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Policy and Procedure Feedback Form

A Policy and Procedure Feedback Form is available on the Western Care Association Intranet (under Procedures) which will provide an opportunity to comment on any policy/procedure. Your comments will be forwarded to the person who has the lead for the on-going development of the policy/procedure. All comments will be collated by the person responsible and will inform the three-yearly review cycle for updating procedures.

Overview – Supporting Person with Epilepsy

Epilepsy Knowledge	Epilepsy Health Management	Epilepsy Risk Management
1. The Person is supported to understand their epilepsy as much as possible. (see Intranet Resources - Health)	1. An Epilepsy Management Plan is developed with the person and their Circle. This is to ensure staff and supporters know what to do when a seizure occurs.	For people living with epilepsy, the risk should take into account what is important to and for the person so that unwarranted restrictions are not placed on them. (see Risk Management Plan for Seizures and also Risk Rating Tool)
2. The person and their Circle of Support are involved in all the planning around needs in this area.	2. The Plan is current, updated annually or more often if required and is informed by person’s medical practitioners.	A Risk Management Plan for Epilepsy is developed by the person and their Circle of Support/Planning Group concerning what to do during every day, recreational and/or sporting activities/night time if the person has a seizure
3. Staff supporting the person develop their knowledge around epilepsy and how to respond to a seizure.	3. Documentation is in place for: (a) Monitoring Seizures using the Epilepsy Seizure Recording Chart (b) Medication Records(MP1 and MR2) (c) Individual observations of sleeping patterns, movement, alertness, communication and moods(daily logs/seizure diaries) (d) Protocols for Use of Emergency Medication	The Plan is clear about what risks present for the person and what needs to happen to manage those risks.
4. Staff Training is provided. Epilepsy Awareness, Safe Administration of Medication, Customised Training events. First Aid.	4. There are annual reviews of epilepsy with the relevant medical practitioner attended by the person with support as required. Part of the evidence to be used to support this process comes from the Epilepsy Seizure Recording Forms.	If aids are prescribed to manage the risk, then they are assessed by the relevant personnel with due regard given to the person’s wishes and rights in this area.
5. Communication between all those supporting person is agreed and understood. Named Staff/identified other co-ordinates plan.	5. The person is supported to prepare for this appointment with all relevant documentation. These are informed by guidance document for attendance at neurology ; Neurology Appointment Preparation Checklist” and Epilepsy Seizure Recording Chart (see Appendices)	

Introduction

Western Care Association encourages people receiving services to pursue best possible health and to take as much responsibility as they can for their own healthcare. This preserves independence, regardless of the service supports received and is important because it prepares people to look after their own health and wellbeing.

This policy describes the support that any child, young person or adult with epilepsy may expect to receive when availing of Western Care Association services in order to achieve and maintain best possible health. Its guidance is to ensure that each person living with epilepsy and their support staff has the confidence, knowledge, skills and support they need to manage the condition as effectively as possible.

The organisation provides training for staff in First Aid, Epilepsy Awareness and Responsible and Safe Medication Management. Service Managers are responsible for identifying, in good time, the training needs of staff to respond to the person's medical condition.

The organisation's Evaluation and Training Department (ETD) will provide information and organise training where the need arises. Where training needs arise which could not be anticipated in advance the manager will liaise with ETD to work out a practical training solution.

The policies, most especially Best Possible Health, Medication and Risk Management, must be referenced when addressing the person's health care and medication needs.

This policy applies to all staff, work experience participants and volunteers who support people using Western Care Association services as appropriate to their role and level of responsibility.

Guiding Principles

- It is a fundamental right of every person to enjoy the highest attainable standard of health.
- To the greatest extent possible, the person is involved in decision making about his/her care and treatment.
- Capacity to consent - all adults are presumed to have capacity unless and until they demonstrate otherwise. If capacity is lacking a broader consultation process must take place. Young adults, 16-17yrs are considered competent to consent for themselves unless otherwise revealed. For children under 16yrs, a parent/guardian must be involved in decision making.
- The person is enabled to make informed healthcare decisions. Information about epilepsy and treatment is accessible to the person.
- Unless the person directs otherwise and where possible, the person, staff and family/guardian and medics work in partnership to support best possible health.
- Issues relating to culture, ethnicity, language, gender and sexuality are considered.
- The person is supported to have a regular review of their epilepsy, at least annually by the clinician responsible for epilepsy management.
- The person has a comprehensive Epilepsy Management Plan.
- The person has a Risk Assessment completed, if appropriate.

- While the health and safety of the person with epilepsy is paramount, any attempt to reduce risk should avoid, as much as possible, compromising other aspects of the persons' safety and dignity or impairing his/her quality of life.
- Staff and supporters must fully consider the 'duty of care' (a moral or legal obligation to ensure the safety or well-being of the person).and 'dignity of risk' (respecting the person's autonomy and self-determination to make choices) for/with the person. 'Duty of care' will override 'dignity of risk' in all circumstances involving the person with epilepsy.
- When required, monitoring and supervision of the person will occur in a manner that is as discreet as possible, minimises disturbance and promotes their health and safety.
- Every therapeutic option is considered for the person with poorly controlled epilepsy. This can include: surgery, vagal nerve stimulation, ketogenic diet and psychological interventions.

Epilepsy

Epilepsy is a common neurological disorder characterised by recurring seizures, Different types of epilepsy have different causes.

People with epilepsy experience a sudden discharge of abnormal electrochemical activity that results in 'seizures' of various types and with characteristic effects. With regular medication and other strategies, many people with epilepsy achieve control of their seizures. However, others may continue to experience seizures despite regular medication.

Most people with epilepsy experience only one type of seizure, although some experience a variety of seizure types. Those experiencing the more severe ('generalised') types of seizures, especially tonic-clonic (convulsive) seizures where consciousness is lost, require assistance during and after a seizure, sometimes including administration of emergency medicine, to ensure their safety, wellbeing and dignity.

It is estimated that about 1 in 115 people have epilepsy in Ireland with 1 in every 20 people having a single seizure at some time during their lives. Seizures are controlled with medication in about 70% of cases.

The effective management of epilepsy is important because people with epilepsy have a risk of premature death that is 2-3 times higher than the general population and most premature deaths in this group are directly related to epilepsy itself.

Therefore seizure control not only increases the quality of life of people with epilepsy, but reduces the risk of death. The goal is to achieve a seizure-free status without adverse effects for the person.

Prevalence – Intellectual Disability

Epilepsy is much more common in people with intellectual disability than in the general population with its occurrence increasing in line with the severity of intellectual disability^[2] (ID) while, reported prevalence rates in people with ID vary widely between studies, it is believed to affect around 1 in 5 people. It tends to be more difficult to diagnose and to be more severe and difficult to treat. Between 1 and 10% of people with Down syndrome and 90% of those with Angelman Syndrome have epilepsy.^[2]In people with Down's syndrome, the onset of epilepsy may form part of the onset of Alzheimer's disease.

Definition

The definition of epilepsy was last revised in 2014 by the International League against Epilepsy (ILAE) which states that Epilepsy is a disorder of the brain defined by any of the following conditions:

1. At least two unprovoked (or reflex) seizures occurring greater than 24 hours apart.
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
3. Diagnosis of an epilepsy syndrome
 - a. Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years.

Item 2 allows a condition to be considered epilepsy after one seizure if there is a high risk of having another seizure. Often, the risk will not precisely be known and so waiting for a second seizure occurs before diagnosing epilepsy.

Item 3 refers to epilepsy syndromes such as benign epilepsy with central-temporal spikes, previously known as benign rolandic epilepsy, which is usually outgrown by age 16 and always by age 21. If a person is past the age of the syndrome, then epilepsy is resolved.

If a person has been seizure-free for at least 10 years with the most recent 5 years off all anti-seizure medications, then their epilepsy also may be considered resolved. Being resolved does not guarantee that epilepsy will not return, but it means the chances are small and the person has a right to consider that she or he is free from epilepsy.

Some Causes of Epilepsy

Epilepsy has many possible causes. Because of its complexity, the underlying cause of someone's epilepsy may not be found. Causes of epilepsy can be put into three main groups: symptomatic, idiopathic and cryptogenic epilepsy.

Symptomatic Epilepsy

Epilepsy is called 'symptomatic' when it has a known cause. This may include:

- A head injury
- An infection like meningitis
- The brain not developing properly
- A stroke
- A scar
- A tumour

A scan, such as a Magnetic Resonance Imaging (MRI), may show the cause.

Some symptomatic epilepsies may happen because of genetic conditions such as Tuberous Sclerosis, which causes structural abnormalities in the brain and other organs.

Idiopathic Epilepsy

Epilepsy is called 'idiopathic' when it is thought to be due to a genetic tendency (which could have been inherited from one or both parents) or due to a change that happens in the person's genes before they are born.

A genetic tendency to have seizures is likely to be associated with a low seizure threshold. A person's seizure threshold often plays a key role in whether they will develop epilepsy.

Seizure Threshold

A seizure threshold is the individual level of resistance to seizures. Anyone has the potential to have a seizure. However, some people will be more likely to have a seizure than others.

The seizure threshold is one part of the person's genetic make-up which can be passed from parent to child. So the chance of having seizures may depend partly on whether either of the person's parents has epilepsy.

If the person has a low seizure threshold, the brain is less resistant to seizures. Hence, one is more likely than someone with a high seizure threshold to start having seizures suddenly for no obvious reason than someone with a high seizure threshold

If the person has a high seizure threshold, he/she is less likely to have a seizure. However, damage to the brain (for example from a severe head injury or an infection) could lower the seizure threshold; making a seizure more likely.

Cryptogenic Epilepsy

This is when the cause for a person's epilepsy has not yet been found, despite investigations.

Seizures

The outward signs of epilepsy are known as seizures, and these vary in appearance depending upon the part of the brain that is affected and how far the disruption has spread. The brain is made up of billions of nerve cells that process information from the senses, thoughts, memories, emotions, and actions, and any (or all) of these activities can be affected. Most seizures are over within a few minutes or less and the person recovers quickly.

