

Epilepsy Information Sheet (may be added to the PHRs of people who have epilepsy)

The material in this sheet has been adapted from the Therapeutic Guidelines book 'Management Guidelines for People with Developmental and Intellectual Disabilities' and updated from the 2005 version 'Management Guidelines – Developmental Disability' which can be consulted for more detailed information.

What is Epilepsy?

Epilepsy is the name given to the condition where a person has recurrent seizures – abnormal discharges of electrical activity in the brain cells which may give rise to abnormal behaviours such as involuntary muscle movements, unusual perceptions, or a disturbed level of consciousness. It is a relatively common condition (up to 2% of the population) which can affect anyone, at any age.

Causes of Epilepsy

Epilepsy can be caused by such things as brain injury or brain tumour, chemical abnormalities, alcohol or drug effects, or there may be an inherited condition. In many cases the cause is unclear. In people with developmental disabilities, epilepsy occurs at a much higher frequency and is often more severe and more difficult to control than it is in other people.

In people with a tendency to have seizures, stimuli such as infection, menstruation, alcohol, stress or lack of sleep may trigger a seizure.

Diagnosis of Epilepsy

Diagnosis is based on an accurate description by those who have observed what happens, the circumstances, and the frequency. It is confirmed by electroencephalogram (EEG) but absence of characteristic abnormalities does not exclude a diagnosis of an epilepsy if the clinical evidence is strong. Some people with developmental disabilities will be resistant to having an EEG and may need desensitisation or sedation. EEG under GA is rarely useful due to the effects of the anaesthetic medication on brain activity. EEG combined with videomonitoring and neuroimaging (MRI, CT scan) can provide additional information where the diagnosis is unclear.

Types of Epilepsy

Seizures may be *partial* when the abnormal electrical activity occurs in one specific area of the brain, or *generalised*, where the whole brain becomes involved.

Partial seizures may be *simple* or *complex*. Some seizures may start as partial then become generalised.

There are several types of generalised seizures – absence, atonic, tonic, myoclonic and tonic-clonic.

Accurate diagnosis of the type of seizure is important in determining which medication is most likely to be effective, and for prognosis and lifestyle advice.

Treatment of Epilepsy

About two thirds of all people with epilepsy will be well-controlled with anti-epileptic drugs (AEDs) and some will go into remission and be able to come off medication.

Most people with epilepsy will need some degree of specialist overview of their management, but the general practitioner is well placed to play a major role in co-ordinating both diagnosis and treatment.

Rationalising the Use of Antiepileptic Drugs (AEDs)

Most people can have their epilepsy controlled by one or, at the most, two AEDs. If combination therapy is required, a second AED should be chosen which complements the first drug and attention should be paid to each one's influence on the other's metabolism.

- Monotherapy with the most appropriate AED should be pursued as far as possible before changing to or adding other agents.
- Care should be taken to find the minimum effective dose for any AED and to cease drugs which are clearly non-efficacious.
- A routine clinical review should be scheduled every three months for people using AEDs.

A careful history and examination is more reliable in determining effectiveness and adverse effects of treatment than drug serum levels in most situations. The exception is phenytoin, which can reach toxic levels with small dose increases.

Monitor for adverse effects, which might indicate the need for dose reduction.

Possible adverse effects:

- Ataxia
- Dysarthria
- Drowsiness
- Agitation
- Other disturbed behaviours
- Nausea and vomiting
- Skin rash
- Decline in cognition
- Gingival hypertrophy (overgrowth of gums) occurs in approximately 30% of people who use phenytoin.
- Rare cases of fatal liver failure have been linked to valproate.
- Vigabatrin and clonazepam may both stimulate aggression in people with developmental disabilities.
- Many people who have developmental disabilities find it difficult to co-operate with sampling for blood tests.

If a person has been seizure-free for 2-3 years at a constant level of AED, a very slow process of withdrawal of treatment may be undertaken. The process is more likely to be successful if the EEG is normal, although this is by no means invariable and the decision to withdraw medication should be based on clinical judgement rather than the absence of EEG abnormalities.

Status epilepticus

Status epilepticus refers to the situation in which a patient suffers from 2 or more generalised epileptic seizures without regaining consciousness between the seizures, or suffers from continuous partial seizures without clear cessation of epileptic activity between the seizures. It is a medical emergency.

Terminating status epilepticus in adults often requires the administration of:

clonazepam 1 mg- 2mg bolus intravenously not exceeding 0.5 mg/minute: repeat once 15 minutes later if status continues. (Child: 0.25 – 0.5 mg bolus IV over 2 – 5 minutes)

OR

diazepam 10 mg- 20 mg bolus IV, not exceeding 2 - 5 mg/minute: repeat once 15 minutes later if status continues. (Child: 0.1 – 0.25 mg bolus IV over 2 – 5 minutes)

OR

Midazolam 5 -10 mg (child 0.2 mg/kg) IM, repeat once 15 minutes later if status continues

In cases where intravenous access is impossible, rectal diazepam may be given. Family members or professional carers may administer rectal diazepam but they must be trained in the procedure and do it according to clear guidelines.

Catamenial epilepsy

Some women may experience a premenstrual exacerbation of their seizure disorder possibly due to fluctuations in endogenous hormones, or to a premenstrual fall in plasma anti-epileptic drug (AED) concentrations.

Combined records of seizures and menstrual cycles on a twelve-month calendar may demonstrate the presence or absence of this association and increasing AED doses in the premenstrual week may help. On rare occasions, pharmacological regulation or even suppression of menstruation might be necessary to prevent premenstrual exacerbations of epilepsy. However, AED intake may have an effect on the required levels of both the AED and the menstrual management drug.

Lifestyle Issues

As epilepsy can be well controlled for most people, it is important that people with epilepsy do not let their diagnosis unnecessarily limit them in their daily lives. However, it is wise to avoid precipitants(such as over-tiredness, excess alcohol, flashing lights, dehydration and illicit drugs), especially in combination.

In considering which activities it would be sensible to avoid, it is important to take account of the nature, frequency and severity of the person's seizures, when they usually occur and the age of the person. Activities which should be carefully assessed to ensure that risks of harm are minimised if a seizure should occur include swimming and other water-related past-times, climbing, bathing and showering, riding, cooking, driving and using machinery. Supervision is often the key to the successful inclusion of people with epilepsy in a range of activities.