An overview of epilepsy with a focus on the effects and implications of the condition for children and their families.

This review is written by a Health Psychologist with a special interest in epilepsy and seizure disorders. It consists of five sections and sub sections;

1 Epilepsy - an overview.

Epilepsy is one of the most common serious chronic central nervous system neurological disorders in the UK (Rajpura and Sethi 2004). Half of patients with epilepsy have sustained brain damage such as trauma or meningitis and onset following this can range from weeks to decades (Spinney 2004). The term ‘epilepsy’ refers to a group of central nervous system disorders manifesting in seizures

(Baxendale 2006) and is the umbrella diagnosis given to people who have recurrent i.e., two or more, (Banerjee 2009) unprovoked seizures (Guerinni 2006), The etymology of the Greek term depicting epilepsy is epi-lambanein - meaning to surprise. However the idea of suddenness is not completely accurate as people can have warnings prior to a seizure and these are important to identify in terms of employing strategies to inhibit seizures (Petitmengin 2006) for both adults and children. Subjective symptoms preceding seizures, precipitating symptoms and strategies to suppress partial seizures have been reported by children and adolescents and some mothers have detected some not felt by children (Galletti, Rinna et al. 1998). Young people with juvenile myoclonic seizures for example report a number of specific precipitating factors and some can use inhibiting strategies to avoid seizures (da Silva Sousa, Lin et al. 2005). A small number of patients with benign focal epileptic adolescent seizures were also found to all experience a subjective feeling of impending danger (Romeo, Chifari et al. 2008).

Considering 'epilepsy' as an umbrella term used for a condition which has various seizure manifestations (Petitmengin 2006). Epileptic discharges are expressed through a range of behavioural symptoms including hallucinations, sudden emotional outbursts, and other psychopathology (Griffiths 1990). [1] Epileptic seizure behaviour can be seen as a stereotyped response to 'unconditional neural stimuli', usually being 'self limited', lasting less than five minutes (Baxendale 2006)(p174) and common to any class of person. Involving altered brain states, epilepsy can be a difficult condition to deal with as both patients and lay and professional carers try and make sense of its manifestations (Cregeen 1996). Because there are so many different forms of epilepsy the condition not similarly experienced by everyone (Faircloth 1998).

1.1 A historical view of epilepsy

Epileptic seizures have a historical association with religion and spirit possession (Carrazana, DeToledo et al. 1999). People with epilepsy have themselves used terminology such as their epilepsy being an unclean spirit, evil, a craziness or mental illness (Schneider and Conrad 1981)(p217). Studies examining social attitudes towards epilepsy globally uncovered generalisations and beliefs about the condition including epilepsy being a punishment for sinning, involving possession or bewitchment, connotations of contagion persist and that it is a brain disease (Andermann 2000).

Teenagers have been found to perceive epilepsy as more stigmatising a condition than, asthma, diabetes, arthritis, migraine, leukaemia and even HIV. The only condition considered worse being Down's syndrome. Some adolescents believing that epilepsy can be 'caught' by bystanders, causes mental handicap and can lead to death (Tsuchie, Guerreiro et al. 2006) not altogether unfounded beliefs**.**

Euphemisms such as, 'the falling illness' or 'falling sickness' were created to describe the condition, as the term 'epilepsy' was often taboo (Lebrun 1992). Terms

[1] Also please refer to the Information Paper on Epilepsy and Treatments on the Cerebra website which explains the mechanisms of epilepsy (14 June 2009)

related to le mal (the disease) grand mal and petit mal seizures are still used by lay and professional people (ibid). The word seizure remains common parlance in lay and neurological settings as does ictus (for seizure, meaning a blow or a stroke) persisting in medical literature describing the temporality of seizures (Baxendale 2006).

Epilepsy is not a condition which a person can take personal responsibility for having (Galvin 2002). Ancient English law has only been recently reviewed in terms of the ramifications caused should people with epilepsy commit a crime as they come out of a seizure, but which they do not remember committing. The philosophical arguments about identity, autonomy and responsibility are relevant here. That is, whether there is a deficit in a person's ontology following a seizure which can absolve a person from being culpable, the brain overriding existing behavioural patterns (Dekkers and van Domburg 2000). In 1992, following the enactment of the 1991 Insanity and Unfitness to plead act, judges could exercise more control over what happened to such people, many sentenced to community work rather than imprisonment (Reuber and Mackay 2008ii).

1.2 Definitions of epilepsy

> 'A sudden, involuntary, time-limited alteration in behaviour, motor activity, autonomic function, consciousness, or sensation, accompanied by an abnormal electro-graphic pattern (EEG).' (Thompson, Osorio et al. 2005)(p71). [2]

In view of the increasing understanding of the 'pathophysiological and anatomic substrates of epileptic seizures and disorders' resulting in new descriptions of epileptic syndromes, classifying the epilepsies is a continuing, evolving process undertaken by the International League Against Epilepsy (ILAE) (Engel 2001)(p316). Epileptic seizures previously unnoticed for example, are also now being detected and assessed for their frequency and gravity following the introduction of the night video in 2006 (Tourniaire 2007). Discussions amongst epileptologists worldwide are therefore continually contributing to updating knowledge gained about epilepsy in the last decade. Another recent definition of epilepsy covers not only the anatomical and physiological aspects, but also takes into account that epilepsy is an evolving condition and that people can move from one syndrome to another and which acknowledges the level of handicap associated with the condition:

> Epilepsy is a disorder of the brain characterised by an enduring, predisposition to generate epileptic seizures and by the neurologic, cognitive, psychological and social consequences of this condition (ILEA 2005).

1.3 Classification

'Loss of consciousness' and 'impairment of consciousness are the criteria used to diagnoses and classify seizure types, for example, impaired consciousness is

[2] This definition of epileptic seizures precludes seizures which are nonepileptic and which children can also exhibit.

implied complex partial seizures (Johanson, Revonsuo et al. 2003)(p280). Thus the two major categories of epilepsy are partial and generalised. Partial (focal) seizures begin in a local area of the brain and are divided into simple partial seizures (where there is no alteration in consciousness) and complex partial seizures (where there is alteration of consciousness) Generalised epilepsy involves the whole of the brain simultaneously and includes seizure types of, absence, myoclonic, tonic-clonic, atonic, tonic and clonic symptoms (see box 1). Generalised epilepsy can also be categorised as partial with 'secondary generalisation' if there is evidence of a 'antecedent symptom (an aura)' with the patient can describe or where there is EEG evidence of this (Banerjee 2009)(p33).

The main attributes of epilepsy are usually recognisable by the attributes of each, see box 1 below for a formulation of these (Baxendale 2006). There are also specific epilepsy types which occur in children and these are described in box 2 below.