For most people with epilepsy, seizures occur without any warning and without any obvious trigger. However, some notice that their risk of having a seizure is increased by factors such as poor sleep, stress, anxiety, fever, excessive alcohol consumption, or (in around 5% of cases) flashing/flickering lights (this is known as photosensitive epilepsy). Some women with epilepsy find that their seizures occur at a specific time in their hormonal cycle. Missing doses of anti-epileptic medication can also increase the chance of having seizures and should be avoided.

Frequent and/or severe seizures can impact severely upon a person's life, and they may even require constant supervision. For others, they respond well to treatment and are able to continue with their lives; albeit with a bit more caution.

Seizure Types

Seizures can be divided into two major groups:

1. Partial Seizures

These seizures can often be very subtle or bizarre, and may go unnoticed or be confused with other events. The seizure activity starts in one area of the brain and may spread to other regions of the brain. These are also known as focal seizures.

Types of partial seizures are:

- Simple Partial (no loss of awareness)
- Complex Partial (change in awareness and behaviour)
- Secondly Generalised* (see note below)

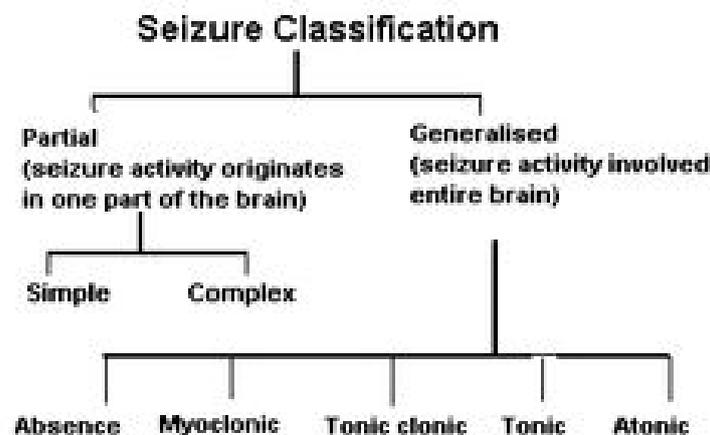
2. Generalised Seizures

Generalised seizures are the result of abnormal activity in the whole brain simultaneously. Because of this, consciousness is lost at the onset of the seizure. There are many types of generalised seizures.

- Generalised Tonic-Clonic
- Absence
- Myoclonic
- Tonic
- Atonic

***Note:** Sometimes a seizure starts as a partial seizure and then becomes a generalised seizure, almost always a tonic-clonic seizure. When this occurs, the seizure is called secondarily generalised. Most people will often only have one or two seizure type(s), which may sometimes vary in severity. In cases where a person has significant damage to the brain, there may be several different seizure types.

Here is a simple diagram showing how seizures are classified:



What Seizures Look Like

Partial seizures (Often called **focal seizures** and previously referred to as "**petit mal**").

Simple Partial Seizures

These seizures are often termed an "aura" or warning by the person experiencing them as they can precede a complex partial or tonic-clonic seizure.

There is no loss of awareness or consciousness and they are usually short lived, less than a minute.

Partial Seizures symptoms are:

- Sensory – numbness, tingling or burning sensation in a region of the body
- Motor – jerking of a limb, twitching of the face
Examples Autonomic – blushing, pallor, increased heart-rate, nausea
- Psychic – déjà'vu, hallucinations (visual, sound, taste or smell), emotions such as fear

Complex Partial Seizures

- Consciousness or awareness is altered, producing a vague, confused or dreamlike appearance.
- The person may respond, but often inappropriately, and display strange, random or repetitive behaviour. This behaviour commonly presents as chewing, fidgeting, taking off clothes, walking around, or mumbling.
- There is often a period of confusion after the seizure and little, if any, memory for the event.
- These seizures can last from approximately 30 seconds to 3 minutes.

Generalised seizures

Generalised tonic-clonic seizure (Sometimes called a **fit or convulsion** and previously referred to as "**Grand Mal**"). These are the most universally recognised seizures.

- They often begin with a sudden cry; if standing, the person will fall to the ground, losing consciousness.
- The body becomes quite stiff (tonic) shortly followed by jerking of the muscles (clonic).
- Breathing is shallow or temporarily suspended causing the lips and complexion to look grey/blue
- Saliva (sometimes also blood if they have bitten their tongue) may come out of the mouth, and there may be loss of bladder control.
- The seizure usually lasts approximately 2 minutes and is followed by a period of confusion, agitation or sleep. Headaches and soreness are common afterwards.

Absence Seizures (Previously referred to as "**Petit Mal**").

- These seizures almost always begin in childhood, and there is sometimes a family history. They are commonly mistaken for daydreaming and in-attentiveness.
- They are characterised by staring, loss of facial expression, unresponsiveness, cessation of activity and sometimes eye blinking or upward eye movements.
- They start and end abruptly, last approximately 2-20 seconds.
- There is usually an immediate recovery of mental function and resumption of previous activity, with no memory of the event.

- **Myoclonic Seizures.** These are very brief muscle jerks, usually involving the upper body, but can involve the lower body or whole body. The person may spill what they are holding or fall off a chair. There is no impairment of consciousness, but if several seizures occur over a short period of time, the person may feel slightly confused or drowsy.
- **Tonic Seizures*** (Also known as **drop attacks**). These are very brief, stiffening of the muscles of the whole body, causing it to go rigid. If a person is standing, they will fall rapidly to the ground. Recovery is swift, but injuries can be sustained. These seizures also occur in sleep.
- **Atonic Seizures*** (Also known as **drop attacks**). Atonic seizures are a very sudden, brief loss of muscle tone of the body. Once again, the person will abruptly collapse to the ground; usually head first, so facial and head injuries are common. No noticeable loss of consciousness, swift recovery unless injured.

***Note: Tonic and Atonic seizures are more likely to occur in people with severe epilepsy with multiple seizure types.**

Status Epilepticus: Most seizures last only a few minutes but some can persist for longer periods. Status epilepticus is defined as a seizure that lasts 30 minutes or more and is considered life threatening. It can be one continuous seizure that last 30 minutes or a cluster of seizures close together whereby there the person doesn't regain consciousness in between for a time of 30 minutes. Individuals usually experience convulsive status epilepticus similar to a prolonged tonic clonic seizure. However some can experience what is referred to as Non-Convulsive Status Epilepticus whereby a person can experience a series of complex partial seizures that can go on for hours or days. This type is not thought to be life threatening however can be disturbing and confusing for the individual.

Status Epilepticus is uncommon and the treatment of epilepsy aims to prevent status occurring and, if it occurs, to treat it rapidly using – Buccal Midazolam and the now lesser used Rectal Diazepam.

Sudden Unexpected Death in Epilepsy (SUDEP)

Sometimes a person with epilepsy dies during or following a seizure for no obvious reason. This Sudden Unexpected Death in Epilepsy (SUDEP) is uncommon.

Diagnosing Epilepsy

Because there is no obvious sign a person has epilepsy, unless they are having a seizure, it can make diagnosing epilepsy difficult. A diagnosis is usually made after a person has had more than one epileptic seizure.

An early and accurate diagnosis is important because it gives people time to come to terms with their condition. It also ensures that the appropriate treatment, support and information about lifestyle and risk reduction are given promptly. An early diagnosis is not always possible, however, as tests can be inconclusive and time may be needed to record and monitor further events to enable a fuller assessment before confirming a diagnosis.

Steps to an Accurate Diagnosis include:

- Written and verbal eyewitness accounts of the seizure episode – including what happened before, during and after the seizure
- A medical assessment by a MEDICAL PRACTITIONER as soon as possible after the event
- Prompt investigation by an epileptologist/neurologist.
- The person's own account/those close to the person of the seizure episode
- A detailed medical history of the person and their family
- Appropriate diagnostic tests
- Close monitoring by the individual, their family or staff following the event
- A written record maintained of all subsequent seizure activity including unusual behaviour, feelings, sensations and events. A home video of seizures can be very useful
- Acceptance that an accurate diagnosis may take time to determine
- Recognition that the worst diagnosis is a wrong one arrived at too hastily

Tests

Most tests do not make or rule out a diagnosis of epilepsy but there are a number of investigations that can guide epileptologists/neurologists and help them form a complete picture of what is going on.

These mostly take place in a hospital but not everyone will need all of the tests – some are only used in particular circumstances or if early tests are inconclusive. See Intranet – Health – Health Conditions – Epilepsy for further resources.

Electroencephalograph (EEG)

In most cases of suspected epilepsy an EEG is likely to be recommended. This measures the brain's electrical activity via electrodes placed on the scalp and identifies disruptions. It is pain free and takes up to an hour to complete. The EEG is frequently normal in people with epilepsy, so a normal EEG does not rule out epilepsy. Often, people are asked to over-breathe and/or flashing lights are used to provoke epileptic abnormalities in the EEG. Sleep or sleep deprivation are also used to increase the chances of recording abnormal activity.

Magnetic Resonance Imaging (MRI)

This is the most sensitive brain scan used in epilepsy. It uses magnetic fields and radio waves to penetrate the brain in a non-invasive and painless way, to identify very small lesions and scars in the brain. It is very useful in cases where surgery is a possibility. Occasionally a dye is injected into a vein to enhance the images. The actual test takes approximately 30 minutes to complete, but some preparation time is also needed (about 30-40 minutes).

Computerised Tomography (CT) scan

CT scans use X-rays of the brain to provide cross section images of the brain that are stored on a computer. Sometimes a dye is injected into a vein to enhance the images. The actual scan takes about 10 minutes, but some preparation time (30-60 minutes) is needed.

Ambulatory EEG

During ambulatory EEG, the person wears a tape cassette recorder to provide up to several days' and nights' recording of the brain's electrical activity.

Video-EEG telemetry

Video-EEG telemetry consists of simultaneous EEG recording of the brain's electrical activity and video recording of seizures. It is usually carried out over a few days, and is mainly used when the diagnosis is uncertain or for assessment for surgical treatment of epilepsy.

