Atos Healthcare

Epilepsy

Version 1 Final

Document control

Version history

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1e	8th May 2009	CPF comments.
1d	8th October 2008	External QA comments
1c draft	9th Sept. 2008	Incorporating Int. QA suggestions and correcting references (CT)
1b draft	11th Aug. 2008	Clarification of classification concepts (CT)
1a draft	6th Aug. 2008	Initial Draft

Changes since last version

1. Introduction

Definition

Epilepsy is a group of disorders rather than a single disease. Seizures can be classified by type as partial (categorised as simple partial, complex partial, and secondary generalised seizures) or generalised (categorised as generalised tonic clonic, absence, myoclonic, tonic, and atonic seizures). A person is considered to have epilepsy if they have had two or more unprovoked seizures.

Prevalence

Epilepsy is common, with an estimated prevalence in the developed world of 500-1000/100 000 population, and an annual incidence of 50/100 000 people. About 3% of people will be given a diagnosis of epilepsy at some time in their lives

2. Aetiology and Risk Factors

Epilepsy is a tendency to spontaneous, intermittent, abnormal electrical activity in part of the brain, manifest as seizures. It may be caused by various disorders involving the brain.

The causes/risk factors include birth/neonatal injuries, congenital or metabolic disorders, head injuries, tumours, infections of the brain or meninges, genetic defects, degenerative disease of the brain, cerebrovascular disease, or demyelinating disease.

Knowing the cause/risk factor can help to classify some forms of epilepsy – for example, idiopathic generalised epilepsies (such as juvenile myoclonic epilepsy or childhood absence epilepsy) are largely genetic.

Symptomatic epilepsies may result from a known cerebral abnormality; for example, temporal lobe epilepsy may result from a congenital defect, mesial temporal sclerosis, or a tumour.

Cryptogenic epilepsies are those that cannot be classified as idiopathic or symptomatic. [1]

3. Classification

The diagnosis of epilepsy has important physical, psychosocial and economic implications for the individual. It is therefore important that the diagnosis is correct. It has been shown that a significant number of diagnoses made by non-specialists are incorrect. Epilepsy may be difficult to diagnose in the early stages especially in the absence of a witnessed account. Differentiation of epileptic seizures and stereotyped behavioural phenomena can be difficult in people with learning difficulties.

The diagnosis of epilepsy should be made by a neurologist or other epilepsy specialist.

Classification

Classification of seizure types and epilepsy syndromes should always be attempted, as both may have implications for the management and prognosis

International Classification

The International Classification of seizures divides them into two major categories, partial and generalized seizures.

Partial Seizures

There are 3 types of partial seizures

a) Simple partial seizures – consciousness not impaired, e.g. focal motor seizures (previously called Jacksonian)

b) Complex partial seizures (previously called Temporal lobe epilepsy). There may be impairment of consciousness but the person does not normally fall or collapse to the ground. Seizure may be precipitated by aura.

c) Partial seizures evolving to generalised tonic-clonic (GTC) convulsions.

Generalised Seizures

In these, abnormal electrical activity affects all or most of the brain from the outset. Consequently, the symptoms tend to be general and involve most of the body.
6 types of generalised seizures are described in this classification.

a) Absence (previously called petit mal)
b) Myoclonic
c) Clonic
d) Tonic

e) Tonic-clonic

f) Atonic

A third category of “unclassified epileptic seizures” is available for use until an adequate description allowing classification into one of the two recommended categories, and usually based on witnessed events, becomes available. [2]

Status Epilepticus

Seizures are almost always self-limiting. Rarely one may follow another in close succession, resulting in status.

Status should be distinguished from serial epilepsy (closely spaced seizures or cluster attacks).

The differentiating factor being that in status there is no recovery of consciousness between seizures while in serial epilepsy regardless of frequency there is recovery of consciousness between seizures.

Status can take a number of forms.

Convulsive status

This is a state of recurrent tonic-clonic seizures without recovery of consciousness between attacks. It represents a medical emergency with a high morbidity and mortality. Status may occur in approximately 3% of epileptic patients but is most common in patients with severe epilepsy who are non-compliant with drug therapy. It may also occur in alcohol withdrawal, in acute meningitis or encephalitis, and in other metabolic disturbances.