Box 1

Names and descriptions of different epileptic seizures

(Adapted from Baxendale 2006, unless otherwise referenced)

Seizure type	Attributes
Partial (focal or local) seizures	Both clinical and EEG measured changes show a 'disruption of a system of neurons limited to one cerebral hemisphere' and sub divided into simple partial seizures (SPS) and complex partial seizures (CPS). Both can spread from one brain area to another (EpilepsyAction 2005).
Simple partial seizures (SPS)	Consciousness is not impaired and, depending on the brain area affected, the subjective experience varies. Involuntary movements can occur, people can experience unusual tastes, smells or epigastric feelings, they can experience déjà vu, jamais vu (feelings of unfamiliarity) and feelings of intense ecstasy, anger or fear. SPS can act as warnings (auras) for the onset of a complex partial or generalised seizure.
Complex partial seizures	Consciousness is impaired, depending on which part of the brain is affected. There can be either no symptoms or, dramatic ones such as 'shouting or posturing'. People are in danger of not responding to traffic, they are not affected by water or heat and may not respond to pain. They will not remember what happened to them during their seizure. These seizures are associated with the temporal lobe and can consist of staring, unresponsiveness and mouth and limb movements for about 1-2 minutes (Blumenfeld 2005).

Generalised seizures	Consciousness is not always impaired (Blumenfeld 2005) Generalised seizures can be convulsive or non convulsive, involve both brain hemispheres and can comprise of absences, (staring, blinking) myocolonic, (short, jerking movements of body parts), Tonic-clonic /Grand Mal seizure (going stiff, falling and convulsing), (Blumenfeld 2005). Tonic (going stiff, falling but without convulsions) and Atonic (flopping to the ground) (EpilepsyAction 2005) and which can leave them tired and aching.
Unclassified seizures	Those which cannot be classified because there is not enough clinical or other information and do not fit easily with any of the ones described above.
Status epilepticus	When a seizure does not stop. This can be fatal in 8 - 10 % of cases and can cause permanent brain damage if a seizure lasts longer than 30 minutes. Urgent medical help should be sought if a seizure does not cease after 10 minutes. This applies to both adults and is more serious for children (see box 2).

1.4 Incidence and prevalence

Incidence (new cases) and prevalence figures (cases in a population) vary and need to be interpreted in the context of study methods and other factors such as culture and social and economic factors affect epilepsy (see section 1.7), its presentation and its care (Banerjee 2009). Epilepsy affects, at any one time, 50 million people worldwide (ibid). In the UK, approximately 30,000 new cases per year are diagnosed (Duncan 2004) equating to almost 1% of this population (Elwyn, Todd et al. 2003).

The incidence in developed countries is highest in the first year of life being 150 per 100,000 falling to 45-50 per 100,000 after the age of nine years (Guerinni 2006) and lowest during adult life, increasing again after the age of 70 (Stefan, Halász et al. 2001). There is a general trend towards an increase in prevalence in adolescents and young adults especially in developing countries (Banerjee, 2008). Annual incidence can be between 24/100,000 and 48/100,000 rising to 62 per 100,000 in populations of aged 65 and over in industrialised countries. This is, in part due to the increasing long term survival of this age group (Abubakr and Wambacq 2005). There appears to be more males with epilepsy than females (Kotsopoulos de Krom., Kessels et al. 2005) although, as alluded to above, cultural stigma can affect these figures. A study undertaken in India (where women are considered 'unmarriageable' if they have epilepsy) showed male prevalence to be significantly higher than female recorded cases because female cases may have been concealed (Banerjee, 2009).

1.5 Epidemiology of epilepsy

70% of people diagnosed with epilepsy are seizure free within five years of onset of treatment and only 20% of people who have experienced a long remission of 2-5

years will relapse. However, only 1% of people with medically intractable epilepsy become completely seizure free (Stefan, Halász et al. 2001). Thus, although the percentages quoted from such studies are positive in terms of advances in pharmacological treatment, between 30% and 40% of people with epilepsy continue to experience seizures and require services for complex epilepsy (Rajpura and Sethi 2004).

People with epilepsy have an increased risk of premature death two to three times greater than the general population (Hargreaves 2002). Most of these deaths are directly related to the epilepsy with around 1000 people in the UK dying each year (NICE 2004) [3] Half of these deaths are sudden unexpected deaths (SUDEP) and mostly occur at home. 59% of childhood deaths and 39% of adult ones are, potentially avoidable. Suicide accounts for 7-22% of deaths in epilepsy, people with epilepsy being five to ten times more likely than the general population to commit suicide. In people with temporal lobe epilepsy this is 25 times more likely (Moore and Baker 2002).

1.6 Treatment

Guidelines for the care of children and adults with epilepsy state that epilepsy care should be delivered across different professionals with access to treatments and interventions which are based on the best available evidence - both medical and psychosocial. Care plans should be agreed between patients, carers, primary and secondary care (NICE 2004). Specialist epilepsy nurses are advocated as being part of the integral care of all people with epilepsy, as in the general practitioner who should review a patient periodically (Goodman 2008).

The aim of all treatments is to limit seizure occurrence, adverse events and to manage and treat any co-morbid conditions**.** First line treatment for epilepsy is anti-epileptic drug (AED) therapy and sometimes surgery (Ryvlin 2003) with nearly 60% of patients gaining seizure control through with these (Jacobs 2009) depending upon how many seizures a person has, their type and syndrome (Stefan, Halász et al. 2001). Some are controlled by one single (AED), others need to try several AEDs before achieving success with some people needing to take two concurrent medications. Of the 70% of people becoming seizure free within 5 years after beginning treatment, 20% of these will experience subsequent relapses (Taylor 2000). Monotherapy is advocated for children and 70% of them control their seizures with one AED, some of the newer ones being specifically licensed for paediatric use (Ackers 2006).

Cognitive Behavioural Therapy can help with strategies to reduce seizure frequency, to lessen the impact of epilepsy on daily life (Goldstein, McAlpine et al. 2003) and for stress and seizure management. Biofeedback can help with depression and patient locus of control (Uhlmann and Froscher 2001).

There are risks and benefits associated with epilepsy surgery (Brodie and Kwan 2002). By alleviating seizure occurrence this can benefit individuals in terms of employment prospects for example, although long term psychosocial outlooks are

[3] More than those dying of Aids each year

not affected (Benifla, Rutka et al. 2008). Temporal lobe epilepsy (TLE) particularly, is associated with cognitive decline (Lagae 2006) and 70% of patients with TLE will become seizure free following surgery thus reducing associated seizure related death rates. Conversely, seizures may not be controlled and verbal memory deficits can ensue (Ryvlin 2003). A number of long term follow up studies have found that there is a decline in seizure free rates as years after surgery increase (Benifla, Rutka et al. 2008).

1.7 Causes and symptoms in epilepsy

Cryptogenic epilepsies are those with no known cause, idiopathic epilepsies have a genetic basis and generally begin in childhood (Banerjee, 2009). Symptomatic epilepsy can develop after brain insult (Banerjee, 2009) and 5% of people admitted to hospital with a non-missile head injury such as a car accident, will later develop epilepsy (Appleton, Baker et al. 1992). Socio-economic factors can play a role in the development of epilepsy, defects, infection, injury, poor nutrition, low educational achievement and poor housing can put both adults and children at risk of developing epilepsy (Banjeree, 2009).