Positron Emission Tomography (PET) scan

This is a non-invasive process that takes 30 to 60 minutes. It creates 3-dimensional images of the brain and uses a tracer to analyse brain function. The most common tracer used analyses glucose in the brain. This test is usually performed between seizures.

Single Photon Emission Computerised Tomography (SPECT) scan

This may be used when people are being assessed for epilepsy surgery. It is similar to a PET scan, and the most common tracer used measures blood flow. The injection of the dye into the vein is usually done during seizures, when video-EEG telemetry is taking place. The scan (which takes about 20 minutes) occurs soon after, and it highlights "hot spots" of seizure activity.

Treatments

Once a diagnosis of epilepsy has been confirmed, the neurologist will recommend a treatment plan based on the person's medical, social and lifestyle needs. Not all of the treatments will be suitable for all types of epilepsy.

Anti-epileptic Drugs (AEDs)

AEDs are usually the first choice of treatment for epilepsy.

Surgery

Surgery for epilepsy has been carried out since the 19th century and has a good success rate in suitable cases. It involves removing or disconnecting areas of the brain where epileptic activity starts.

Surgery may be an option if:

- Adequate trials of AEDs fail to control seizures
- Tests clearly indicate that the epileptic activity starts in a single identifiable area of the brain, and removal of this area is unlikely to cause significant damage or disability

A full assessment by a specialist team is necessary before the person with epilepsy and the surgical team can make a final decision about surgery. This assessment usually involves a number of tests and may take up to a year.

Vagus Nerve Stimulator (VNS)

A VNS is a small device that is surgically implanted near the left collarbone in an hour-long operation.

It is attached to the vagus nerve and is programmed to send electrical messages to the brain to reduce the frequency and duration of seizures. It does not cure seizures.

VNS may be an option if:

- AEDs have failed to control seizures
- epilepsy surgery is not an option

A VNS should only be fitted after a thorough epilepsy evaluation and most people will continue to need AEDs.

Ketogenic Diet

The ketogenic diet is sometimes used in children with difficult-to-control seizures that do not respond to AEDs. It is based on a high-fat, low-carbohydrate intake and needs to be carefully worked out and monitored by a dietician.

Families and people with epilepsy can find the diet challenging to maintain, but recipe books with varied and imaginative meal suggestions are available and success in controlling seizures has been reported.

Diet

A balanced diet with regular healthy meals is of benefit in maintaining general health and wellbeing. Eating plenty of fresh fruit and vegetables, regulating alcohol intake and avoiding foods and drinks that are high in additives are all recommended.

Seek the medical practitioner's advice on the following issues:

- The body's vitamin and mineral stores can be affected by AEDs and specific supplements may be Advisable.
- Women planning to become pregnant should take a higher daily supplement of 5mg of folic acid
- Food allergies can occasionally trigger seizures

Complementary Therapies

Many complementary therapies are becoming popular and may be of benefit to people with epilepsy. The most useful are those that aid relaxation and reduce stress. However, some complementary therapies are potentially harmful for people with epilepsy – for example there are certain aromatherapy oils and herbal remedies that may provoke seizures. It is therefore very important that the medical practitioner's advice is sought before trying a complementary therapy.

If approval for the complementary therapy is given, find a qualified therapist who is registered with a national governing body, and make sure that he/she knows about epilepsy.

Support and Counselling

Support and counselling are an important part of the treatment programme to:

- Provide information about epilepsy, seizures and treatment
- Help the person come to terms with a diagnosis of epilepsy
- Enable the person to ask questions especially about their fears and anxieties
- Suggest ways of managing epilepsy and seizures
- Support families, friends and carers
- Provide epilepsy education

Other Care Considerations

Medications are only part of the management of epilepsy. These are other aspects to consider:

Self management involves taking control of the way the person thinks and feels about epilepsy, and how he/she copes in everyday life. It is about playing an active rather than a passive role in the management of one's epilepsy- living life to the fullest.

These are practical measures to help prevent seizures:

- Be informed about the condition as much as possible.
- Take Medications as Prescribed
- Check Before Taking Other Medications or Supplements
- Avoid Large Amounts of Caffeine or High Energy Drinks
- Adequate Sleep
- Recognise and Respond to Stress
- Be Aware of Seizure Triggers

Information

- Where possible, provide the person with as much information as possible, in a way that he/she finds easiest to understand. In this way the person is supported to learn how to manage their epilepsy to the greatest extent possible. Knowledge can reduce anxiety and concerns by helping the person feel more in control. See Intranet - Health to access a range of easy read/pictorial resources.
- The person may be enabled to take a more active role asking questions and discussing treatment options with the medical practitioner.
- A greater understanding of epilepsy can help the person to identify their own seizure triggers.
- The correct information can dispel myths and make the person feel more comfortable talking about epilepsy to others.

Take Medications as Prescribed

Medications don't cure epilepsy, but they can control seizures. Taking doses as prescribed by the medical practitioner is essential to gaining seizure control. The person should be supported to be involved in the management and administration of their own medications where this is possible. How much support the person may need is determined and documented in their "Self Administration of Medication Support Plan" Appendix 1 Medication Policy.

Other Medications or Supplements

Other medications may interact with antiepileptic medications or make the person more prone to having seizures.

It is recommended the person consult the medical practitioner before commencing herbal medicines, homoeopathic substances and supplements such as Gingko Biloba, St Johns Wort and Evening Primrose Oil. These are believed to affect seizure control because they interfere with the metabolism of antiepileptic medications.

Vomiting and diarrhoea can also cause seizures because antiepileptic medications may not be properly absorbed and fluid and electrolyte imbalances can occur due to dehydration.

Constipation can also affect the efficacy of antiepileptic medications and needs to be monitored in people so disposed.

Brands and Generic Medications

There can be a slight variation between brand medications for epilepsy and the cheaper, generic medications the pharmacist may offer. Studies have shown that even small differences between medications can cause more seizures or different side effects. It appears that the change in medication is what causes problems, whether it is from brand to generic, generic to a brand, or even generic to generic. So it is wise to continue with whatever medication the person originally commenced with, either brand or generic. If the person requires a particular brand, request the prescriber to write “Do Not Substitute” on the prescription sheet.

Caffeine and High Energy Drinks

There have been a number of reported cases where excess caffeine has contributed to the increase in frequency of seizures or uncontrolled seizures.

Caffeine is a stimulant and is found in coffee, tea, chocolate, many soft drinks and medications, antihistamines and decongestants, for example.

Guarana is a natural caffeine source and a stimulant. It is one of the ingredients often used in energy drinks and herbal ‘weight loss’ teas, and may be combined with other substances to produce an even stronger stimulant effect. The combination has been known to cause irregular heartbeats, increased urination, insomnia, higher blood pressure, irritability and seizures. Frequent use may actually cause dependency.

Grapefruit and Seville Oranges

There are substances in grapefruit that can interfere with the way the body absorbs and breaks down (metabolises) certain medications, increasing or decreasing its levels in the bloodstream. One of these medications is Tegretol (Carbamazepine). Avoid grapefruit or Seville oranges if you are on this medication.

Sufficient Sleep

Lack of sleep is a common trigger for seizures. The amount of sleep a person needs will differ between individuals, but it is recommended that people with epilepsy observe a regular bedtime and try to get a full night’s sleep (7-8 hours) as often as possible.

People with epilepsy do not need an excessive amount of sleep. Constant tiredness and sleepiness may be a sign that medications may need adjusting.

Recognise and Respond to Stress

Stress can’t always be avoided, but the person may be able to minimise its impact by changing the way he/she responds. It is important to identify the cause of stress and find practical solutions that work best for the person.

Awareness of Seizure Triggers

Identifying seizure triggers and learning how to avoid them is important for seizure control. Avoiding seizure triggers can be very difficult at times. Consider the risks and quality of life issues.

Common seizure triggers include missed medications, sleep deprivation and stress. But seizure triggers can also include:

- Low blood sugar
- Extreme heat or cold
- Startle such as a loud noise
- Depression, boredom
- Dehydration
- Flashing lights
- Hormonal changes in females
- Constipation
- Alcohol
- Drugs

Seizure Observation and Recording

Good observation and recording of seizures is vital to the diagnosis and ongoing management of epilepsy.

Seizures present in many different ways. However, few medical practitioners see their patients having seizures. A good description from family or staff can greatly assist with identifying the seizure type. Knowing the seizure type will assist the medical practitioner in prescribing the most effective treatment.

When observing a seizure, try to note what happens before, during and after the event. Write down what happened as soon as possible. See Epileptic Seizure Recording Charts – Appendix 3. Include as much detail about the following areas:

Behaviour Before The Seizure – what was person doing- change in mood or behaviour hours or days before, ‘warning’ or ‘aura’ shortly before event.

When Events Occur – date, time

Possible Triggers of Factors that may Make Event More Likely to Occur

- Time of day or month
- Menstruation
- Missed, late, or changes in medicines
- Irregular sleep patterns, not enough sleep, other sleep problems
- Irregular eating patterns, specific foods
- During or after exercise or hyperventilation (fast breathing)
- Alcohol or other drug use
- Emotional stress, worry, excitement
- Sounds, flashing lights, bright sunlight
- Other illnesses or infections.

What Happens During the Event

- Change in awareness, alertness, confusion
- Ability to talk and understand
- Changes in thinking, remembering, emotions, perceptions
- Sensations – changes in seeing, hearing, smells, tastes, feelings
- Facial expression – staring, twitching, eye blinking or rolling, drooling
- Changes in muscle tone – body becomes stiff or limp
- Movements – jerking or twitching movements, unable to move, body turning, falls
- Automatic or repeated movements – lip-smacking, chewing, swallowing, picking at clothes, rubbing hands, tapping feet, dressing or undressing
- Walking, wandering, running
- Changes in colour of skin, sweating, breathing
- Loss of urine or bowel control

Part of Body Involved – where symptom started, spread to other areas, side of body (right, left or both)

What Happens After Event

- Response to voice or touch
- Awareness of name, place, time
- Memory for events
- Ability to talk or communicate
- Weakness or numbness
- Changes in mood or how person acts
- Tired, need to sleep

How long it lasted - length of aura, seizure, after-effects or postictal phase, how long before person returns to normal activity.