An initial presentation with status epilepticus may occur with frontal lobe lesions such as tumour or abscess.

Absence status

This may be seen in children who exhibit confused behaviour, and an epileptic basis for this mental state may not be immediately apparent. The presence of blinking or minor myoclonic jerks may be helpful and the EEG will show continuous spike-wave activity. The condition usually responds well to intravenous diazepam and is much more commonly seen in secondary generalised epilepsies of childhood than in idiopathic generalised epilepsy.

Complex partial status

This phenomenon is rarer than absence status. Patients exhibit an abnormal mental state, with confusion and disorientation which is frequently associated with both automatic behaviour and subsequent amnesia for the period of time during which these events occurred.

Relative frequency of seizure types

Data on the relative frequency of seizure types is unsatisfactory, and is largely based on populations of patients with relatively severe epilepsy, including large numbers of patients with partial epilepsies. Furthermore, the milder the epilepsy the more difficult it is to determine on clinical and electroencephalographic grounds whether it is of primary generalised or partial type. With these restrictions in mind, most series would suggest that approximately one-third of epilepsies may be of a generalised type, whilst two-thirds are partial, most commonly with a temporal lobe origin [3]

In all comprehensive surveys, partial seizures account for most cases; complex partial and secondarily generalised seizures comprise 60% of prevalent cases, primary generalised tonic-clonic seizures about 30%, and generalised absence and myoclonus less than 5%. Other seizure types are rare. [4]

Classification of Epilepsy Syndromes

It is important to make the distinction between Idiopathic Generalised Epilepsies (IGEs) and partial/focal (localisation-related) epilepsies, as this affects treatment choices, investigation, prognosis and counselling. Identifying the aetiology is important in focal epilepsies.

Features suggesting idiopathic generalised epilepsies:

- Childhood or teenage onset
- Triggered by sleep deprivation or alcohol
- Early morning tonic-clonic seizures or myoclonic jerks
- Short absence seizures
- Photoparoxysmal response on electroencephalography (EEG)
- Generalised 3 per second spike and wave or polyspike and wave on EEG

Features suggesting partial/ focal epilepsies

- History of potential cause
- Aura
- Focal motor activity during seizure
- Automatisms

4. Diagnosis

A clear history from the individual and an eyewitness to the attack give the most important diagnostic information, and should be the mainstay of diagnosis.

Investigations

EEG

The main role of EEG in newly presenting epilepsy is to assist classification of seizure type and syndrome, and to determine whether the patient is photosensitive. Most studies of EEG in first unprovoked seizures have addressed the issue of prediction of recurrence. Patients with unequivocal epileptiform abnormalities in an EEG performed within a few weeks (4) of the seizure are significantly more likely to have a second seizure if untreated. In a systematic review, the pooled risk of recurrence at two years was 27% if the EEG was normal, 37% if there was non-specific abnormality and 58% if epileptiform activity was present. Early EEG - within 24 hours of the first unprovoked seizure - has higher diagnostic yield with respect to syndrome type, but at present there is insufficient high quality evidence that inter-ictal EEG within this period increases the likelihood of obtaining inter-ictal epileptiform discharge.

The recently published NICE guidelines for diagnosis and management of the epilepsies in adults and children recommend that an EEG should be performed to support a diagnosis of epilepsy in adults in whom the clinical history suggests the seizure is likely to be epileptic in origin. In children, EEG is recommended after the second or subsequent seizure, studies having shown that yield of information gained from EEG after a first seizure was too low to affect treatment decision. Although EEG is most likely to contribute to syndromic diagnosis in younger subjects, i.e. under the age of 25 years, some caution is required when setting age limits for EEG investigation, as idiopathic generalised epilepsies can present beyond adolescence. Late onset IGE has the same electro-clinical features as younger onset cases, and the diagnosis will be missed if EEG is not requested in the assumption that all new onset generalised seizures in adults are secondary to partial epilepsy.