In older people, dementia is a risk factor for epilepsy (Kotsopoulos de Krom., Kessels et al. 2005). Ageing affects how medicines work within the body and AEDs can react negatively with other medications taken potentially contributing to 'central nervous system related adverse events' in older people (Krämer 2003)(p20).

Notwithstanding sophisticated medical imaging technology, one review found that the causes of epilepsy are difficult to ascertain (Banerjee, 2009). In 70% of cases the underlying causes of epilepsy, which can include brain injuries, brain infections, brain tumours, stroke, fevers, poisoning, maternal injury (Hingley 1999) migraine and cardio vascular disease (Dekkers and van Domburg 2000) is never found. One study however, did suggest that brain tumours and cerebrovascular disease were the causes of epilepsy in 35% of cases (Kotsopoulos de Krom., Kessels et al. 2005).

1.8 Implications associated with being diagnosed with epilepsy

Close surveillance is required on the part of individuals and significant others to constantly accommodate the condition in an attempt to manage and minimise its disruptive influence and keep people physically safe (Featherstone 2004; Baxendale 2006) Being diagnosed with epilepsy seriously affects all areas of a person's life. There are many occupations closed to people with epilepsy and a diagnosis can result in financial hardship, unemployment amongst people with epilepsy being double that of people with other disabling conditions (Fastenau, Shen et al. 2008; Bawden 2009). As adults, between one third and one half of people with epilepsy experience some social maladjustment (Kanner 2003). They experience social isolation, a lack of confidence, poor locus of control and anxiety and depression (Moore and Baker 2002). The chance to drive is nearly always affected - a major concern for people with epilepsy. Loss of consciousness or altered awareness with no clinical evidence that a first seizure is epilepsy, disqualifies a person from driving for six months (DVLA 2008). DVLA regulations relating to epilepsy and seizures are very clear; a single attack whilst awake disqualifies a person from driving until they

have been seizure free for a year whereupon a three year licence will be issued if a person still has epilepsy but is seizure free. However, patients have been known to lie to their general practitioners and employers about seizure occurrence to ensure they can still drive (pc, JD, 9/8/04 & CJ, 21/9/04).

Being diagnosed with epilepsy has particular health implications for women, in terms of how seizures and AED's can affect menstruation, contraception, fertility and foetal formation (Krämer 2003; Cross 2009). AED's taken by the mother are linked to cognitive impairment, developmental delay and major malformations in babies (Jacobs 2009). These are twice as common as in mothers not taking AEDs and the relative risk of individual AEDs has not yet been ascertained although pregnancy registers are now contributing to this data (Cross 2009).

2 Co-morbidities in epilepsy

'The burden of the *illness* is experienced even when the *disease* is not severe'
(Levisohn 2002)(p489).

Some argue that seizures are only the tip of the iceberg in terms of treatment considerations (Moore and Baker 2002; Kanner 2003) and that the fear, uncertainty and unpredictability of seizures is cited by people with epilepsy as being the worst aspects of living with the condition (Fisher, Vickrey et al. 2000). Thus, although the pharmaceutical treatment of epilepsy is predominantly an attempt to manage and control seizures, psychological factors affecting behaviour need to be considered in the context of epilepsy care (Taylor 2000; Rajpura and Sethi 2004). Neurological disorders are present in around 30% of people with epilepsy as having (Baxendale 2006).

People with well-managed epilepsy have positive psychological profiles and generally do not suffer significant intellectual decline (Moore and Baker 2002). However, one review of the world literature did find relationships between seizures and adverse cognitive change in adults and adolescents with generalised tonic-clonic seizures (Dodrill 2002) and other studies have argued that epilepsy can be an ongoing process in terms of developing other conditions (Trimble 2001) and in terms of cognitive deficits (Devinsky 2003).

Epilepsy and psychiatric illness are closely linked and it has been discovered that suppressing seizures can aid in the development of severe psychopathology. (Trimble, 2001). Differing patterns of co-morbidities of depression, anxiety and cognitive impairment can occur within different epilepsy syndromes or in one single syndrome. It can be associated with the location of the epileptic focus and AEDs themselves can produce symptoms (Jacobs 2009) and can affect academic performance (Wagner, Sample et al. 2009).

2.1 Depression in epilepsy

Depression is a common psychiatric disorder in people with epilepsy. Compared to a prevalence of 8.7% in the general population,16% in people with asthma,17% in people with diabetes, it rises to 29% in people with epilepsy (Kanner 2003) and this trend is mirrored in children (Ekinci 2009).

It is vital to screen all people with epilepsy for depression as it exerts a major influence on the quality of life of people both young and old and is not necessarily associated with seizure related factors (Canuet, Ishii et al. 2009). Psychiatric disorders are now seen as integral to the phenomena of epilepsy rather than being seen as poor adaptation to a chronic condition (Ekinci 2009). It is often linked directly to seizure attacks seizure suppression medication sometimes contributing to this (Stefan and Pauli 2002) the effect being potentially cumulative (Kanner 2003). Population based studies have shown a bi-directional relationship between epilepsy and depression and there is a possibility 'that the pathophysiology that leads to depression may lower the seizure threshold as well.'(ibid)(p4). Depression in people with epilepsy can differ from those in the general population, the range of symptoms being a 'waxing and waning' course and not meeting the DSM IV criteria (Jacobs 2009)(page 442.

Implications for cognition and depression are also discussed below with the implications for children and young people and their overall everyday competency (Rantanen, Timonen et al. 2009).

3 Epilepsy in children

Epilepsy is the most commonly encountered neurologically conditions in children. Incidence in children under the age of 11 being around seven to eight cases per 1000 every year (Dulac 2005). Prevalence in childhood is estimated to be 0.05 -1% (Ekinci 2009). 10.5 million children worldwide under 15 years old have epilepsy and represent 25% of the global figure of 3.5 million people who develop the condition each year, over 80% of these children living in developing countries (Guerinni 2006). Estimated incidence rates in developing countries are between 61-124 per 100,000 and in developed countries between 41-50 per 100,000 (ibid).

Although 'epilepsy' as an umbrella diagnosis is useful, the picture for children is more complex as childhood epilepsies differ from adult epilepsy and classifying seizures accurately is crucial to their management. [4] A range of childhood epilepsy syndromes exist which do not occur in adults although some do and these can persist into adulthood (Wolf 2005). Childhood epilepsies fall into four groups in terms of prognosis, i) some are benign (for example, benign rolandic epilepsy), ii) some are sensitive to AEDs such as absence epilepsies and will go into remission in time, iii) some require life long AEDs (drug withdrawal resulting in relapse) and finally, iv) refractory epilepsies i.e., those that are resistant to AEDs and where prognosis is poor (Guerinni 2006). See box 2 below.

Box 2: Childhood epileptic syndromes and their symptoms (adapted from Dulac, 2005, unless otherwise referenced).