Describing Seizures

Describe what the seizure looks like before, during and after – never just name a seizure such as ‘absence’ without a brief description of what the seizure looks like. Not everyone who reads the plan may understand this language.

Record precisely what was observed. In this way the medical practitioner will have the most accurate information available upon which to make decisions.

Seizure Diary

Keeping a seizure diary/log/record is helpful in identifying and avoiding triggers. Information recorded in the diary can also help the medical practitioner to determine how effective the current medication is, and to plan future treatment.

Times and dates of seizures may be recorded in the diary, along with any other relevant information such as medication changes, menstrual cycle or illness.

If considered helpful, a seizure diary template along with other epilepsy related resources can be accessed via the Intranet – Health – Health Conditions – Epilepsy.

Emergency Medication

Emergency Medication

Most seizures subside after a few minutes but for some people seizures can become prolonged and may require emergency intervention in order to stop the seizure. After a certain period of time (this might be individual to each person) if a seizure has not stopped, there is a risk that it will develop into status epilepticus (Cole *et al*, 2009; Klimach, 2009). Due to this risk, many people with epilepsy will be prescribed an emergency medication to help stop a prolonged seizure.

In the past, rectal diazepam was the commonly prescribed emergency medication prescribed to people however in the last decade, buccal midazolam has taken its place in great part as it is seen to be a less invasive and more dignified approach to managing prolonged seizures in the community/home setting and it is still as effective as rectal diazepam. Both diazepam and midazolam are chemically related and are classed in a group of medications called benzodiazepines. Benzodiazepines are used to treat a number of conditions including prolonged seizures.

All staff required to administer rescue medication must receive specific training for the safe administration of the drugs and must have received Epilepsy Awareness Training. Furthermore, this medication can only be administered when the protocol for its administration has been completed by the prescribing medic and it is also written up on the person's MP1. See Appendix 2 – Epilepsy Management Plan

Buccal Midazolam

How is it given?

This medication is given into the buccal cavity. The buccal cavity is in between the gums and the cheek (see image below). The buccal cavity is rich with blood vessels and by administering the medication here; it is absorbed directly into the bloodstream.

The medicine should not need to be swallowed, but if swallowed accidentally it will cause no harm however will take longer to work.



Buccal midazolam is available in various forms:

Epistatus®

Here it comes in a box containing a bottle of sugar-free buccal liquid. The strength of the medication in this box is **10mg in 1ml**. The bottle of buccal midazolam will contain four 10mg doses. Also in the box you will find four 1ml single use syringes.



Buccolam®

Here the buccal (also referred to as oromucosal solution) midazolam is specially prepared as “*age specific, single use, prefilled oral syringes*”.

Each pack contains four ready to use syringes with an already calculated dose in each.

Each pre-filled syringe is enclosed in a plastic tube for convenient storage.

The strength of the medication varies in each (see below) **{different volumes to Epistatus®}**



Label colour	Midazolam dose	Prefilled volume
Yellow	2.5 mg	0.5 ml
Blue	5 mg	1.0 ml
Purple	7.5 mg	1.5 ml
Orange	10 mg	2.0 ml

Side effects of Midazolam

- Drowsiness and sedation – recovery is usually fast.
- Amnesia or short-term memory loss – the individual may not remember having had a seizure (this is common if a person has a generalised seizure even if they don't receive emergency medication).
- Breathing difficulties – Midazolam slows down breathing so it is important that after administration that the person is observed and monitor closely. If the correct dose is given it is unlikely that they will experience breathing difficulties. If breathing difficulties do develop, seek medical assistance immediately.
- Restlessness, agitation and disorientation – these can occur but are usually rare.
- Headache/hangover feeling
- Coughing/hiccups
- Dizziness / unsteadiness

Important information

- Give the medicine as prescribed by the medical practitioner/ consultant- per Section 4 of the persons Epilepsy Management Plan (EMP)
- Keep midazolam at room temperature (not in a fridge), away from bright light or direct sunlight and away from heat.
- Epistatus® should always be stored upright to prevent the liquid evaporating into the lid.
- When transporting the medicine ensure it is in a secure box with no key but coded lock.

Contraindications of midazolam include hypersensitivity, acute narrow angle glaucoma, shock and hypotension.

Stesolid (Rectal Diazepam)



Stesolid rectal solution contains diazepam which belongs to a group of medicines called benzodiazepines. The solution is inserted into the anus using the nozzle provided.

Where Stesolid (Rectal Diazepam) is administered consideration must be given to protection of the person's right to privacy.

The drug should be administered efficiently in accordance with the protocol per Section 4 of the persons Epilepsy Management Plan (EMP) and the person covered as quickly as possible.

After giving into the anus, the medicine is quickly absorbed and will usually start to take effect within 5 minutes.

Before moving the person on recovery, care should be taken to ensure that clothing on the lower body has been secured.

When fully recovered the person should be informed that they have had a seizure and that Stesolid has been administered.

Before this medication can be administered, staff must receive the necessary training.

Possible side effects of Stesolid include

- Drowsiness, including drowsiness and lightheadedness the next day.
- Confusion.
- Shaky movements and unsteady walk (ataxia).
- Loss of memory (amnesia).
- Muscle weakness.
- Tremor.
- Slurred speech.
- Skin rashes.

Seizure Management:

Response to a Usual Seizure

3.1 When the seizure starts:

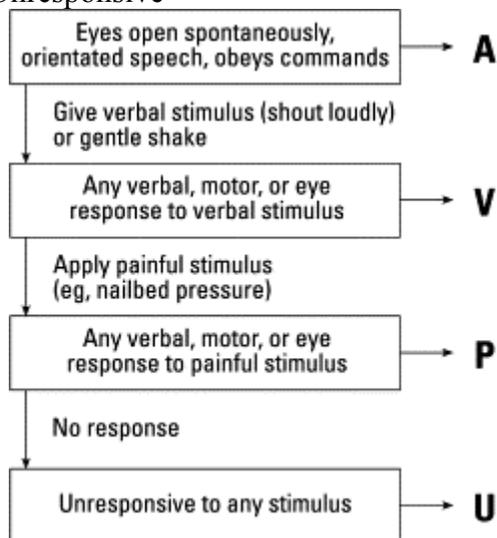
- a) Note what time the seizure starts.
- b) Stay and observe the person during the seizure.
- c) Protect the person from harm during the seizure, place something soft under the person's head and loosen tight neckwear.
- d) Give medication if prescribed by the medical practitioner
- e) Call an ambulance if necessary (see below for further guidance)
- f) Staff to use the AVPU scale to assess the conscious level of the individual

A - Alert

V - Voice

P - Pain

U - Unresponsive



- g) However if the person does not recover after one hour contact the MEDICAL PRACTITIONER or sooner if the person needs medical attention.

3.2 While the seizure continues:

- a) Stay with the person and protect from harm.
- b) Maintain the person's privacy and dignity as far as possible.
- c) Call an ambulance if necessary

3.3 After the seizure stops:

- a) Reassure the person.
- b) Observe the person's breathing pattern.
- c) Note what time the seizure stops.
- d) During the recovery period, continue to monitor the person for confusion, agitation, drowsiness, headache or other pain.
- e) Provide care to prevent inhalation of fluid or foods during the recovery period.
- f) When the person is fully awake assist the person to wash and change clothing if needed.
- g) Complete the person's Seizure Chart and other daily records.

3.4 Call an ambulance (Dial 999/112) if:

- a) You are in doubt about responding to the seizure.
- b) The seizure lasts more than 5 minutes, or some other time interval specified for this person by the medical practitioner.
- c) The person does not respond to emergency medication.
- d) Food, water or vomit cannot be removed from the person's mouth.
- e) The seizure occurs in water and if head was submerged or the person got water on their face or in their mouth during the seizure
- f) A second seizure occurs before complete recovery from the first one, if this is not the normal pattern for the individual.
- g) The person has breathing difficulties or goes blue in the face.

3.5 Responding to a Seizure when the Person is in a Wheelchair.

If the person starts to have a seizure while sitting in a wheelchair, seated on a bus or train or is strapped in a pushchair:

- Apply the brake and ensure the chair is secure
- Don't restrain the person or attempt to stop the seizure
- Allow the person to remain seated in the chair during the seizure – this is safer than moving them which could lead to injury
- Move objects that could cause injury to the person
- The seat belt or harness should prevent falling from the chair. If there is no belt you may need to support (not restrain) the person to prevent him/her from falling out of the chair.
- Cushion the head area by supporting it. A rolled up coat or cushion will suffice in the absence of a head rest.
- Continue to hold the person's head to maintain a clear airway.
- At the end of the seizure the person can be moved from the chair and placed in the recovery position. Ensure the person is sufficiently recovered and that it is safe to do so.

Section 3.4 describes the circumstances for calling an ambulance on 999/112.

DO NOT

Try to remove the person from the seated position during the seizure, as in most cases the seat provides support.

Medical Appointments/Reviews

A person with a diagnosis of epilepsy should have their health reviewed with the relevant medical practitioner annually or more often if deemed necessary. In most cases this will be with the neurologist.

Preparing for Appointment

Depending on the level of support the person needs to communicate their information, it still remains the responsibility of the supporting staff to ensure the medical practitioner is provided with sufficient information about the person's health, health history, medications and symptoms, and to report any specific changes in his/her condition since the last medical appointment. See Appendix 4 Neurologist Appointment Preparation Checklist.

It is very important that the staff member attending such appointments knows the person very well and is fully briefed beforehand.

