

14. EPILEPSY

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14.3	Introduction	
	14.3.1 The condition of epilepsy refers to a liability to attacks in which there is sudden loss of consciousness or altered awareness which may or may not be accompanied by a convulsion. Apart from the liability to attacks, the person with uncomplicated epilepsy is not otherwise impaired physically or mentally by virtue of the epilepsy alone.	
	14.3.2 The vast majority of people with epilepsy successfully hold down suitable jobs, marry, bring up children and in every way lead full lives. People with epilepsy cannot generally be considered as being in substantial danger. The liability to have fits does not in itself mean that a person needs attention or supervision. Only a very small minority of people with epilepsy in whom there are either special features relating to their fits or complicating conditions will be sufficiently disabled to require attention or supervision to any significant degree.	
14.4	Classification and Clinical Description	

14.4.1 There are many classifications of epilepsy. A full classification would be extremely complicated, but the following is likely to be useful in determining the care and mobility needs a person is likely to have.

14.4.2 Partial seizures. These are seizures which begin locally or focally affecting a single part of the body or resulting in a particular type of abnormal behaviour. Various types of partial seizure may occur:-

- (i) Simple partial seizures in which consciousness is not impaired and where there may be just abnormal and uncontrolled movement of one part of the body.
- (ii) Complex partial seizures (formerly known as temporal lobe or psychomotor epilepsy). In these the person has impairment of consciousness or disturbed awareness. He may continue to do what he is doing without being aware of the fact or he may behave in a bizarre or inappropriate way.
- (iii) Partial seizures becoming secondarily generalised. In these, partial seizures end with the person having a convulsion.

14.4.3 Generalised seizures. These include disorders which were previously known as grand mal or generalised tonic-clonic seizures; petit mal, and myoclonic seizures.

- (i) In the major type of generalised seizure the person loses consciousness with or without warning, may go rigid or have repeated movements of arms and legs (a convulsion). He may bite his tongue and may be incontinent
- (ii) Absence seizures. These are either typical (previously known as petit mal) or atypical. In both types, the person usually has a momentary loss of consciousness. The person will be unaware that this has happened, but it may be apparent to an observer who may note a blankness or brief interruption in conversation. These attacks may be very frequent.

14.5 Factors Influencing Care Needs

14.5.1 There are a number of factors which, in combination, will influence the amount of attention or supervision a person with epilepsy needs. A knowledge of as many of these facts as possible will give an overall picture of the disability caused by the attacks in the individual person and determine the care needs. No single factor can be decisive. The factors include:-

- (i) The duration of the epilepsy
- (ii) The nature of attacks.
- (iii) Whether the person gets any warning, either of a general nature such as restlessness or irritability for some time prior to the attack, or of a more specific nature in the form of an aura (a subjective sensation which

precedes, and may give warning of, an impending epileptic fit), as this will influence the opportunity to protect himself against injury. If there is an aura, its duration will affect the person's ability to put himself out of danger from the impending fit. The aura takes various forms and may include an unusual smell, or taste, or a tingling sensation in some part of the body.

- (iv)** The duration of the loss of consciousness or altered awareness.
- (v)** Whether there is a convulsion.
- (vi)** Whether the fit is accompanied by incontinence.
- (vii)** Whether the attack is followed by confusion or automatic behaviour. This type of behaviour varies widely and may be very specific to the individual. It may range from bizarre but harmless behaviour to instances where the disabled person may for example smash furniture or strike out blindly. Even when aggressive or violent behaviour is present it may vary in its extent, thus influencing the amount of danger the person is likely to encounter.
- (viii)** The frequency of attacks. Here, the care needs will be influenced by the pattern rather than the overall average frequency. For example, a person who has 6 or 7 attacks in one day followed by a week or more without any is likely to be at greater risk of danger than the person whose attacks are more evenly spaced, but where there is only one attack on an affected day. This is not to say that a person with a pattern of evenly spaced attacks will not require continual supervision: it will depend on the circumstances in which attacks occur, and on all the associated factors.
- (ix)** Whether the attacks occur only in bed, only when the person is up and about or both.
- (x)** Whether the person has received anti-convulsant drugs and, if so, whether they have reduced the frequency or severity of the attacks.
- (xi)** Whether the person ever injured himself or others during an attack and if so, how often, how recently and with what severity.
- (xii)** Whether the person has ever experienced status epilepticus. Status must be differentiated from serial epilepsy. Status is a series of attacks between which the person does not recover consciousness. 'Serial epilepsy' is a number of attacks following in quick succession but with at least partial recovery between attacks. Both are potentially serious, but if status is not arrested rapidly by appropriate treatment, there is a serious risk to life. [See para 14.8]

14.6 Care Needs:

14.6.1 The frequency of attacks is not in itself a sufficient guide. One person may have as many as 20 or 30 brief absences per day without significant interference with his lifestyle or work, whereas another with only one attack per day may be disabled because the attack is followed by a prolonged period of confusion during which he is a danger to himself or others. Equally the occurrence of a period of post-epileptic confusion cannot be decisive because one person may perform only purposeless harmless activity, whereas another may expose himself or others to danger. Nor is a history of injury decisive. People with epilepsy may suffer minor injury such as cuts or bruises, but it is rare for them to sustain serious injury. It is likewise uncommon for those who experience post-epileptic confusion or automatic behaviour to harm themselves or others.