An appropriate strategy for EEG investigation in a newly presenting case of suspected epilepsy is to perform a routine wake EEG with activation procedures, and offer treatment if epileptiform discharges are identified, as risk of seizure recurrence is high. If the first EEG is normal or non-specific, perform a sleep EEG (sleep deprived or drug induced; sleep deprived may be more informative in patients with suspected idiopathic generalised epilepsies) or obtain a prolonged inter-ictal recording using ambulatory monitoring, preferably for 24 hours.

Ictal EEG

Some seizure types have specific ictal EEG patterns, such as 3 per second generalised spike-wave discharge in a typical absence seizure, the evolving temporal theta rhythm (5 - 7 Hz) in mesial temporal lobe epilepsy, high frequency discharge in tonic seizures, and irregular slow spike and wave (< 2.5 Hz) in an atypical absence attack. Ictal changes may

however be obscured by artefact from movement or muscle, and scalp EEG may be unchanged or unhelpful in simple partial seizures, some frontal lobe epilepsies and epilepsia partialis continua. In such cases, the epileptogenic focus may be anatomically circumscribed or at a distance from the recording electrodes. Frontal lobe ictal EEG onset patterns are usually generalised or widespread, in part due to widespread anatomical connections, and variability in size and distribution of epileptogenic regions. Overall, the localising value of ictal scalp EEG is significantly less in extra-temporal epilepsy compared with temporal lobe seizures, particularly those of mesial temporal origin. [5]

General EEG Considerations

- Electroencephalography (EEG) is not routinely indicated and should not be performed to exclude a diagnosis of epilepsy.

- EEG can be used to support the diagnosis in patients in whom the clinical history indicates a significant probability of an epileptic seizure or epilepsy.

- EEG should be used to support the classification of epileptic seizures and epilepsy syndromes when there is clinical doubt

- EEG should be performed in young people with generalised seizures to aid classification and to detect a photoparoxysmal response.

- Video EEG and other specialist investigations should be available for patients who present diagnostic difficulties.

Brain Imaging

Brain imaging detects lesions in 21-37% of patients presenting with epilepsy. Such lesions require treatment in only a small minority, but their detection may have implications for future management should the epilepsy become intractable. Idiopathic generalised epilepsies are not associated with an increased prevalence of brain lesions.

Magnetic Resonance Imaging

Magnetic resonance imaging (MRI) scanning is the current standard of reference in the investigation of patients with epilepsy. Routine MRI brain scanning using simple standard sequences will detect lesions (e.g. small tumours, vascular malformations and cortical dysplasia) that are not detected by computed tomography (CT) scanning. MRI carried out for the assessment of drug-resistant epilepsy requires specialised protocols and expertise.

Computed Tomography Scanning

CT scanning has a role in the urgent assessment of seizures, or when MRI is contraindicated (e.g. in patients who have pacemakers or metallic implants).A non contrast CT scan will fail to identify some vascular lesions and tumours. CT has only a limited role in the assessment of intractable epilepsy.

MRI is the modality of choice for brain imaging in patients with epilepsy.

Conditions which may be confused with epilepsy.

Breath-holding attacks

Day-dreaming

Panic attacks

Episodic dyscontrol syndrome

Pseudoseizures

Hyperventilation

Syncope

Hypoglycaemia

Transient global amnesia

Migraine

Transient ischaemic attacks

Movement disorder

Vertigo

Night terrors [6]

5. Treatment

Starting treatment with an antiepileptic drug (AED) is a major event for a patient and should not be undertaken without careful evaluation of all relevant factors. Therapy is long term, usually for at least three years and, depending on circumstances, sometimes for life. All the implications of long-term therapy must be fully explained to the patient, as agreement with the treatment policy and full adherence to the drug regimen are essential for the treatment to be successful. Treatment is usually started with a single drug at a small dose. When carefully monitored, treatment is ideally no more than a small inconvenience. Potential complications in some patients are withdrawal seizures (due to inadvertent or deliberate poor adherence to treatment), and acute or chronic toxicity. The latter is especially associated with polytherapy.