- Preparation for the appointment may need to commence some weeks in advance e.g. arrange blood tests so that the results are available before the appointment date. Bring a record of any medical test results and reports related to the condition.
- Ensure all supporting documentation; MP1, seizure records, test results etc. are taken to the appointment.
- Bring any supplements the person takes, or a list of these, to the appointment as some medications can interact poorly with these.
- Bring a record of the person's symptoms and seizure history. These are required to help track the condition's progression and to better determine what treatments or medications are working. See Epileptic Seizure Recording Chart Appendix 3.
- Know about the person's health and any other co-existing health conditions. Refer to person's Health Action Plan.
- Consider the questions you may need to ask e.g. medication side effects, what to do if a seizure occurs.
- The role of the staff member is to support the person through the process of the appointment. It is important that the staff member is aware of any anxieties the person may have about attending the appointment and of the strategies that have been used at previous appointments to reduce and manage those anxieties.

At the Appointment

- Ensure the person arrives on time and has time to relax before going into the consultation room. Also ensure the receptionist is aware that the person has arrived for the appointment. The person may wish to use the toilet etc. prior to the consultation.
- If a family member is attending the appointment, then the role of the staff member is to be an appropriate support to the person and the family.
- Be specific in describing symptoms and how they affect the person's daily living activities, including estimated periods of time when the symptoms became apparent or worsening. Identify the symptoms or problems that are most severe to discuss during the appointment.
- Be prepared to answer questions e.g. about other medical conditions the person has, any adverse reaction to medications? How and when did symptoms of epilepsy begin? How have symptoms changed since that time? What activities does your condition make difficult to do? What makes symptoms worse? What makes symptoms better?

- If the person has started a new medication or therapy regimen, be prepared to discuss any side effects or results of the treatment. Have a list of three or four key questions you would like to discuss with the neurologist
- At the conclusion of the consultation the staff member may, if appropriate, check if the person and, if in attendance, family member are clear about the decisions made at the appointment. This is also an opportunity for the staff to ask questions to clarify any outcomes from the consultation that they are not clear about. The purpose here is to enable accurate feedback to the person and later to the wider team supporting the person. Checking the date of the next planned appointment is also important.

After the Appointment

- Make appointments for any follow-up tests, therapies or other medical orders immediately. Make sure your primary care physician received a copy of your neurologist's report. There may be a list of recommendations to discuss with your medical practitioner.
- Organise prescriptions; update MP1 if changes have been made.
- Begin taking any medication prescribed immediately, unless advised otherwise, and report any troubling side effects to the medical practitioner as soon as they appear.
- Consult the medical practitioner if there is any sudden change in the person's condition.
- Complete the Medical Appointments Form, MAF.

Risk Management for Seizures

The Risk Assessment is undertaken to help identify areas of potential risk for the person. It may indicate areas of risk that require further investigation or action.

It must be remembered that risk cannot be eliminated from a person's daily life but there are some activities that require risk management or advice to enable to individual to make informed choices.

The management of risk is an ongoing process that is informed by a Risk Assessment, informed by knowledge of the person's lifestyle.

Risks identified and the steps/measures to address these are contained in the person's Risk Management Plan, (PRMP) where all risks that arise for the person are recorded and reviewed at agreed intervals. See Appendix 1, Risk Management for Seizures template.

Under are some (not an exhaustive list) of the common risks encountered in daily life by people experiencing epilepsy and guidance to address these.

Safety while eating

- Any person who sustains a seizure while eating is at risk of choking.
- If the person needs support while eating – stop the activity immediately and remove food from in front of them.
- If a person is having a seizure while there is food in their mouth it is important **NOT** to put anything into their mouth to try and get it out. To do so puts the person at risk of breaking their teeth.
- The food may spontaneously fall out of the mouth when muscle tone is altered.
- Slightly tip the person's head forward for a brief second to encourage the food to come out with gravity but be careful not to tip too far forward in case their airway becomes blocked.

Safety while showering/bathing

Staff should encourage individuals with epilepsy and on-going seizures to shower rather than use the bath, as a shower is less risky.

If the person chooses to shower without staff support, this will be agreed after the completion of a Risk Assessment.

Some considerations for assessing risk for showering:

- Temperature controls on water
- Emergency call button in the bathroom;
- Door that can be opened from the outside if needed.
- Shower curtain can increase the risk of strangulation
- If possible use a walk in shower with shower unit – wet room.
- Have soap dishes etc., flush to the wall as possible
- Consider the use of an alarm or call system

However, whether an individual with epilepsy and on-going seizures chooses to have a bath or shower, the staff member may be required to remain in the bathroom with the person for their safety (level of supervision required will be decided on completion of the risk assessment). This must be addressed with full attention to the person's dignity as set out in the Intimate Care procedure. If full supervision is required the staff member must not leave the bathroom to answer the telephone or fetch equipment or to conduct any routine action.

- The Front Line manager (FLM) is responsible for ensuring that an automatic system for removing the plug or a plug with a chain attached to the tap is installed in the bathrooms of all accommodation where individuals with epilepsy and on-going seizures live that have baths. This is to ensure that in emergency situations when a bath has to be drained; time is not lost searching for the plug.
- The FLM is responsible for ensuring that staff understand the procedure for responding to seizures that occur while an individual is in the bath or shower, as documented in the Individual's Risk Management Plan.

Safety while Swimming

- If a person with epilepsy and on-going seizures chooses to go swimming, the Risk Management Plan for Seizures, Appendix 1, must identify the support required to ensure that there is sufficient support available to respond to the person in the event of a seizure.
- Ensure that there is a second person on the pool side to help as well as a support person in the water. (this may be a staff, volunteer or a lifeguard)
- The supporting person in the water should always face the individual where possible.
- In the event of a seizure support the person's head in the water.
- Do not move the person until seizure has ceased. Get assistance to remove the person from the water once the seizure has ceased.
- Once out of pool, immediately place the person into the recovery position.
- Call for medical attention if the person was compromised in the water as there is an increased risk of aspiration
- Check the person's breathing and pulse. If either or both are absent commence first aid resuscitation and ensure an ambulance is called immediately.
- As a precaution if a person has a seizure while out of the water they should not undertake any further swimming or water sports for that day

Safety on Transport

- Avoid sitting directly beside a window if possible, if not ensure a pillow/cushion is in the vehicle to support/cushion an individual's head should they experience a seizure.
- Ensure sufficient ventilation and temperature controls to avoid increasing the risk of seizures due to heat accumulating from sunlight or other sources.
- Ensure staff accompanying individuals with epilepsy on transport are familiar with how to respond to a seizure

Safety in the Kitchen

- Consider the equipment the person uses in the kitchen/meal preparation area – oven, hob, knives, blender etc. that could present a risk of burn, scald etc. Consider alternative safer appliances e.g. induction hob.
- A person who has epilepsy and experiences frequent seizures resulting in falls may be at risk of suffering a head injury. On occasion the risk may be deemed significant enough to recommend the use of protective headgear by the medical practitioner. The decision on the need for use of headgear is to be made in consultation with the medical practitioner, the individual and their Support Circle paying due consideration to all the risks and restrictions involved.

- The FLM is to ensure that the need for a protective headgear and the conditions for use are regularly reviewed by relevant health professional in consultation with the individual and their Support Circle.

Bed Rails

Some individuals may require the use of bed rails. An assessment must be completed by an Occupational Therapist to indicate this requirement and a bed rails risk assessment completed.

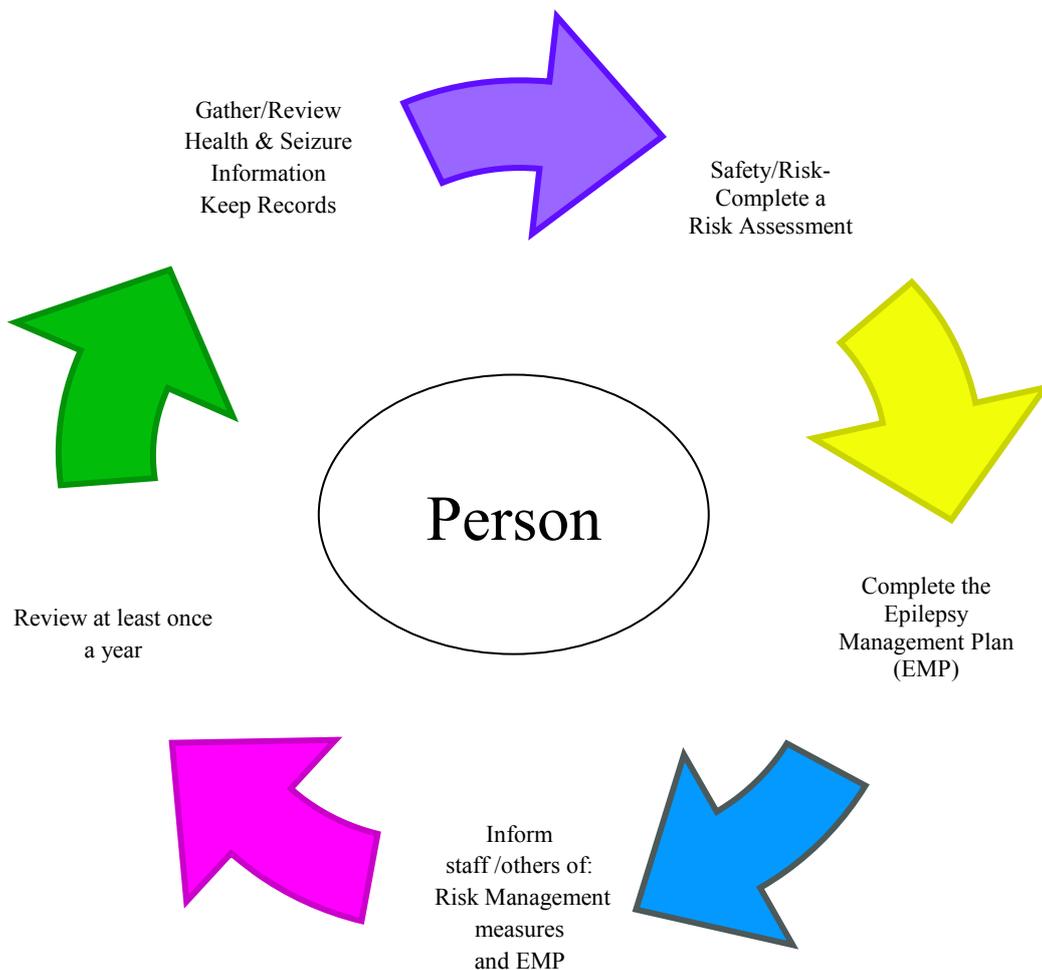
A plan for use needs to be outlined in the person's Risk Management for Seizures – Appendix 1. Always ensure that if the bed rails need to be padded then the material used need to be breathable.

