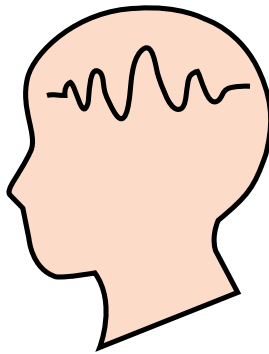


**Understanding and Managing Epilepsy  
of  
People with Profound and  
Multiple Learning Disabilities**



## Introduction

Epilepsy is a disorder of brain function characterised by recurrent seizures that have a sudden onset. A seizure is a brief disturbance in the brain's normal electrical activity causing the nerve cells to fire off random signals. The result is like an electrical storm that causes a temporary overload in the brain. This electrical storm causes a brief stereotyped event (seizure), whereby the individual's awareness of their surroundings is impaired and their behaviour may change. Seizures can be from a few seconds to a few minutes and usually end spontaneously followed by a period of drowsiness and confusion.

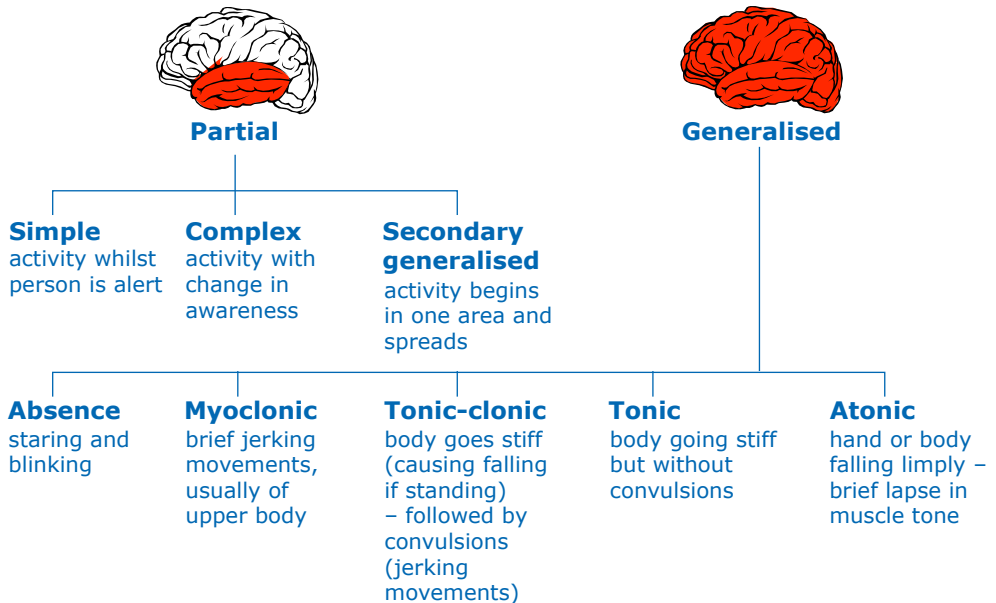
Epilepsy is one of the most common and persistent health problems in people with profound and multiple learning disabilities (PMLD) with over 60% affected. The more severe the developmental delay the higher the risk of epilepsy and the risk is also increased if there is associated cerebral palsy. Epilepsy is often misdiagnosed because the symptoms resemble a number of other conditions, e.g. a variety of repetitive behaviours, muscular movements, and apparent unresponsiveness are often interpreted as epileptic seizures when there is no evidence of epileptic discharges.

Seizures are not only frightening for the person that is experiencing them but they cause great anxiety for the carers. It is very important that carers have appropriate training so that they can not only understand what is happening, but they recognise the symptoms, and can keep a detailed history of the person's epileptic events. This history, which could include video recordings from a mobile phone, is essential for aiding health professionals to the correct diagnosis and the corresponding treatment. Epilepsy is usually controlled with appropriate medication but for people with PMLD it can be more difficult due to the severity of the epilepsy and the effects of other health problems exacerbating the condition. Epilepsy medication can have severe side effects so it is also important to get the balance correct between reducing the seizures and the quality of life for the individual and their carers.