[4] A number of childhood epilepsy syndromes are rare and will not be mentioned here, these include Angleman's syndrome, Rasmussen's syndrome, Sturge-Weber syndrome, Angelman's syndrome with epilepsy and Ohtahara syndrome. JEC (nodate). Epilepsy syndromes of childhood and adolescent, Joint Epilepsy Council.

.

Syndrome	Manifestation	Prognosis
Status epilepticus	Affect 2-5% of children between 3 and 6 months More prevalent in children than adults, requiring urgent treatment (Nagai, Yamano et al. 2007) Seizures that last for more than 30 minutes without regaining consciousness between seizures (Neville, Chin et al. 2007).	Can be life threatening and can cause brain damage Nagai, Yamano et al. 2007)
Simple febrile convulsions	Febrile convulsions occur in 2 – 4 % of children between 6 months and 6 years of age (MacDonald, Johnson et al. 1999; Oostergard 2008). The consist of tonic clinic, generalised tonic or atonic seizures lasting less than 10 minutes and can recur (Oostergard 2008). They are usually due to a high temperature or fever caused by an infection. Simple febrile convulsions can consist of body twitching, ridigity or shaking and loss of consciousness. Children may be unresponsive, foam at the mouth, vomit or wet or soil themselves. **Complex febrile convulsions** are more serious and when they are prolonged, occur more than once in the same illness (Oostergard 2008) one side of the body twitches harder than the other and they last more than five minutes. Convulsions, therefore, should be timed.	Only 1 in 100 children who suffer febrile convulsions will later develop epilepsy (BMJ 2009). Around 1 in 11 patients presenting with epilepsy by the time they are 25 will have had febrile seizures (MacDonald, Johnson et al. 1999) Whether to treat or not is debated, treating with AEDs does not necessarily reduce subsequent epilepsy and prolonged treatment can have adverse effects (MacDonald, Johnson et al. 1999). Most febrile seizures last a few minutes, do not need medication and have an excellent outcome in terms of not developing epilepsy, declining IQ or increased mortality (Oostergard 2008) Risk factors for whether children develop epilepsy following febrile seizures are; their age, how many they have, if they are complex, their temperature at the time, any pre existing neurological abnormalities and family history. One longitudinal study found that 6% of patients developed epilepsy by the age of 13 years old which is greater than in the general population and some developed neurodevelopmental delay or abnormalities (MacDonald, Johnson et al. 1999).

Idiopathic generalised epilepsies	Generalised absence, myoclonic and tonic clonic. 30% of children and genetically determined. Not generally associated with brain pathology, neurological disorders of cognitive dysfunction (Soria, Callu et al. 2008).	Imaging not necessary Seizure control easily achieved with medication and spontaneous remission occurs after a few years. Social adjustment good although some children have behavioural/ learning difficulties (Guerinni 2006) and often have specific language impairments (Martland 2009). Depending on seizure type, cognitive impairment may vary (Mandelbaum, Burack et al. 2009)
Childhood absence epilepsy. (Petit mal) (Blumenfeld 2005)	12% of childhood epilepsy. Onset between 5 & 7 years. Genetic background. Very frequent seizures, up to 100's per day.	This disappears before adulthood in 90% of cases. If absences persist, tonic clonic seizures may follow (Guerinni 2006) Consciousness is impaired, children will stare and be unresponsive for around ten seconds. There does not appear to be immediate deficits but 'missed 'time' of frequent seizures can impair educational achievement (Blumenfeld 2005)
Juvenile absence epilepsy	10 – 12 years old overlapping with juvenile myoclonic epilepsy. Absence seizures cluster when child awakes. Generalised tonic clonic seizures can also occur. Can be precipitated by sleep deprivation.	Long term prognosis is not clear (Guerinni 2006)
Temporal lobe epilepsy	'Chronic and unremitting' (Hermann, Seidenberg et al. 2002)(p429)	Onset in childhood is significantly associated with a reduction in brain tissue and subsequent reduced intellectual and memory capacity (Hermann, Seidenberg et al. 2002) with evidence of added distress in adult hood (Moore and Baker 2002)
Infantile spasms/West syndrome	Brief axial contractions lasting longer than myoclonic jerks and repeated in clusters every 5 - 15 seconds.	When seizures occur with major paroxysmal activity and psychomotor delay, this constitutes West syndrome.
Rett syndrome	Affects girls only and not	No specific diagnostic tests so may

(JEC nodate)	usually more than one in a family. Usually begins between 6 and 30 months old. Epilepsy occurs in 70% of cases with various types of seizures.	not be diagnosed until 3 – 5 years of age. Controlling seizures is difficult. Seizures may lessen in adolescence and adulthood. Complete lifetime care is needed and lifespan is limited to early and middle adulthood
Lennox-Gastaut syndrome (LGS)	Associated with tonic, atypical absence (blank spells), & atonic (drop) attacks (Guerinni and Parmeggiani 2006) and cognitive deterioration. This syndrome usually appears either in children with a history of West syndrome or focal epilepsy. Onset peaks between 3 – 5 years of age and can account for 4% of childhood epilepsies (Gallop, Wild et al. 2009).	Major physical input on child and family with frequent seizures and seizure related injuries. AEDs do not control the seizures and they can continue into adulthood. LGS can halt a child's intellectual and social development and this impacts of the quality of life of the child and their family (Gallop, Wild et al. 2009)
Myoclonic astatic epilepsy	Usually presents in children between the ages of 2 and 5. Characterised by tonic-clonic and myoclonic seizures.	Drug treatment can control seizures but no spontaneous remission will occur (Guerinni 2006)
Symptomatic focal epilepsy	Affects 20% of patients	Drug treatment with no spontaneous remission (Guerinni 2006)
Dravet's syndrome		A severe disorder with medically intractable seizures and severe cognitive impairment (Jacobs et al, 2009)
Generalised epilepsy with febrile seizures	A relatively mild form of epilepsy (Jacobs et al, 2009)	Family history implicated (Abou-Khalil, Krei et al. 2007).
Benign Rolandic Epilepsy (JEC nodate)	A good outcome and a common epilepsy in children affecting 25% of children. No family history in 60% of cases. Onset is between ages 3 and 12 and can stop around puberty. Children generally do not have overall learning difficulties.	History of seizure and EEG which shows up the abnormality of the rolandic area of the brain causing the epilepsy. AEDs not always used as seizures will cease at puberty and some children only have one or two seizures. Relapse is uncommon. Sleep problems can occur as

		seizures occur during sleep.
Light sensitive epilepsy	Seizures precipitated by light. Onset around 11 years.	EEG response to flickering light

3.1 Causes of epilepsy in children

The cause of epilepsy in children can be genetic, developmental or related to an abnormality acquired early in life in association with learning difficulties and impairments (Martland 2009). In a study examining the family histories of nearly 2000 patients, it was found that there was family history in first and second degree relatives of children with febrile seizures. Family history was strongly implicated in generalised epilepsy and research has recently found a number of genetically determined partial epilepsies, and partial epilepsies are often preceded by febrile seizures (Abou-Khalil, Krei et al. 2007). Up to 60% of children having neurological disorders which are associated with, or have caused, their epilepsy (Ekinci 2009).