The single seizure

There has long been debate about when treatment should be started in people with few or infrequent seizures. A recurring issue has been whether seizures beget seizures, and therefore whether failure of early treatment leads to chronicity. Recent evidence shows no difference in the long-term prognosis of epilepsy for deferred versus immediate treatment. This vindicates the practice of waiting for further events rather than commencing treatment immediately. Patients perceived to be at high risk of recurrence due to the presence of a structural abnormality deemed to be responsible for the seizure, an abnormal EEG, the presence of a pre-existing neurological deficit, or an initial high density of seizures should, however, still be offered treatment at the first opportunity.

Precipitating factors

Treatment may be held back or delayed if avoidable precipitant factors have been identified, including drugs, alcohol, acute metabolic stress, fever, photosensitive mechanisms (television, discos, videos, computer games), loss of sleep and emotional stress.

Adherence to treatment

In view of the long-term nature of treatment and public attitudes to drug therapy, poor adherence to treatment is common and this is the most frequent cause of relapse of seizures. It is sometimes associated with personality disorders, additional psychosocial handicaps and drug abuse. Such patients may sometimes be better off without any treatment

Starting treatment

The goal of AED therapy should be maintenance of a normal lifestyle by complete seizure control without drug-related side effects. When prescribing an AED for the first time, the clinician must discuss all common side effects, including the risk of teratogenesis in women of child-bearing potential. Similarly, if applicable, the regulations surrounding driving should be raised with the patient.

Time should be taken to deal with the patient's fears, misconceptions and prejudices, as well as those of his or her family. The importance of adherence to the therapeutic regimen should be stressed.

A single drug should be introduced at a low dosage with increments over weeks to months to establish an acceptable regimen. This will help avoid concentration-dependent side effects, in particular central nervous system toxicity, the presence of which is likely to discourage the patient from persevering with long-term therapy. An additional benefit of a cautious approach is that is less likely to lead to sedation or cognitive impairment. Such a policy will also detect early the emergence of serious idiosyncratic reactions, such as rash, hepatotoxicity and blood dyscrasias. It is better to aim at a predetermined target dose or concentration rather than await the next seizure. Poor tolerability may well provide the ceiling to dosing in an individual patient. Measuring the drug concentration when steady-state has been reached will confirm appropriate adherence to treatment, and provide a baseline for further increments in dosage or a subsequent discussion on adherence.

Choice of drug

Drugs are usually chosen according to seizure type. The choice of drug should be made by a specialist, and there are a number of choices for both generalised and partial seizures.

Lamotrigine, controlled-release carbamazepine, topiramate or sodium valproate are options for partial seizures.

For generalised seizures lamotrigine, topiramate or sodium valproate are the options and, as these drugs are broad spectrum, they should also be used when there is doubt about the classification.

For children and adolescents with clear-cut idiopathic generalised absences ethosuximide is still an option. Controlled-release carbamazepine is better tolerated than the standard formulation and can be prescribed once or twice daily in all patients.

Although as effective as the other drugs, phenytoin is no longer used as a first-line treatment because of its saturation kinetics and, therefore, the necessity of routinely monitoring its concentration. Another problem with phenytoin is its side effect profile, particularly with chronic use.

Problems

If the patient develops an idiosyncratic side effect or cannot tolerate the first drug chosen, then it should be substituted by another drug appropriate for the seizure type. If the problem is lack of efficacy despite a reasonable maintenance dose, substitution with a second drug is less likely to be a successful policy. In this eventuality, the clinical situation should be re-assessed:

- Is the diagnosis of epilepsy correct?
- Is there a progressive condition?
- Is the seizure classification correct?
- Is he or she a covert abuser of alcohol or drugs?

Drug levels should be measured to confirm reasonable adherence to treatment and give some idea of the leeway for further dosage titration.

If the diagnosis is correct and the patient fully adherent to treatment, it is possible to increase the dose by increments to the limit of tolerability.