This leaflet gives a brief overview of the symptoms of epilepsy, causes, diagnosis and appropriate treatments.

Although each person's experience of epilepsy is unique, the seizures can be classified into different types.

## Some types of seizures



It is important when a person has a seizure that the correct procedure is followed.

### What to do when a seizure starts

#### Do

- note the time
- clear a space around the person
- cushion the head to prevent head and facial injury
- loosen tight neckwear
- loosen chest and leg safety straps on wheelchairs
- remove spectacles, if worn
- turn on side if possible, to aid drainage (recovery position)
- reassure others and explain what you are doing.

#### Do Not

- put anything in their mouth
- restrain or restrict movement during the seizure
- give anything to eat or drink
- move the person unless they are in danger.

## Diagnosis

Accurate history taking by carers of people with PMLD is essential to give the health professionals a clear picture of the nature of the seizures. Behavioural descriptions, including duration times, should be recorded in seizure diaries which should be kept with the individual at all times. Also recording the events, either by mobile phone or video, is very useful.

Once a person is referred by their GP to an epilepsy specialist, which may be a neurologist or an epilepsy nurse, further tests will be carried out. These usually include an electroencephalography (EEG) which records the brain's spontaneous electrical activity over a short period of time, usually 20–40 minutes. Another diagnostic tool is neuro-imaging either Magnetic Resonance Imaging (MRI) or Computed Tomography (CT). Neuro-imaging may be difficult for people with PMLD without sedation or general anaesthetic, but it should be made available.

## Treatment

There are different anti-epileptic drugs (AEDs), available to treat different types of seizures and syndromes. For example, for generalised seizures the first line of treatment is usually Sodium Valproate (Epilim) or Lamotrigine (Lamictal) and for partial seizures Sodium Valproate (Epilim), Carbamazepine (Tegretol) or Lamotrigine (Lamictal). It can be difficult with people with PMLD to ensure they are completely seizure free with just one drug. Usually more than one drug is used. It is often trial and error with different dosages of drugs until a combination is found that has the best result. This can be a long process as introducing and withdrawing AEDs has to be done slowly in a controlled way. *PAMIS* has developed a medication checklist that is useful to record and monitor drug changes (see references).

## Medication side effects

There are concerns over the recognised medication side effects of anti-epileptic drugs. It is about getting a balance between the potential medication side effects and the impact of the seizures on the individual and their carers. It is important that carers know the possible side effects for individual drugs – so do ask what they are. For example Topiramate (Topamax) has the side effects of -

slowed cognition, memory problems, severe weight loss, confusion, depression, upper respiratory tract infection and renal stones. It is also important to remember that drugs interact and that side effects can be dose related or chronic, temporary or permanent.

### **Common side effects of epileptic medication include:**

- headaches
- depression
- nausea, vomiting
- sedation/ drowsiness
- cognitive impairment
- lack of co-ordination
- double vision
- slurred speech/dry mouth.

## **Epilepsy and Osteoporosis**

There have been a number of studies that suggest that there is a link between the long term use of AEDs and decreased bone density leading to osteoporosis. It is important that anyone who has been on long term AEDs to have their bone density checked. Treatment includes vitamin D and calcium supplements.

## **Emergency Medication**

Most tonic-clonic seizures last less than 2 minutes. A prolonged seizure lasting more than 5 minutes or a series of seizures are more likely to progress to status epilepticus (or 'status' for short). Status during a tonic clonic (convulsive) seizure is a medical emergency and needs emergency treatment, such as rectal diazepam or buccal midazolam. It is important that there is an individual protocol for carers to follow for such emergencies and that carers are given the necessary training (updated every two years) to carry out these procedures.

### **The protocol should include:**

- exact instructions on when to administer medication
- dosage, strength, route for administering medication
- if a second dose should be given, how much and when?
- what to do if the seizures don't stop?