Precisely why age related syndromes appear is not fully understood. Specific causes of childhood epileptic syndromes range from gene mutation, inheritance, chromosomal abnormalities and malformations of the cerebral cortex which account for nearly 40% of drug resistant epilepsies. Cerebral palsy is associated with epilepsy as is hippocampal sclerosis - which occurs in 20% of children with temporal lobe epilepsy and in over half of children with refractory seizures. Epilepsy seizures can occur during an acute infection of the central nervous system (CNS) and a small number of children with CNS infections develop epilepsy. Seizures following a minor head injury will normally resolve but acute head injury can result in the occurrence of later seizures with an incidence of 9% (Guerrini, 2006). Most children are diagnosed within 2 years following EEG and other neuroimaging tests, detailed history taking from family and carers helping greatly in diagnosis (Guerinni 2006; Guerinni and Parmeggiani 2006).

Children are particularly susceptible to seizures at the time of birth because of potential trauma, infection and intra-cranial bleeds. There is also a propensity for the developing brain to have a lower seizure threshold than that of a mature brain in that there is enhanced excitatory potential for seizures in a brain which has not yet developed inhibitory networks (Holmes 2009).

3.2 Treatment and outcome for children

For children, a comprehensive care strategy means involving and consulting with children, their families/carers, primary and secondary care providers, taking into account their cultural and any other specific needs. They should have a review at least once a year by an epilepsy specialist and this will probably be more frequent (NICE 2004a). Diagnosis should be undertaken in a child centred environment and consists of EEG (electroencephalogram), neuroimaging (MRI (Magnetic resonance imaging or CT (computed tomography) and possibly blood tests to indicate whether there are other reasons for the epilepsy and to exclude other diagnoses, and neuropsychological assessment (NICE 2004a).

Good management of childhood epilepsy is vital to outcome and everyday function in terms of reducing the risk of cognitive impairment, accessing therapies for targeting attentional and behavioural difficulties with possible adjunctive drug therapy for these (Wolf 2005). Speech therapy, especially for non-idiopathic epilepsy is available as is psychomotor therapy and psychotherapy (Soria, Callu et al. 2008). All treatment depends on the epilepsy syndrome, seizure type, how severe it is and how a child responds to treatment (Wolf 2005).

Childhood surgery should be seriously considered for those whose seizures do not respond to AEDs (Soria, Callu et al. 2008) refractory seizures often leading to major neurological impairments and morbidity (Ottenberger, Byme et al. 2005). Surgery for children can not only achieve long term remission but it can also be of benefit in terms of reducing the effects AEDs have on learning and, therefore, their educational achievement (Martland 2009). One study following 42 children for 20 years following surgery for temporal lobe epilepsy found that 67% were seizure free at 20 years follow up - although there was a decline in seizure free rates over time depending on the clinical profiles of patients i.e., this did not necessarily remain a stable state (Benifla, Rutka et al. 2008). This outcome, however, has to be weighed against the social benefits patients gained later in terms of their education and subsequent employment (Soria, Callu et al. 2008). Careful assessment with additional FDG PET scans are useful in complex cases however, in that they provide additional information to other methods and can also result in children being excluded from surgical interventions which would not benefit them (Ottenberger, Byme et al. 2005).

The predominance of research into Anti Epileptic Drugs (AEDs) for adults can result in problems for children. Age related side effects are not identified, some are enhanced in children and worsening some epileptic syndromes, although more recent AEDs cause less side effects and have less potential for adverse reactions with other medication (Ackers 2006). Drugs that may be useful for specific childhood epilepsies are not identified and children may be exposed to AEDs which are not of use to them (Dulac 2005). AEDs not only can significantly affect cognitive function but can also increase aggression and hyperactivity (Wagner, Sample et al. 2009). Clinical trials specifically for children are advocated when new drugs are being developed. Low dose monotherapy is advocated initially to test out seizure control and minimise side effects and this is achieved in nearly 75% of children (Dulac 2005). That is, most children respond well to AEDs (Holmes 2009**.** However, despite an improved classification system and pharmacological advances, a quarter of children with epilepsy do remain resistant to AEDs (Dulac 2005). Compliance to medication can be an issue with young people with epilepsy, to an extent depending on family support and circumstances. Adolescents have been found to adhere to medical regimens as this reduces seizure occurrence and are also more compliant with a once daily regiment against one which necessitates taking tablets several times a day (Asadi-Pooya 2005).

In terms of outcome, 64% of people who have childhood seizures will be in remission as adults with only 16% of them being on medication, depending on the epilepsy syndrome (Guerrini 2006). Children experiencing an initial seizure are at risk of reoccurring seizures, especially if their EEG is abnormal, if they have a seizure whilst asleep and if they have a history of febrile seizures (ibid).

For children, that epilepsy is still stigmatised (Wagner, Sample et al. 2009) can cause low self esteem compared to children with other chronic conditions such as asthma or diabetes (Soria, Callu et al. 2008). It can trigger mental health problems and reduce their quality of life (Vona, Siddarth et al. 2009). Epilepsy, with its acute and very visible manifestations gives a difficult context in which to exist for a child (Soria, Callu et al. 2008). Children with epilepsy have to cope with unpredictable seizures which take away their control over their 'body and mind'. This can result in uncertainty and vulnerability, marginalisation from peers, possible stigma (Verhey, Kulik et al. 2009)(p410) and potential bullying (Hamiwka, Yu et al. 2009).

3.3 Cognitive and behavioural difficulties in children

Many epilepsies directly impact on a child's brain and, therefore, on their cognitive development, language and social skills (Martland 2009). Cognition in epilepsy is complex because problems may be intrinsic to the epilepsy itself and its underling neuropathology, seizures can affect cognition as can interictal EEG activity, psychosocial and family problems. Also, although AEDs can suppress/decrease seizures by suppressing epileptiform discharges, the way in which they do this can also interfere with cognitive functioning (Mandelbaum, Burack et al. 2009). Children with symptomatic epilepsy can suffer more from neurological disorders underlying the epilepsy and which can affect cognition, attention, mood and behaviour. Even in children with idiopathic epilepsy, the different seizure types carry with them the possibility of different levels of various impairments in cognitive abilities (Mandelbaum, Burack et al. 2009), parents reporting learning difficulties and memory problems even in this benign epilepsy with obvious implications for day to day functioning (Soria, Callu et al. 2008). The onset of childhood temporal lobe epilepsy can be particularly detrimental to ongoing cognition (Hermann, Seidenberg et al. 2002). In terms of life stages, there is evidence that continuing seizures can result in reducing the mental abilities of developing children and adolescents, AEDs contributing to this loss (Dodrill 2002).