The target range should not be the only indicator to dosage; indeed, some patients will have seizures controlled with no side effects with levels outside the target range. If seizure control is still not optimum (i.e. 100%), it is now time to add another drug appropriate for the seizure type. The dose of the original drug should be reduced if the patient complains of sedation or cognitive impairment. This approach demands an element of forethought when starting treatment with the original drug as one should always consider what to do next if matters do not go according to plan.

It is reasonable to add sodium valproate in a patient taking lamotrigine or start low-dose lamotrigine if the first choice was sodium valproate, noting the potential for interactions. Sodium valproate, lamotrigine, levetiracetam and topiramate are reasonable alternatives in a patient with partial seizures not satisfactorily controlled with carbamazepine. The choice depends on severity of the epilepsy, patient characteristics, and personal preference. If dual therapy is successful, a decision needs to be taken on whether or not to withdraw the first drug.
The patient should be fully involved in this decision.

6. Prognosis

Outcome for the newly diagnosed patient on carefully monitored monotherapy is good, with 70 - 80% entering prolonged remission. Factors that contribute to poor prognosis are the presence of structural lesions and associated neuropsychiatric handicaps.

The prognosis for untreated epilepsy is unknown. It has been suggested that early treatment may improve long-term prognosis Circumstantial evidence, however, on the efficacy of AED treatment in patients with chronic untreated epilepsy do not seem to support this proposition. On the other hand, the more seizures the patient experiences in the early stages the more likely it is that the epilepsy will prove refractory. An MRC study group (MESS) is currently carrying out a controlled trial, randomising patients with seizures at the time of a first epileptic attack to either treatment or delayed treatment. It is hoped that the results of this study will shed light on the role of treatment in the long-term prognosis of epilepsy. [7]

AED Withdrawal

Estimates of the risks of seizure recurrence after discontinuation of AEDs were provided by a large, multicentre, randomised, prospective trial of continued antiepileptic treatment versus slow withdrawal in adults and children with epilepsy, who had been seizure free for at least two years. AED withdrawal was associated with an increased risk of seizure recurrence, which was influenced by the duration of seizure freedom, the history of seizure types, the occurrence of one or more seizures after the start of treatment and whether one, or more than one, AED was being taken. The data from the study were used to develop a prognostic index for seizure recurrence. This has been used to calculate the risks of seizure recurrence with continued treatment or with slow AED withdrawal.

An abnormal EEG at the time of entry into the study was associated with only a small increased risk of seizure recurrence. Since this is unlikely to influence a decision about whether to withdraw AED treatment or not in adults, EEG recording is not necessary for an informed decision to be made. The higher risks of seizure recurrence with a history of myoclonus reflect the high risk of seizure recurrence following AED withdrawal in juvenile myoclonic epilepsy. The prognostic index has not been validated on an external population and should be used with caution. No information is available on the risk of seizure recurrence following drug withdrawal in adults who have been less than two years seizure free, although for children the risks are higher after less than two years seizure freedom than for more than two years. The effect of different rates of AED withdrawal on the risk of seizure recurrence has not been adequately studied.

Important factors influencing a decision about AED withdrawal in adults include:-

- Driving
- Employment
- Fear of further seizures
- Risks of injury or death with further seizures
- Concerns about prolonged AED treatment

The Driver and Vehicle Licensing Agency recommends that driving should cease during the period of AED withdrawal and for six months afterwards, and for many this factor alone may lead to a decision to continue treatment.

A Prognostic index indicator can be used to give an estimate of the risk of seizure recurrence following AED withdrawal after a minimum remission of seizures of two years. [8]

The question of continued treatment or AED withdrawal should be discussed with people with epilepsy, who are at least two years seizure free, so they can make an informed choice.

The rate of withdrawal of AEDs should be slow, usually over a few months, and longer with barbiturates and benzodiazepines.

One drug should be withdrawn at a time. [2]

Epilepsy and Pregnancy

Where possible women should have their epilepsy treatment reviewed before becoming pregnant. They should be advised about the risks of AEDs and effects on the foetus

If the woman's epilepsy is in remission, the risk of recurrent seizures is low and the woman is aware of the consequences of recurrent seizures, consideration may be given to withdrawal of AEDs prior to conception.