**N.B.** Large doses of diazepam may cause breathing difficulties, or it may have the opposite effect causing the person to become alert or hyperactive.

*PAMIS* has designed a multi-sensory sensitive story, which can be borrowed from our library, to help people with PMLD understand the use of rectal diazepam in an emergency.

### **Some factors which can trigger seizures**

- missed medication
- illness/infections e.g. urinary tract infections
- lack of sleep, heat
- stress – including stress caused by constipation and pain
- menstrual cycle.

**A care plan** should be drawn up in consultation with the GP and/or specialist service and used by all carers. This should include:

- a record of triggers that cause seizures and seizure warning signs
- descriptions of seizures including length, frequency and recovery
- pattern – night/day, menstruation etc
- prescribed medication
- seizure recording sheets (including annual charts)
- who records the seizure
- protocols
- who should be contacted afterwards
- all relevant correspondence from GP, hospital etc.

## **Complementary Therapy**

There are a number of studies that show that listening to Mozart's music has a significant effect on reducing the number of seizures or decreasing their severity in people with epilepsy, especially when a person is 'in status'. There is also some evidence to show that essential oils, and the use of aromatherapy massage, can help those with epilepsy (see references).

## **Ketogenic diet**

The ketogenic diet is a high fat diet where fat is broken down to provide energy rather than sugars. It is often used when the epilepsy does not respond to traditional drug treatment. The diet involves more thought than the average diet but 'Matthew's Friends' (see useful websites) provides advice and recipes. People who are gastrostomy fed often find the diet easier as it can be given in pre-prepared liquid format. The diet can be given in combination with AEDs and this is

necessary, in the first instance, while the AEDs are gradually reduced.  
**N.B.** Please check with your GP before embarking on this diet.

## References

All the references listed below, and many others, are available at the PAMIS library – contact [j.t.taylor@dundee.ac.uk](mailto:j.t.taylor@dundee.ac.uk) or tel: 01382 385 154

Betts, T. (2003) Use of aromatherapy (with or without hypnosis) in the treatment of intractable epilepsy: a two-year follow-up study. *Seizure*, **12**: 534-8.

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Scottish Intercollegiate Guidelines Network (SIGN) (2005) *Diagnosis and management of epilepsies in children and young people: a national clinical guideline*. Edinburgh: NHS QIS.

Working Group of the International Association of the Scientific study of Intellectual Disability (2001) Clinical guidelines for the management of epilepsy in adults with an intellectual disability. *Seizures* **10**: 410-409.

## Medical Consent

In Scotland if you are over the age of 16 you are legally an adult. The law assumes you can then make decisions about your medical treatment. People with profound a multiple learning disabilities may not be capable of giving informed consent. Under the ***Adults with Incapacity Act (Scotland) Act 2000***, parents (and others) are able to apply to become ***welfare guardians***. This involves an assessment of the ability of the adult concerned to make informed decisions and an application to the Sheriff's Court for a ***guardianship order*** to authorise a particular person to make decisions on her/his behalf.

## Recommended Websites

### **[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)**

Epilepsy Scotland has numerous factsheets and publications available on the website to download.

### **[www.epilepsy.org.uk](http://www.epilepsy.org.uk)**

A useful feature on the website is 'drugwatch' which gives up-to-date information on latest changes to different drugs used to control epilepsy.

### **[www.scottishepilepsycentre.org.uk](http://www.scottishepilepsycentre.org.uk)**

The Scottish Epilepsy Centre, provides the only residential assessment and treatment centre in Scotland for adults with epilepsy.

### **[www.epilepsynse.org.uk](http://www.epilepsynse.org.uk)**

A national epilepsy medical charity.

### **[www.jointepilepsycouncil.org.uk](http://www.jointepilepsycouncil.org.uk)**

The Joint Epilepsy Council for the UK and Ireland (JEC) is an umbrella organisation which represents the various epilepsy charities.

### **[www.matthewsfriends.org](http://www.matthewsfriends.org)**

Provides the latest information on the ketogenic diet, including recipes and research.

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