Any Risks identified have been addressed and are included in the person's Personal Risk Management Plan (PRMP). Staff must read the person's PRMP to identify and manage the risks the person may face e.g. bathing, swimming, mobility, eating after a seizure.

For each risk identified, a supporting strategy needs to be documented in the PRMP so that staff are not only aware of the risk, but know how to address it.

Developing an Epilepsy Management Plan – The Process

People living with epilepsy usually have seizures at unpredictable times. Because epilepsy varies so much between individuals, it is crucial that everyone understands how to support the person. An Epilepsy Management Plan (EMP) documents the person's seizure types, support needs and emergency procedures. It must be current, accurate and easy to understand, and developed by the person or people who have the most knowledge and experience of that person's epilepsy and seizures. To the greatest extent possible, the person with epilepsy is involved in the development of the EMP.



Epilepsy Management Plan (EMP) Guidance

1. An Epilepsy Management Plan, see Appendix 2, must be completed when a person has a diagnosis of epilepsy.
2. The Epilepsy Management Plan documents the person's seizure types, support needs and emergency procedures.
3. It must be current, accurate and easy to understand.
4. To the greatest extent possible, the person with epilepsy is involved in the development of their EMP.
5. Risks identified, see Appendix 2, associated with the person's epilepsy are recorded in their personal Risk Management Plan (PRMP)
6. **Residential Service** - If the person with epilepsy lives in a full time residential service – the EMP is developed by the Named Staff with input from the person and relevant others as required or as determined by person.
The EMP must be copied to all relevant others where the person spends time e.g. Day Service, family, WCA transport etc...
7. **Respite Service** – The family is responsible for providing the required information to staff to complete the EMP. The process is initiated and co-ordinated by the Named Staff where this arrangement exists or otherwise by Social Work/nominated other.

If the person is prescribed emergency medication, the family is responsible for having the EMP reviewed by the medical practitioner at the intervals specified in the EMP and notifying/copying the service.

8. **Day Service** - The family is responsible for providing the required information to complete the EMP. The process is initiated and co-ordinated by the Named Staff.

If the person is prescribed emergency medication, the family is responsible for having the EMP reviewed by the medical practitioner at the intervals specified in the EMP and notifying/copying the service.

9. **Home Sharing** – As with all other health related information shared with the host family concerning the person, Social Work arrangements ensure co-ordination and sharing of all necessary information.

10. As Named Staff responsibilities may vary across services, another staff may be nominated to complete the form by their line manager,

If the person with epilepsy is not prescribed emergency medication, staff/family completes Sections 1, 2 and 3 only.

If the person with epilepsy is prescribed emergency medication, staff /family complete sections, 1, 2, 3, and the medical practitioner completes section 4.

Section 4 refers to the protocol to observe if emergency medication is required when an unusual seizure arises and when to seek further help. It also identifies how often and/or in what circumstances the protocol needs to be reviewed.

11. Endorsement by the treating medical practitioner

If the person is prescribed Emergency Medication then the medical practitioner needs to provide written direction about the circumstances in which it is to be administered. Complete all sections of the Epilepsy Management Plan except Section 4 – administration of Emergency Medication before visiting the surgery. In this way the medical practitioner may be as informed as possible about all aspects of the person's seizures before detailing the circumstances in which the emergency medication is to be administered.

Name and telephone number of the person's medical practitioner is to be included in the plan to allow emergency services and hospital staff to consult when necessary. Include with other information accompanying the person if admitted to hospital.

12. People are informed of the Risk Assessment and EMP

Many people may contribute to the person's plan and may provide input when the plan is due for review. The Named Staff/nominated other will take responsibility for the maintenance and review of the plan which should occur yearly or more often if circumstances change or the medical practitioner directs otherwise.

The content of the plan is shared with all people who support the person - staff in different settings that person spends time e.g. day service, residential, respite, wca transport as well as the person's family if the person spends time with them.

References

^[1] (Fisher RS et al) A practical clinical definition of epilepsy, *Epilepsia* 2014; 55:475-482) and adopted as a position of the Executive Committees of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy.

^[2] Leung and Ring, 2013; Smith *et al*, 2004; Carpay *et al*, 2009

^[3] Bhalla, D.; Godet, B.; Druet-Cabanac, M.; Preux, PM. (Jun 2011). "Etiologies of epilepsy: A Comprehensive Review."

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- Epilepsy Ireland
- Epilepsy Society UK

Risk Management for Seizures

Name: _____ **DOB:** _____

Address: _____

Form Completed by: _____

Date: _____

Date of last known seizure: _____

Seizure type (if known): _____

Describe nature of seizures and frequency _____

Any history of prolonged seizures, repeated seizures or cyanosis:

Any hospital admissions due to seizures? _____

Any history of falls due to seizures? _____

Personal Circumstances

Does the person live alone?

Yes

No

Is support available to the person in the event of a seizure?

Yes

No

Based on the above information, what risks may be present: _____

Have these risks ever resulted in harm to this person? _____

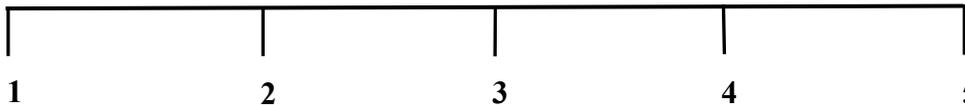
How often? _____

When was the most recent occurrence?

How important is it to the person to remain living as they do?

Least Important

Most Important



How can we help to keep this person safe? _____

Use of Kitchen

Does the person use equipment in the kitchen alone?

Yes No

Does the person prepare meals alone?

Yes No

With support?

Yes No

Not involved in this

Yes No

Based on the above information, what risks may be present: _____

Have these risks ever resulted in harm to this person? _____

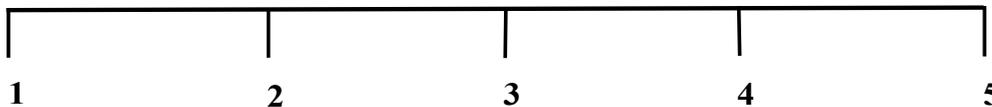
How often? _____

When was the most recent occurrence?

How important is it to the person to continue using the kitchen?

Least Important

Most Important



How can we help to keep this person safe? _____

Eating

Does the person have their food modified in any way?

Yes No

Is there a FEDS Plan in place?

Yes No

Does the person feed themselves?

Yes No

Does the person wear dentures?

Yes No

Based on the above information, what risks may be present: _____

Have these risks ever resulted in harm to this person? _____

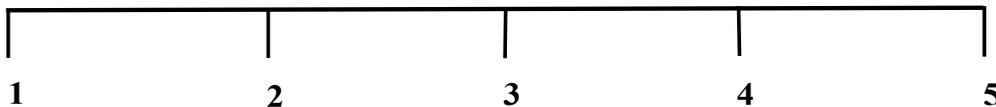
How often? _____

When was the most recent occurrence?

If the person feeds themselves, how important is this to the person to continue feeding themselves?

Least Important

Most Important



How can we help to keep this person safe? _____

Personal Care

Has the person a Personal/Intimate Care Plan?

Yes No

Does the person use the bath?

Yes No

Does the person use the shower?

Yes No

**Does the person shower/bath?
Alone?**

Yes No

With support?

Yes No

Based on the above information, what risks may be present: _____

Have these risks ever resulted in harm to this person? _____

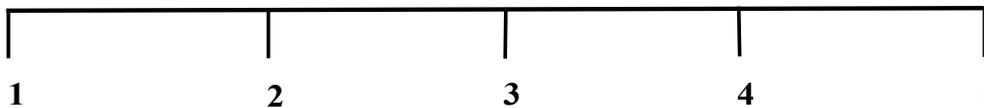
How often? _____

When was the most recent occurrence?

How important is it to the person to maintain their privacy in this area?

Least Important

Most Important



How can we help to keep this person safe? _____

Mobility

Is the person ambulant?

Yes No

Ambulant with support?

(Please describe e.g. walking frame, rollator, stick etc.)

Yes No

Using a wheelchair?

Yes No

Based on the above information, what risks may be present: _____

Have these risks ever resulted in harm to this person? _____

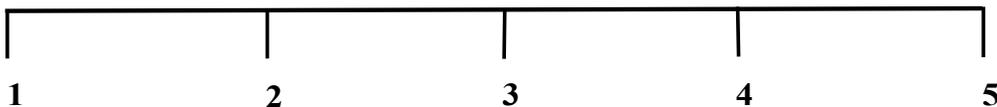
How often? _____

When was the most recent occurrence?

How important is it to the person to continue their independence in this area?

Least Important

Most Important



How can we help to keep this person safe? _____

Travel

Is the transport that the person mainly uses.....

Organisation Transport?

Yes No

Staff?

Yes No

Own?

Yes No

Does the person cycle?

Yes No

Based on the above information, what risks may be present: _____

Have these risks ever resulted in harm to this person? _____

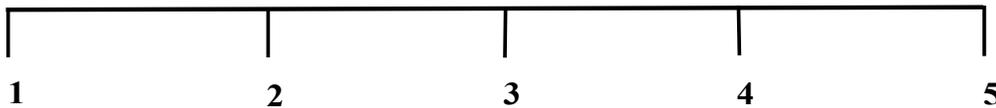
How often? _____

When was the most recent occurrence?

How important is it to the person to continue their independence in this area?