If AEDs are to be used in pregnancy the relative risks of seizures and foetal abnormality should be discussed with the woman.

Whenever possible, a woman should conceive on the lowest effective dose of one AED appropriate for her epilepsy syndrome. If she has good seizure control and presents already pregnant there is probably little to be gained by altering her AEDs.

Any woman who has given birth to a child with a malformation while taking AEDs should be offered a review by an epilepsy specialist before becoming pregnant again. [2]

7. Epilepsy in Children

Many children with a first seizure, and in whom there will be a range of possible diagnoses, will present to their General Practitioner or to an Accident and Emergency Department

Five per cent of medical paediatric accident and emergency attendances follow a seizure.

Only a minority of such patients turn out to have epilepsy. A first seizure is extremely stressful for the family. Parents witnessing the event often believe their child is dying.

Children are often febrile at the time of a first seizure. This may be a febrile convulsion, but there is an important group of children whose apparent febrile convulsion is due to bacterial meningitis or other central nervous system infection, and for whom early recognition and treatment is required.

Children without a fever may have had a non-epileptic event, an unprovoked epileptic seizure or an acute symptomatic seizure, the latter requiring urgent investigation and treatment

Diagnosis

The accurate diagnosis of one of the epilepsies of childhood can be very difficult. The differential diagnosis of a paroxysmal event in childhood is extensive and non-epileptic seizures are common.

In a birth cohort long term follow up study at 11 years, nearly 7% of children had a history of seizures or other episodes of loss of consciousness.

2% had a history of febrile convulsions and in a similar number the diagnosis of epilepsy was refuted.

There are many features, commonly thought to be unique to epileptic seizures, which may also be found in non-epileptic events.

The misdiagnosis of epilepsy is recognised as a diagnostic pitfall and may occur frequently.

Almost half of the children referred to a tertiary paediatric neurologist with a suggested diagnosis of epilepsy did not have that condition and in children referred with apparently poorly controlled epilepsy, misdiagnosis rates varied from 12% to 23%.

Syncopal seizures accounting for almost 50% of these cases, behavioural disorder for 20% and breath holding for 11%.

Others included migraine and night terrors. Non-epileptic seizures may also occur in treated patients with epilepsy. In a large video electroencephalogram (EEG) series of paroxysmal events in children, half of the recorded events were shown to be non-epileptic although 40% of these children also had epilepsy.

The misdiagnosis of epilepsy has significant implications for the iatrogenic adverse effects of medication and adverse psychological impact.

The inappropriate treatment of young pregnant women with antiepileptic medication risks subsequent damage to an unborn child.

Given these concerns regarding misdiagnosis, the breadth of epilepsy syndromes and the range of differential diagnosis, a service for children with epilepsy should have specialists with skills and interest in the management of epilepsy.

The history taking skills required to ascertain comprehensive witness accounts of events are built upon thorough training, continuing education and experience. They can be acquired only with an understanding of the range and complexity of the differential diagnosis that exists in children.

The diagnosis of epilepsy should be made by a paediatric neurologist or paediatrician with expertise in childhood epilepsy.

Genetics

Epilepsy often runs in families, and the recurrence risk for siblings or children of an affected person is increased compared with the background rate of epilepsy in the general population.

In most cases, the inheritance of epilepsy is multifactorial, with a contribution from more than one susceptibility gene, as well as from environmental factors. Where one person in a family has idiopathic epilepsy the recurrence risk for siblings is 2.5 - 6.7% and for children is 1.6 - 6.3%.

The recurrence risk for symptomatic epilepsies relates to the underlying aetiology. Facilities for mutation testing are currently limited but testing may be indicated where three or more family members have idiopathic epilepsy.

This should be done in conjunction with a clinical genetics service.

i. In all patients with newly diagnosed epilepsy, a three generation family history should be taken i.e. siblings parents and grandparents, uncles and cousins.
ii. Families with a history of epilepsy should be referred to the Clinical Genetic Service particularly if three or more members of the family are affected
iii. Families should be given information about the genetic aspects of epilepsy and likely recurrence risks.