14.6.2 The problems of epilepsy are largely related to supervision. The risks arising from epilepsy are likely to be very specific to the individual person and it is not possible to make assumptions from the effects of epilepsy in general. So, for example, a person who most days has one or more grand mal attacks without warning with severe convulsions in which he often sustains significant injury would be at substantial risk, at least by day. A person who has even more frequent 'absences' which do not interfere with work or social life and which have not led to injury faces little more danger than a person who does not suffer from epilepsy.

14.7 Mobility Considerations

14.7.1 A person with epilepsy which is not complicated by any other disabling condition is physically fit and should be capable of walking.

14.7.2 A person whose epilepsy is such that continual supervision by day is required to avoid danger to self or others will also most likely require supervision when walking out of doors.

14.7.3 If epilepsy is complicated by brain disease of some kind the situation may be different. [See para 14.9]

14.8 Status Epilepticus

14.8.1 This is a serious form of epilepsy in which seizures occur in such rapid succession that recovery of consciousness between the episodes does not occur. About 5% of people with epilepsy will have status epilepticus at some time. It is the most serious problem likely to be encountered in people with epilepsy and a significant number die during an attack.

14.8.2 When a person has been in status epilepticus the consequences will depend

on whether this was brought about by an avoidable precipitating factor such as sudden withdrawal of anticonvulsant drugs or overindulgence in alcohol. In these circumstances the risk of recurrence is small and can be disregarded. If the status was spontaneous then recurrence, with its attendant danger to life, cannot be excluded hence supervision by day and watching over at night is required. The risk of recurrence declines with the passage of time and returns to the baseline approximately three years from the date of the last episode.

14.8.3 Status epilepticus should be distinguished from serial epilepsy. In serial epilepsy, although the fits are very frequent, the person recovers consciousness in between attacks. It is not associated with the same risks as status epilepticus.

14.9 Complicating Factors

14.9.1 Epilepsy may be associated with, and a consequence of, brain disease such as head injury, cerebrovascular disease, tumour, degenerative and inflammatory conditions. The epilepsy and the complicating condition may not lead to a need for a great deal of attention or supervision when considered alone, whereas taken together, they may well do so.

14.10 Epilepsy in Parents of Young Children

14.10.1 A parent (mother or father) with epilepsy, who is caring for an infant or young child may pose a risk. In the event of an attack occurring without warning the parent may drop or fall upon the child. In cases where the risk of this happening is considerable, the parent may need supervision through the day. The risk becomes much less as the child becomes more independent.

14.10.2 It should be emphasized that it is the parent and not the child that needs supervision, to prevent substantial danger to the child.

14.11 Nocturnal (Night-time) Attacks

14.11.1 Once a person is in bed the risk of falling or otherwise sustaining injury in an attack is removed. Fear is often expressed that a person may choke or be smothered in an attack, but with a suitably firm pillow or sleeping without a pillow, the risk is remote. There may also be fear that following an attack in bed the person may get up and wander in a state of post epileptic automatism and so come to harm. When the type of attack experienced by the person makes this a possibility, danger can be obviated by taking suitable precautions.

14.11.2 It is rare for epilepsy to be so severe that the affected individual needs watching over at night.

14.12 Duration of Needs

14.12.1 If there has been a documented episode of spontaneous status epilepticus [see para 14.8] the risk of recurrence declines with the passage of time and returns to a stable state approximately three years from the date of the spontaneous episode, at which time reassessment of the needs may be considered.

14.12.2 There are a number of factors which can cause an alteration of the pattern of epilepsy, most notably drug treatment. If in an adult who requires continual supervision, at least by day, there has been no change in the pattern of epilepsy after two years, despite adjustment of his drug regime, then no further change is likely. If, however, a further modification of treatment is anticipated, the situation may well be different.

14.12.3 Where epilepsy in the parents of young children is considered to put the child at risk [para 14.10], the age of the child (children) at risk will assume critical importance, since the risk should become very substantially less as the child becomes increasingly independent and aware.

14.12.4 In persons with epilepsy whose mental competence is severely impaired such that they would be unable to assess their risk of danger in an epileptic attack, the requirement for supervision, at least by day, is likely to be life long.

14.13 Further Evidence:

14.13.1 As explained in para 14.5, establishing the needs of a person with epilepsy (particularly those related to a requirement for supervision to avoid danger to the affected person or others) is based on a number of features which characterize the nature, pattern, frequency and severity of the epileptic episodes. Evidence from the following sources may be helpful in determining needs in individual cases:

14.13.2 A specific disease-orientated factual report from a doctor who cares for the person will provide information on the diagnosis and type of epileptic attacks, their frequency and severity. This will be particularly helpful when, despite anticonvulsant treatment, the affected individual reports several attacks each week. Information from this source may also help to determine whether any change in the pattern of epilepsy can be expected.

14.13.3 When the diagnosis is not in doubt, assessment of the effects of the disability and the needs posed by it will be made easier by a factual report from a social worker or doctor who is conversant with the person's needs.