Least Important

Most Important



How can we help to keep this person safe? _____

Leisure Activities

Swim? Yes No

Cycle? Yes No

Horse Riding? Yes No

Other activity that may be considered risky e.g. alcohol consumption? Yes No

Other Activity (Please State): _____

Is the person being treated for any other conditions with medication that may lower seizure threshold? Yes No

Is there someone available to support the person in the event of a seizure? Yes No

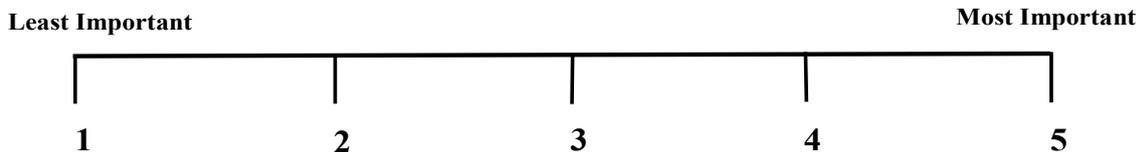
Based on the above information, what risks may be present: _____

Have these risks ever resulted in harm to this person? _____

How often? _____

When was the most recent occurrence?

How important is continuing this activity to the person?



How can we help to keep this person safe?

Is there anything that “brings on” the person’s seizures?

- Missed Medication? Yes No
- Getting hot? Yes No
- Feeling ill? Yes No
- Not enough sleep? Yes No
- Stress? Yes No
- Around your periods (for females)?
(Women can experience increased seizure activity either before or during their period – it is individual to the person) Yes No
- TV or flashing/flickering lights Yes No
- Constipation Yes No
- Other (please state): _____

Based on the above information, what risks may be present: _____

Have these risks ever resulted in harm to this person? _____

How often? _____

When was the most recent occurrence?

How can we help to keep this person safe?

Is there anything that the person would like to do, that Epilepsy is preventing them from doing?

State the reasons why?

How might we address this?

Risk Considerations

Be careful not to just place restrictions on the person because there is a degree of risk. Risks can be reduced by thoughtful planning. If the activity is high risk check how important it is to/for the person, referencing findings in this document.

The more important the activity is to the person, the stronger the obligation on all to find a solution.

Having considered all of the above - use the information to complete a Personal Risk Management Plan.

Epilepsy Management Plan (EMP)

Please read the following guidance.

1. An Epilepsy Management Plan must be completed when a person has a diagnosis of epilepsy.
2. The Epilepsy Management Plan documents the person's seizure types, support needs and emergency procedures.
3. It must be current, accurate and easy to understand.
4. To the greatest extent possible, the person with epilepsy is an integral part in the development of their EMP.
5. Risks identified, associated with their epilepsy, are recorded in their personal Risk Management Plan (PRMP)
6. **Residential Service** - If the person with epilepsy lives in a full time residential service – the EMP is developed by the Named Staff with input from the person and, depending on the particular circumstances, their family. The EMP must be copied to all relevant others where the person spends time e.g. Day Service, WCA transport, family if person spends time in their company away from the service setting.
7. **Respite Service** – The family is responsible for providing the required information to complete the EMP. The process is initiated and co-ordinated by the Named Staff where this arrangement exists or otherwise by Social Work.
If the person is prescribed emergency medication, the family is responsible for having the EMP reviewed by the medical practitioner at the intervals specified in the EMP and notifying/copying the service.
8. **Day Service** - The family is responsible for providing the required information to complete the EMP. The process is initiated and co-ordinated by the Named Staff.
If the person is prescribed emergency medication, the family is responsible for having the EMP reviewed by the medical practitioner at the intervals specified in the EMP and notifying/copying the service.
9. **Home Sharing** – As with all other health related information shared with the host family concerning the person, Social Work are responsible for co-ordination and sharing of all necessary information.
10. As Named Staff responsibilities may vary across services, another staff may be nominated to complete the form by their line manager,

If the person with epilepsy is not prescribed emergency medication, staff/family completes Sections 1, 2 and 3 only.

If the person with epilepsy is prescribed emergency medication, staff /family complete sections, 1, 2, 3, and the medical practitioner completes section 4.

Section 4 refers to the protocol to observe if emergency medication is required and when to seek further help. It also identifies how often and/or in what circumstances the protocol needs to be reviewed.

Epilepsy Management Plan

Section 1,2,3 of this Plan has been completed by:

(Person, Family/Guardian, Staff according to circumstances.) who sign under

SECTION 1a

THE PERSON		
Name	DOB:	Age:
Signature:		
Address:		
GENERAL PRACTITIONER	NEUROLOGIST	
Name:	Name:	
Address and Phone Number:	Address and Phone Number:	
FAMILY MEMBER/GUARDIAN		
Name:	Date:	
Signature:		
Address and Phone Number:		
STAFF MEMBER		
Name:	Date:	
Signature:		
Address and Phone Number:		

OTHER	
Name:	Date:
Signature:	
Address and Phone Number:	

<u>First Emergency Contact Name:</u>	<u>Phone</u>
<u>Second Emergency Contact Name:</u>	<u>Phone</u>
<u>Third Emergency Contact Name:</u>	<u>Phone</u>

SECTION 1b REVIEW OF THE PLAN

This section to be completed by Named Staff and Line Manager

Plan reviewed by:	
Name:	
Signature:	Position:
Date:	
Plan reviewed by:	
Name:	Date:
Signature:	Position:
Contact details:	
Plan reviewed by:	
Name:	
Signature:	Position
Date:	

Plan reviewed by:	
Name:	
Signature:	Position:
Date:	

Plan reviewed by:	
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Signature:	Position:
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Signature:	Position:
Date:	

Plan reviewed by:	
Name:	
Signature:	Position:
Date:	

Plan reviewed by:	
Name:	
Signature:	Position:
Date:	

SECTION 2: INFORMATION ABOUT SEIZURES

DESCRIBE THE PERSON'S USUAL SEIZURE/S including Length and what typically happens

If the person experiences more than one type of seizure, describe each type including movement of limbs, noises etc. and give a code A, B, C.

TYPE A	
Length of seizure:	
How often seizures occur:	
Known causes (triggers):	
Typical signs after seizure stops:	
Usual recovery pattern:	
Other observations	

TYPE B	
Length of seizure:	
How often seizures occur:	
Known causes (triggers):	
Typical signs after seizure stops:	
Usual recovery pattern:	
Other observations	

TYPE C	
Length of seizure:	
How often seizures occur:	
Known causes (triggers):	
Typical signs after seizure stops:	
Usual recovery pattern:	
Other observations	

Record the following details in the table under ‘Other Observations’ if any of these occur during or after a usual seizure.

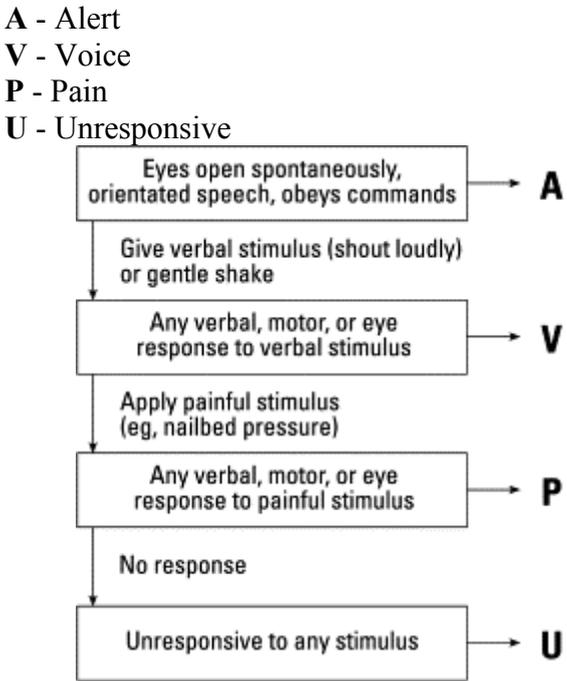
- The person doesn’t respond.
- The face changes colour (what colour?).
- Speech is slurred or the person makes other sounds.

- The person falls.
- The person bites tongue or salivates.
- The person is incontinent.
- The face moves involuntarily.
- The breathing pattern is unusual.
- The person has seizures while sleeping.

SECTION 3: RESPONSE TO A USUAL SEIZURE
To be read and observed by all Staff supporting this person

3.1 When the seizure starts:

- a) Roll the person onto one side.
- b) Note what time the seizure starts.
- c) Stay and observe the person during the seizure.
- d) Protect the person from harm during the seizure, place something soft under the person’s head and loosen tight neckwear.
- e) Give additional medication if prescribed by the medical practitioner (see Section 4).
- f) Call an ambulance if necessary (see Section 3.4).
- g) Staff to use the AVPU scale to assess the conscious level of the individual



- h) However if the person does not recover after one hour please contact the GP or sooner if they need medical attention.

3.2 While the seizure continues:

- a) Stay with the person and protect from harm.
- b) Maintain the person’s privacy and dignity as far as possible.
- c) Call an ambulance if necessary (see Section 3.4).

3.3 After the seizure stops:

- a) Reassure the person.
- b) Observe the person’s breathing pattern.

- c) Note what time the seizure stops.
- d) During the recovery period, continue to monitor the person for confusion, agitation, drowsiness, headache or other pain.
- e) Provide care to prevent inhalation of fluid or foods during the recovery period.
- f) When the person is fully awake assist the person to wash and change clothing if needed.
- g) Complete the person's Seizure Chart Appendix 3 and other daily records.

3.4 Call an ambulance (Dial 999/112) if:

- a) You are in doubt about responding to the seizure.
- b) The seizure lasts more than 5 minutes, or some other time interval specified for this person by the medical practitioner (Section 4).
- c) The person does not respond to emergency medication (Section 4).
- d) Food, water or vomit cannot be removed from the person's mouth.
- e) The seizure occurs in water.
- f) The person has been injured.
- g) A second seizure occurs before complete recovery from the first one.
- h) The person has breathing difficulties or goes blue in the face.
- i) The person has diabetes j) The person is pregnant.