Information for Schools

Families may be concerned about their child having a seizure at school and the possible associated stigma.

School staff are keen to provide a safe environment for the child but this can lead to the child not being allowed to participate fully in some activities. Schools should be given written information and school staff should be offered further discussion on epilepsy and its management, ideally involving the parent(s).

Some voluntary organisations have leaflets on epilepsy safety specifically written for teachers. Discussions about any possible restrictions on activities within the school should always involve the parents, the child, school staff and a health professional/voluntary sector worker who is knowledgeable about epilepsy. There may be additional risk of minor injuries for some children who have epilepsy but inclusion and independence should be prioritised and joint decisions made about risk and safety.

Many children feel that more open discussion about epilepsy and education of their peers is the best way of reducing stigma and dispelling myths leading to greater acceptance of them and their seizures. The child should make the decision about what information is given to classmates. Epilepsy awareness training can be provided by health professionals, field workers or staff from voluntary organisations. Children with epilepsy which is difficult to control may require extra support to enable them to participate in all aspects of the curriculum. Educational and clinical psychologists can be helpful in supporting school staff and the child and family throughout school life. If seizures are not controlled or treatment is causing adverse effects, this should be taken into account at examination time.

When children have a history of prolonged seizures, training on administration of emergency (or rescue) medication should be given to all school staff who are willing to do this, and a care plan agreed with the school and family. Training of school staff (usually by the school nurse) in the administration of emergency medication should be updated regularly.

Provision should be made for children with a short recovery period to be allowed to stay in school and rejoin the class when able.

In Summary:
Children should be enabled to participate in the full range of school activities.

Children who have epilepsy should have a written care plan for their epilepsy, drawn up in agreement with the school and family.

Epilepsy awareness training and written information should be offered to school staff and advisors.

Management of Risk

Safety

When a diagnosis of epilepsy is made safety may be a major concern for carers. Children may be inappropriately restricted from participating in some sports, social activities and school .In fact children with epilepsy do not appear to have a higher rate of injury than their peers without epilepsy.

Few children need medical attention for seizure related injuries.

Water based activities have different risks and require levels of supervision appropriate to the situation. Supervision during water activities (swimming, bathing, showering) reduces the risk of accidental drowning.

Scalds and burns can occur during seizures. These are most commonly sustained during cooking, or by falling against radiators.

Children with learning difficulties have an increased risk of injury compared with the general population and epilepsy may compound this.

Safety in some common situations

Bathing/showering - Taking a shower is considered less of a risk than taking a bath. High sided shower bases should be avoided as they can trap water. Thermostatically controlled taps and showers minimise the risk of scalds. Bathing and showering are best undertaken with the bathroom door unlocked and with someone nearby.

Scalds and burns - Radiator covers may help prevent burns. Specific information is produced by the voluntary agencies.

Swimming - Swimming alone is not advised. The level of supervision required for an individual child should be based on the environment and the type of epilepsy.

Road safety - Crossing at traffic lights where possible should minimise the risk of being knocked down should a seizure occur. When cycling, children with epilepsy should avoid traffic and cycle with a friend if possible. Cycling helmets should be worn.

Heights - Rubberised flooring in play areas and crash mats in gymnasiums allow most children with epilepsy to participate in climbing activities with their peers. Abseiling and climbing can often be undertaken as long as those in charge of the activity are aware of the possibility of a seizure occurring and feel it can be managed safely.

Photosensitivity - Only around 5% of children with epilepsy have seizures triggered by flickering lights and this is commonest between the ages of 7 and 19 years. Antiepileptic treatment usually abolishes the photosensitive response.

Children with epilepsy should be encouraged to participate in normal activities with their peers. Supervision requirements should be individualised taking into account the type of activity and seizure history.[9]

8. Main Disabling Effects

Mild Condition

A person with mild epilepsy would normally have a fit frequency of less than monthly. He/she may have brief absence seizures or infrequent generalised seizures with useful warning and no dangerous post-fit behaviour.