One Dutch study underwent a detailed examination of when educational and psychosocial deprivation begins in children newly diagnosed with epilepsy. It found that early on, children need special assistance at school. However, the cognitive and behavioural difficulties experienced were not only due to the epilepsy. Rather, other contextual factors affected this, major factors being if children perceived their condition as provoking more shame than other conditions and the negative emotions and anxious reactions of parents to their child's epilepsy can affect their academic skills, learning and attention and how they adapt to their condition (Oostrom, Smeets-Schouten et al. 2003; Jacobs 2009)**.**

Children with epilepsy have higher rates of ADHD, learning disorders and behavioural problems, disruptive behaviour and aggression for example (Fastenau, Shen et al. 2008; Jacobs 2009). Cognitive difficulties in children arise from a variety of factors, the main explanatory ones being a combination of the underlying brain dysfunction with the epilepsy syndrome and age of onset. Refractory epilepsies can result in higher rates of cognitive decline than well controlled epilepsies (Lagae 2006). Seizure occurrence can result in negative psychological reactions from children in terms of disruptive behaviours whereas even very young children with

well controlled seizures compare favourably with their peers in many domains, including social skills and attention although behavioural issues can remain (Rantanen, Timonen et al. 2009).

These may not necessarily be part of their epilepsy, however, in an exploration of the past histories of newly diagnosed children, higher than normal rates of learning disorders and behavioural problems were found to be present before diagnosis. Longitudinal studies are imperative in terms of the trajectories of childhood epilepsy as there is evidence that brain areas can function well at one time point in a child's life but under-function at another (Jacobs 2009) which has implications for treatment and therapeutic interventions.

3.4 Depression in children

For children and adolescents with epilepsy there is an element of grief in their life as their expectations of their life may not be fulfilled (Wagner, Sample et al. 2009). This can cause high risks of depression and anxiety and these conditions need addressing as they can affect quality of life and carry life threatening risks such as attempted suicide (Ekinci 2009). Children should be screened for these disorders as they can go undetected (Fastenau, Shen et al. 2008)

3.5 Sleep problems in epilepsy

Epilepsy affects sleep and sleep problems and tiredness are reported frequently by parents of children with epilepsy, particularly in non idiopathic epilepsy (Soria, Callu et al. 2008). Seizures can delay sleep, lead to awakenings during the night, disrupt quality of sleep and decrease total sleep time (Soria, Callu et al. 2008; Modi 2009) and lead to memory problems, for example, to the consolidation of recently learned materials) (Soria, Callu et al. 2008).

Young people with epilepsy have reported feeling tired, the need for more sleep interfering with the participation of social pursuits (Wagner, Sample et al. 2009). Children with Juvenile myoclonic epilepsy often have seizures on awakening and benign rolandic and mesial frontal seizures often occur during sleep. A combination of AEDs and seizures can produce excessive day time sleepiness. This in turn, affects parents and families, behavioural treatment can be effective and can significantly improve how stressed mothers, in particular, feel, how it affects their perceived control and their ability to cope with the child's sleep issues (Dorriss, Scott et al. 2008). Parents also suffer from sleep deprivation as they regularly wake to check on their children during the night (Modi 2009).

3.6 Quality of life for children and adolescents with epilepsy, their parents and siblings

In addition to the 'normal' influences of demographics, cultural, cognitive and behavioural factors in their development, children and adolescent with epilepsy can experience social incompetence at school, with their peers and in other relationships, in sport and in obtaining part time jobs One study found that girls experienced lower social competence than boys. The reduced social competence could be due to several factors, the severity of the epilepsy, subtle cognitive defects, subclinical

behavioural disorders, over protection from their family and fear of seizures (which can be transmitted by parental anxiety and negative attitudes towards epilepsy) (Jakovljević and Žarko 2006).

Adolescence is a time when major biological changes take place and children develop their own identities. Any difficulties with this can affect quality of life, that is, as evaluated by an individual in terms of their personal expectations and this is the criteria by which it should be measured. Any shortfall in expectations can result in low self-esteem, depression, loneliness, anxiety and behavioural problems. Epilepsy impacts on this process, especially in terms of autonomy and developing independence, major risk factors being, 'active' epilepsy, greater seizure severity, higher numbers of medications, having epilepsy for a long time and co-morbid learning difficulties (ibid). (Mcewan, Espie et al. 2004).

One study examining their quality of life with adolescents in focus groups (rather than relying on parental and clinician's assessment of this) highlighted two major themes. One related to identify formation, the other to epilepsy related variables (Mcewan, Espie et al. 2004). Psychosocial development was a major theme especially in relation to developing a personal identity with issues of peer acceptance, development of autonomy from parental restrictions, school related issues, what the future held for them in terms of independent living (for girls this involved thoughts about contraception and pregnancy) and epilepsy as being an integral part of their personal identity be it positive or negative. Closely related were epilepsy related issues such as complying with medication, being under constant surveillance from parents, fears relating to seizure occurrence, their knowledge of their epilepsy and the overall sense of uncertainty having epilepsy brings to life (Mcewan, Espie et al. 2004).

3.7 Parental stress and its effects of children

In addition to the medical issues involved in having epilepsy, the family play a big part in how children function psychologically (Sbarra, Rimm-Kaufman et al. 2002). A diagnosis of epilepsy brings with it the risk of family stress and a risk of psychological effects to all (Chiou and Hsieh 2008; Holmes 2009). This is particularly salient in parents of newly diagnosed children (Modi 2009). Given the physical, cognitive, behavioural and psychosocial correlates in children with epilepsy, and that this can affect their social integration and educational achievement, it is becoming increasingly important to assess their quality of life and that of their families. Mothers in particular report difficulties with the impact on their lives of their child's condition (Soria, Callu et al. 2008). Quality of life does not always correlate with the type of epilepsy syndrome, more complex factors being at play (Verhey, Kulik et al. 2009).

That is, the family can act as a buffer or stressor for all children and for those with epilepsy the stress a parent feels can affect the way they behave towards their child and the psychological impact upon the child's adaptation to their condition and thus, the child's self concept (Chiou and Hsieh 2008; Modi 2009). Parents may be anxious about their child's diagnosis (Modi 2009; Rantanen, Timonen et al. 2009; Wagner, Sample et al. 2009) seeing them as different to other children. Parents can encourage dependence on them so that children do not develop their own

competencies as parents can overprotect children (Wagner, 2009) at times being overly intrusive (Mcewan, Espie et al. 2004; Chiou and Hsieh 2008).

Epilepsy is unpredictable, seizures can impact on family activities increasing the responsibilities of the parents adversely affecting the amount of time they can spend with other children (Chiou and Hsieh 2008; Modi 2009) and sibling children do recognise this deficit in attention towards them (Tsuchie, Guerreiro et al. 2006). Parents recognise that siblings of children with epilepsy are affected as they can experience restrictions in family activities, and the effect of their sibling's condition can cause them stress, anxiety, behavioural and emotional problems. They can also feel responsible for their sibling with epilepsy, abdicating from their own activities to protect them and care for them during a seizure. Some children voiced being 'scared' or 'sad' about their siblings' predicament and that they were different from their peers, especially in cases of developmental delay (Tsuchie, Guerreiro et al. 2006).

