a sample plan and please fill out appropriately for each student but most of all, it is important to keep calm and know where to find help.

When to call an ambulance - dial 112 or 999

- If you know it's the students first seizure
- The seizure continues for more than 5 minutes
- Or longer than is normal for that individual
- One seizure follows another without the student regaining awareness between seizures
- The student is injured during the seizure
- You believe the student needs urgent medical attention

Resources

www.epilepsy.ie

Download information and read the latest news and advice about epilepsy.

http://www.epilepsy.ie/index.cfm/spKey/training_for_success.html

Training for Success is Brainwave's Pre-employment Training Programme for people with epilepsy

www.epilepsy.org.uk

Download information and read the latest news from Epilepsy Action in the UK.

Brainwave The Irish Epilepsy Association

Brainwave was established in 1966 by a group of individuals concerned to improve the quality of life of people with epilepsy in Ireland. Over the 45 years since our inception, the Association has grown and expanded and now provides a range of services from headquarters in Dublin and from its network of regional offices.

Mission Statement

Brainwave is committed to working to meet the needs of all its members living with epilepsy.

Objectives

- To provide support, information and advice to people with epilepsy
- To provide information and advice to health professionals in dealing with epilepsy
- To improve public understanding of epilepsy (in order to eliminate fear and prejudice) through awareness campaigns and education programmes
- To undertake, encourage and assist research into the causes of, cure for and management of epilepsy and into the social and psychological effects of the condition
- To promote legislative and civil rights for people with epilepsy and to campaign to eliminate all discriminatory practices and policies affecting them
- To assist in the development of support groups for people with epilepsy in the area of training and employment
- To provide information on issues related to driving: insurance and changing legislation
- To provide practical aids to people with epilepsy (pillows, bracelets)
- To operate as a public forum and an advocate for the condition of epilepsy
- To raise funds to support its work in an awareness creating manner

Regional Office

East Region

(Counties Dublin, Kildare & Wicklow)

Brainwave Head Office, 249 Crumlin Road, Dublin 12.

01-455 7500

imurphy.brainwave@epilepsy.ie