Such people may hold a driving license depending on fit frequency.

Care

A person with this condition, with a mild degree of disability, would normally be able to carry out all self-care activities for most of the time. This includes washing, bathing or showering, dressing, taking medication, and being able to prepare and cook a meal.

There would be no problem in managing stairs.

For a small part of the time, the person may have a generalised convulsion and would be likely to feel unwell for a short time afterwards, but this would be for the minority of the time, The risk of falling would normally be very small, as a person with mild epilepsy would have an aura which would give useful warning of an impending fit, and he/she could take steps to avoid injury. Alternatively, the person has absence seizures which cause momentary blankness, but which do not significantly affect day to day function.

Mobility

A person with epilepsy, which is not complicated by any other disabling condition, is physically fit, and would normally be capable of walking an unlimited distance. He/she would normally be safe outdoors and could find their way around.

Moderate Condition

A person with moderate epilepsy has a degree of epilepsy which will impinge on daily life to some degree. He/she would have a fit frequency of around one to two a month. He/she would normally have useful warning of a seizure, but may have post seizure manifestations such as confusion and drowsiness, which can last from one to five hours. He/she may experience complex partial seizures with some minor behaviour disturbance. Such people would not hold a driving licence.

Care

The care needs of a person with moderate epilepsy will be specific to the individual, depending on the type and frequency of the epilepsy .

However, for the majority of the time a person with moderate epilepsy would be able to safely self care that is, bathing, dressing, attending to toilet needs and preparing and cooking a main meal.

Normally the person would have adequate warning of a fit, and be able to remove themselves from danger, that is, get out of a bath or shower, and stop using a knife to cut vegetables.

There would normally be confusion and drowsiness for at least an hour after a fit, and for this period of time, the person would benefit from the presence of a responsible adult to watch over them, but this would be for the minority of the time.

The person would normally be physically fit and be able to manage stairs most of the time.

Mobility

A person with epilepsy, which is not complicated by another disabling condition, is physically fit, and would normally be capable of walking an unlimited distance, unless in the post-ictal phase. At this time the person would also have difficulty finding his way out of doors, but this would be for the minority of the time. For the rest of the time he/she would not normally be unsafe out of doors and could find his/her way around.

Severe Condition

A person with a severe degree of epilepsy would normally have frequent grand mal attacks, (at least more than twice a month), without warning which are manifest with severe convulsions, in which injury may often be sustained and which might require hospital care. Anoxic episodes which could occur during seizures, especially those of a prolonged or serious nature, may result in intellectual deficit. Status epilepticus may have occurred in the last year. Dangerous post-ictal behaviour may occur which could last for several days.

Such a person would not hold a driving licence.

Care

The problems are largely related to supervision. For some of the time, when well, the person would be able to self care in activities such as dressing, personal hygiene, attending to toilet needs and taking medication.

However, because of the absence of useful warning, the frequency and severity of fits, and the prolonged recovery phase, he /she would normally require the presence of another person for the majority of the time, to safely carry out activities of daily living (for example when bathing). The person would not normally be able to safely prepare and cook a meal without supervision.

He/she may be a danger to themselves or other people, because of confusion or aggressive behaviour, and he/she may be at increased risk of falling and injury.

Once in bed the risk from an epileptic fit is reduced, but there may be the risk of choking, or developing status epilepticus. If at night confusion or automatic behaviour leading to wandering is a feature of fits, the person may need someone around to prevent danger to the person or other people.

The person would normally be able to manage stairs physically but because of the risk of fits without warning would normally need to be accompanied.

Mobility

A person with epilepsy, which is not complicated by any other disabling condition, is physically fit, and would normally be capable of walking an unlimited distance.
A person with severe epilepsy would normally experience a period of prolonged post-ictal effects lasting more than five hours, however this would be for the minority of the time.

Such a person is likely to have unpredictable, frequent generalised seizures with prolonged post-ictal disturbances of behaviour. He/she may therefore be at risk when going out alone, and post-ictal confusion may prevent the person finding their way about or home. [10]

9. References

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