It has been found that parental stress is linked to behavioural problems in children with chronic conditions, and, as alluded to above, is often unrelated to how severe the condition is or how old they were at onset (Chiou and Hsieh 2008). One study compared the stress of parents of children with asthma and epilepsy (both characterised by unpredictable episodes and alarming symptoms). This highlighted that children with epilepsy had a higher rate of behavioural problems, lower self esteem and more negative attitudes towards their condition. This affects, in turn, their attitudes towards their treatment and psychological adjustment to their condition and their cognitive development (Chiou and Hsieh 2008).

4 Support for children with epilepsy

Everyday handicap for children with epilepsy is profound especially for those with complicated epilepsy and they should be screened for depression and psychosocial impact upon diagnosis. It is important to note if problems pre-dated the epilepsy, if AEDs precipitated it or if these are due to the epilepsy itself. Children need assistance with personal hygiene and other activities such as tidying their rooms (Sillanpää and Cross 2009). In the UK epilepsy care for children is mainly in hospitals with paediatricians some with a special interest in epilepsy and recent NICE guidelines have recommended that children with epilepsy should be managed by paediatricians with expertise in epilepsy as they are in conditions such as diabetes or cystic fibrosis (NICE 2004; Mar, Dunkley et al. 2005). This condition specific model being applied to children with other conditions, for example asthma, diabetes and other neurodevelopmental disorders (Mar, Dunkley et al. 2005).

One retrospective study compared the pros and cons of initial epilepsy care in terms of clinically important information being recorded for 44 children given in a General Paediatric clinic to that given in seizure clinics. Less children were diagnosed with epilepsy in the seizure clinic and the type of epilepsy was more likely to be defined. Care given in seizure clinics, being staffed by people knowledgeable about epilepsy was advantageous to the children in that urgent assessments could be given and children were attended to quickly and efficiently and neurological development was recorded (Mar, Dunkley et al. 2005).

On the other hand, attending a specific clinic could be seen as stigmatising with the staff only seeing this element of the whole child and could, potentially, reduce the expertise in epilepsy in general paediatric clinics (Mar, Dunkley et al. 2005). An Italian study undertaken in a seizure clinic however, found that, given the opportunity, children will talk about their private seizures experiences to someone they trust, younger children entering into a play situation and adolescents talking about existential aspects of having epilepsy to older, more experienced doctors (Galletti, Rinna et al. 1998).

Services for children with epilepsy have been historically, under the umbrella of 'general paediatrics'. There has been high rates of misdiagnosis and lack of access to specialist services. The NICE guidelines mentioned above and others (SIGN 2005) may be difficult to implement however given the lack of national expertise in the area (Martland 2009)(pS51). According to the British Epilepsy Association, in 1999, there were only 60 adult and 40 children specialist epilepsy clinics in the UK (Taylor 2000) and there remains insufficient numbers of epilepsy nurses, psychologists, psychiatrists and allied health professionals specialising in epilepsy (Martland 2009). Children with epilepsy are at risk of not receiving adequate mental health assessment and care because psychological and psychiatric symptoms can be missed (Wagner, Sample et al. 2009).

Adolescents, in particular, form a vulnerable group that need support as they have the task of the transition from child to adult services, no longer being under the official watchful eye of their parents (Smith, Myson et al. 2002). Establishing a good one to one relationship with their doctor can be beneficial for them and an investment for their future care (Galletti, Rinna et al. 1998) and in terms of doctors learning what the clinical needs of this patient group are (Smith, Myson et al. 2002).

4.1 Children in school

Knowledge about epilepsy in school settings is scarce and educating parents and teachers goes a long way to putting in place appropriate interventions (Sillanpää and Cross 2009) in that it can alert teachers to the potential mental health needs of children (Vona, Siddarth et al. 2009). Given children spend a lot of time there, parents of children with epilepsy advocate that school is the place for education about epilepsy for both pupils and teachers (Vona, Siddarth et al. 2009; Wagner, Sample et al. 2009). In terms of the implications of having epilepsy for teachers and other school professionals, epilepsy is rated as having an impact in terms of children needing extra attention and there is concern about emergency occurrences associated legal liability issues. It is advocated that professionals receive information from people other than the child's parents about the condition (Olson, Siedler et al. 2004 ; Sillanpää and Cross 2009; Vona, Siddarth et al. 2009). Ideas from epilepsy USA to help parents include regular meetings with teachers and other staff such as school nurses, in order to discuss their children's seizures, the practicalities and implications of their occurrence in the classroom and how to respond to them, the child and other children (Frueh 2007).

Conclusions

5 From the horse's mouth. More research into the quality of life in children and young people is needed.

Much of the literature about children's epilepsy is from the perspective of the parent regarding information about seizures descriptions or effects and from objective medical methods such as EEG when talking to the child themselves can not only reveal more information about their seizure type, but also gain insight into the discomfort of having epilepsy for children and adolescents (Galletti, Rinna et al. 1998). Having epilepsy can be a challenge for children, adolescents and their families, it fundamentally alters relationships and life trajectories. More qualitative studies are needed in this area, by interviewing adolescents themselves (Mcewan, Espie et al. 2004) and siblings of children with epilepsy directly (Tsuchie, Guerreiro et al. 2006; Wagner, Sample et al. 2009) particularly in more severe epilepsies (Gallop, Wild et al. 2009). Qualitative research delves into the lived experiences of people and elucidates very different data from that of studies using quantitative measures. Existing studies have been from the perspective of the parents given the children's possible cognitive and communication difficulties and, although useful, these do not give the full picture. Perspectives and perceptions can differ greatly, for example, parents can think children are concerned for their future whereas this is not the case. Children have a wish to 'be normal' which parents are not always aware of i.e., personal experiences and feelings are private to the child whilst parents concern themselves with their child's future (Verhey, Kulik et al. 2009)(p408). Using focus group methodology to quality of life research can 'add in' elements that were not previously identified in quantitative methodological studies. Using the words of adolescents can contribute to face validity of future scales and the groups can act as a fora for expressing age related concerns such as alcohol use and pregnancy (Mcewan, Espie et al. 2004).

5.1 Developments in the medical treatment of epilepsy in children

There is evidence that the newer AEDs for children have a safer profile in terms of affecting a child's cognitive abilities, although they may affect attention and processing of information which still affect learning and cognition (Lagae 2006). Newer drug trials should address the 'cognitive safety' and other side effects on adults as this is of increasing significance in children (Lagae 2006)(p236). There is a move towards improving the regulation and research into medications for children by the European Commission with the advent of the Task Force of European Drug Development for the Young – TEDDY - and this includes AEDs for epilepsy (Ackers 2006). Many of these have been licensed for adults and this specific focus in research studies on AEDs for children is vital because they are continually developing and this affects the efficacy and safety of AEDs prescribed to them as they develop (Verdru 2005).