RESPONDING TO A SEIZURE WHEN THE PERSON IS IN A WHEELCHAIR

If the person starts to have a seizure while confined in a wheelchair, seated on a bus or train or is strapped in a pushchair:

- Apply the brake and ensure the chair is secure
- Don't restrain the person or attempt to stop the seizure
- Allow the person to remain seated in the chair during the seizure – this is safer than moving them which could lead to injury
- Move objects that could cause injury to the person
- The seat belt or harness should prevent falling from the chair. If there is no belt you may need to support (not restrain) the person to prevent them from falling out of the chair.
- Cushion the head area by supporting it. A rolled up coat or cushion will suffice in the absence of a head rest.
- Continue to hold the person's head to maintain a clear airway.
- At the end of the seizure the person can be moved from the chair and placed in the recovery position. Ensure the person is sufficiently recovered and that it is safe to do so.

Section 3.4 describes the circumstances for calling an ambulance on 999/112.

DO NOT

Try to remove the person from the seated position during the seizure, as in most cases the seat provides support.

RESPONDING TO A SEIZURE THAT OCCURS IN WATER

A seizure in water is a potentially life-threatening situation. If someone is having a seizure in water e.g. bath, swimming pool:

- Support the person in the water with the head tilted so the face and head stay above the surface and call for assistance.
- Get help to remove the person from the water as soon as the active movements of the seizure have ceased.
- If the person is in a bath pull out the plug, and cover the person and make comfortable until help arrives.
- Check to see if the person is breathing and has a pulse. If either or both are absent commence first aid resuscitation and immediately call 999/112.
- Even if the person appears to be fully recovered, call an ambulance. The person should have a full medical check as inhaling water can cause lung or heart damage.

Precaution: If a seizure happens out of the water during swimming activity, the person should not continue with swimming or water sports that day, even if the person appears to be fully recovered.

End of Section 3

Is this person prescribed Emergency Medication? Yes No

If the answer is yes, proceed to Section 4.

The medical practitioner must complete Section 4 - Emergency Response to an Unusual Seizure.

SECTION 4: EMERGENCY RESPONSE TO AN UNUSUAL SEIZURE

Protocol for Administration of Buccal Midazolam (Epistatus or Buccolam)

To be authorised by the Medical Practitioner

When/in what circumstances should Buccal Midazolam be administered?

How much should be given initially?

Methods of Administration – Buccal (side of mouth)

1. Check that the liquid is clear and in date with no crystals visible. Discard if you can see crystals. (Epistatus only).
2. Push down and twist lid off bottle. Insert syringe to top of bottle and turn upside down (Epistatus only).
3. Pull back the plunger of syringe until prescribed amount is reached. (Epistatus only).
4. Insert it gently into the side of the mouth between the teeth and the cheek. Tilt down and slowly push the syringe plunger until half -empty. Remove and repeat process on opposite side until syringe plunger is empty .If swallowed accidentally it will cause no harm however will take longer to work. Please check this instruction with prescriber as guidance may differ depending on individual circumstances
5. Place person on their side, check time and observe



After how long can you give a 2nd dose of Midazolam?

When should further action be taken and describe what needs to happen?

Do not administer more than _____ of Midazolam in 4 hours.

Do not administer more than _____ of Midazolam in 24 hours.

This protocol has been discussed and agreed by:

_____ (The Person) _____ (Family)

_____ (GP/Consultant) _____ (Staff)

Date: _____ **Review** Plan every _____ months or if the following changes arise:

Staff must not to transcribe the person's medications into this Plan. MP1 must be written up for Midazolam.

SECTION 4: EMERGENCY RESPONSE TO AN UNUSUAL SEIZURE

Protocol for Administration of Stesolid (Rectal Diazepam)

To be authorised by the Medical Practitioner Marian this looks like a repeat of the page above?

Name: _____ **Service:** _____

When/in what circumstances should Stesolid be administered?

How much should be given initially?

After how long can you give a 2nd dose of Stesolid?

When should further action be taken and describe what needs to happen?

Do not administer more than _____ of Stesolid in 4 hours.

Do not administer more than _____ of Stesolid in 24 hours.

This protocol has been discussed and agreed by:

_____ **(The Person)** _____ **(Family)**

_____ **(GP/Consultant)** _____ **(Staff)**

Date: _____ **Review** Plan every _____ months or if the following changes arise:

Staff must not to transcribe the person's medications into this Plan. MP1 must be written up for Stesolid.

EPILEPTIC SEIZURE RECORDING CHART

It is important to record when a person has an epileptic seizure. It is necessary to note the frequency of seizures, their type and duration. This information helps establish the effectiveness of prescribed medication in managing seizures and is therefore of use for review medical appointments.

This form should be stored with the person’s other health information and Epilepsy Management Plan (EMP)

Name of Person: _____

<i>Date</i>	<i>Time</i>	<i>Warning Sign (Before)</i>	<i>Description of Seizure (During & After)</i>	<i>Number of Seizures</i>	<i>Incontinence</i>		<i>Duration</i>	<i>Signature</i>
					<i>Bowel Movement</i>	<i>Passed Urine</i>		

NEUROLOGIST APPOINTMENT PREPARATION CHECKLIST

Name: _____
Date of Birth: _____
Name and Address of GP: _____

PRIOR TO APPOINTMENT

Area	Checklist	Tick
MEDICATION	Bring MP1 Prescription Sheet	
	Note when each medication was started, reviewed and why	
	Note any vitamins and supplements being taken as they can interfere with anticonvulsant medication	
	List previous epileptic medication, dosage, when it was stopped and why	
	Bring actual medication containers with all tablets	
<i>Notes:</i>		

Area	Checklist	Tick
RESULTS	Note the results of all medical tests	
	Bring results of MRI scan (brain and spine) CT, ECG and metabolic or genetic tests	
<i>Notes:</i>		

Area	Checklist	Tick
BLOOD TESTS	Ensure an up-to-date blood test is done and results are available for appointment.	
	Levels of different anti-convulsion medication	
	Liver and kidney function	
	Bone marrow	
	Bring all blood test results	
	Note any abnormalities in blood results	
<i>Notes:</i>		

Area	Checklist	Tick
GENERAL INFORMATION	Collect information on the person's mood, sleep, eating, energy and behaviour	
	Bring behavioural, mood, sleep, and menstrual pattern recordings if applicable.	
<i>Notes:</i>		

Area	Checklist	Tick
SEIZURE ACTIVITY	Bring Epileptic Seizure Recording Chart	
	- When did first seizures occur?	
	- How often do seizures occur?	
	- How long do seizures last?	
	- When was the last seizure?	
	- Describe a typical seizure	
	- How do you know a seizure has just happened e.g. person asks for a drink, goes to sleep etc.	
	- What is the protocol for when a person has a seizure e.g. administer Midazolam/Diazepam	
	- How does the person seem after the seizure e.g. confused, sleepy	
	- Are there warning signs e.g. sensations, physical change	
	- What, if anything, seems to improve or worsen the seizures?	
	- Are seizures triggered by certain events or conditions?	

SEIZURE ACTIVITY	Checklist	Tick
	- Were there unusual circumstances present e.g. very hot, stress, menstruation, mood swings, running, isolating themselves	
	- What was person doing leading up to seizure?	
	- Any changes in seizure pattern e.g. nature, time of day etc.	
	- Any recent life changes or stressors	
	- Know personal and family history e.g. does a family member have epilepsy, previous head injury, infections or tumours etc.	
<i>Notes:</i>		

Area	Checklist	Tick
INTERVENTIONS IN PLACE	Bring the following reports (if applicable)	
	Reports from other supports (if possible ask other supports to send a copy directly to Neurologist) e.g. Psychiatry <input type="checkbox"/> Psychology <input type="checkbox"/>	
	Reports from other medical consultants: Name: _____	
	Reports from Day Service, Residential Service, Respite Service and home	
	Healthy Lifestyle Plan	
<i>Notes:</i>		

PREPARE TARGET QUESTIONS TO ASK AT THE APPOINTMENT

For example:

- What are the potential side-effects of the medication?
- Is there a possibility of an allergic reaction?
- What special precautions should the person/family/staff be aware of?
- Will anti-epileptic medication interfere with other medication or supplements the person takes? Or will other medication interfere with the anti-epileptic medication?
- What is the treatment plan in relation to the epilepsy?
- What do we do if a seizure occurs?
- How is the epilepsy affecting the person?

DURING APPOINTMENT

Obtain the following information if possible

- Name of the registrar/consultant who spoke with you
- Name of the neurologist secretary
- Name of the clinical nurse
- Ask for clarification if you do not understand
 - Jot down information during the appointment
 - If problem arises after appointment and there are side effects from medication who do the service contact e.g. back up service

AFTER APPOINTMENT

- Make follow-up appointments immediately
- Fill out M.A.F
- Inform relevant people of outcome e.g. Circle of Support, family etc.,
- Fill any prescriptions
- Ask for Medical Report to be sent to family

PREPARATION CHECKLIST

Checklist	Tick
The lead staff member supporting the person is be fully briefed about all relevant issues.	
Up to date Blood Test Results	
Up to date MP1 Prescription Sheet	
Up to date Appendix 4- Epileptic Seizure Recording Chart	
M.A.F Medical Appointment Form	
All past blood test results	
All Relevant Reports	
Period Service Review (PSR)	
Psychiatry Information	
Medical Consultants information	
Psychology reports	
Reports from Day Centre, Residential Home, Respite and family etc.,	
Recording Charts	
Behavioural	
Mood	
Sleep	
Menstrual pattern	
Records of all tests and results including MRI scan (brain and spine) CT, ECG and metabolic or genetic testing	
Medication containers with all tablets	
Medical Card	
Appointment Letter	

Some Safety Equipment to Support Person with Epilepsy

When completing the Epilepsy Risk Management Plan, staff to consider the requirement for the following equipment:

Anti-Suffocation Pillow

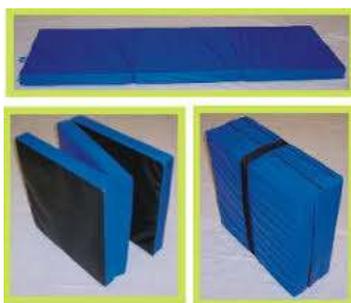


Voice Monitor



Mobile Seizure Alert Systems

Crash Mats



Bed rails



Sensor Under Mattress