The first large study examining paediatric prescribing of AEDs to children in the UK found that NICE guidelines were being adhered to in that children were receiving just one medication. Newer AEDs are being given to children, some of these are particularly suitable for childhood epilepsies and in 'child friendly formulations'. However, the safety of these newer drugs needs to be established (Ackers 2006)(p695). One randomized, double-blind, placebo-controlled study (the gold

standard design) examined one new epileptic drug, Levetiracetam, and found that it was well tolerated and its adverse event profile was similar to that in adults with the result that it has been submitted for 'paediatric indication' and appears to qualify as the newest AED suitable for the treatment of refractory partial epilepsy in children (Verdru 2005).

5.2 Genetics and epilepsy research

Epileptogenesis - the transformation of brain tissue into that which is capable of generating spontaneous seizures and one which can last from minutes to years, offers the potential for exploration and potentially, the identification of associated physiological markers and factors which promote seizure-prone circuits with the potential to intervene in this process (Jacobs 2009). During the last decade and with the completion of the human genome project, the clinical features of the epilepsies and their basic mechanisms have been increasingly delineated, human epilepsy genes having been identified with the hope for a cure for epilepsy during the next decade (Jacobs 2009). Animal models are illustrating the capacity of the brain to adapt although the epileptic brain presents a challenge to being repaired given the diversities of the condition and the many complex functional and structural aetiologies, the main task being to counteract the epileptogenesis process (Kokaia 2009). Uncovering these mechanisms can assist in the development of drugs to prevent epilepsy rather than just managing the condition (Spinney 2004).

Conclusion

Genetics, hormones, gender and psychological states all modulate how epilepsy develops and how severe it is. Cognitive, emotional and behavioural co-morbidities of epilepsy are also worthy of study. Once viewed as side effects of epilepsy, they are now seen as possibly preceding seizures and thus may not resolve even if seizure control is good. Notwithstanding this, they need to be ameliorated but are under-researched and not fully understood (Jacobs 2009).

Overall, given the burden of epilepsy for sufferers and their carers, increased funding in all areas of epilepsy research, treatment and care can promise to improve their lives and prognoses.

References

Abou-Khalil, B., W, L. Krei, et al. (2007). "Familial genetic predisposition, epilepsy localization and antecedent febrile seizures." Epilepsy Research **73**: 104 - 110.

Abubakr, A. and I. Wambacq (2005). "Seizures in the elderly: Video/EEG monitoring analysis." Epilepsy and Behaviour **7**(3): 447 - 450.

Ackers, R., Murray, Macey, L., Besag, Frank, M., C., & Wong, Ian, C., K. (2006). "Prioritizing children's medicines for research: a pharmacoepidemiological study of antiepileptic drugs." British Journal of Clinical Pharmacology **63**(6): 689 - 697.

Andermann, L. F. (2000). "Epilepsy in Our World: An Ethnographic view." Epilepsy and Behaviour **1**: 169 - 175.

Appleton, R., G. Baker, et al. (1992). Epilepsy. London, Martin Dunitz.

Asadi-Pooya, A., Akbar (2005). "Drug compliance of children and adolescents with epilepsy." Seizure **14**: 393 - 395.

Banerjee, P., Nina., Filippi, David., Hauser, W., Allen. (2009). "The descriptive epidemiology of epilepsy- A review." Epilepsy Research **85**: 31 - 45.

Bawden, A. (2009). Ineffective epilepsy care costs too much. The Guardian. London. **2**.

Baxendale, S. (2006). Epilepsy: An approach to case formulation. Formulation and treatment in Clincical Health Psychology. V. Nikcevic Ana, A. Kuczmierczyk, R and M. Bruch. Hove, Routledge.

Benifla, M., J. Rutka, T, et al. (2008). "Long-term seizure and social outcomes following temporal lobe surgery for intractable epilepsy during childhood." Epilepsy Research **82**: 133 - 138.

Blumenfeld, H. (2005). "Consciousness and epilepsy: why are patients with absence seizures absent?" Progress in Brain Research **150**: 271 - 286.

BMJ (2009) Febrile convulsions. BMJ Group **Volume**, DOI: http://clinicalevidence.bmj.com/ceweb/conditions/chd/0324/febrile-seizures-standard-ce_patient_leaflet.pdf

Brodie, M. J. and P. Kwan (2002). "Staged approach to epilepsy management." Neurology **58**(Supplement 5): S2 - S8.

Canuet, L., R. Ishii, et al. (2009). "Factors associated with impaired quality of life in younger and older adults with epilepsy." Epilepsy Research **83**: 58 - 65.

Carrazana, E., J. DeToledo, et al. (1999). "Epilepsy and religious experiences: Voodoo possession." Epilepsia **40**(2): 239 - 241.

Chiou, H.-H. and L.-P. Hsieh (2008). "Comparative Study of Children's Self-Concepts and Parenting Stress between Families of Children with Epilepsy and Asthma." Journal of Nursing Research **16**(1): 65 - 73.

Cregeen, S. (1996). "Making Sense: Brain Trauma, epileptic seizures and personal meaning." Psychoanalytic Psychotherapy **10**(1): 33 - 44.

Cross, H., J (2009). "Neurodevelopmental effects of anti-epileptic drugs." Epilepsy Research **in press**.

da Silva Sousa, P., K. Lin, et al. (2005). "Self--perception of factors that precipitate or inhibit seizures in juvenile myclonic epilepsy." Seizure **14**: 340 - 346.

Dekkers, W. and P. van Domburg (2000). "The role of doctor and patient in the construction of the pseudo-epileptic attack disorder." Medicine, Health Care and Philosophy **3**: 29 - 38.

Devinsky, O. (2003). "A 48-year-old man with temporal lobe epilepsy and psychiatric illness." Jama **290**(3): 381 - 393.

Dodrill, C. (2002). "Progressive cognitive decline in adolescents and adults with epilepsy." Progress in Brain Research **135**: 399 - 407.

Dorriss, L., N. Scott, et al. (2008). "Sleep problems in children with neurological disorders." Developmental Neurorehabilitation **11**(2): 95 - 114.

Dulac, O. (2005). "Issues in paediatric epilepsy." Acta Neuroligica Scandinavica **112** (Suppl. 182): 9 - 11.

Duncan, J. S. (2004). Clinical update: Epilepsy in Adults. The Royal Society of Medicine Symposia The Royal College of General Practitioners, London

DVLA (2008). At a glance guide to the current medical standards of fitness to drive. DVLA, Driving and Vehicle Licensing Agency.

Ekinci, O., Titus, Jeffrey, B., Rodopman, Ayse, A., Berkem, Meral., & Trevathan, Edwin. (2009). "Depression and Anxiety in children and adolescents with epilepsy: Prevalence, risk factors, and treatment." Epilepsy & Behavior **14**: 8 - 18.

Elwyn, G., S. Todd, et al. (2003). "A 'real puzzle': the views of patients with epilepsy about the organisation of care " BMC Family Practice. **4**(4).

Engel, J. (2001). "Classification of Epileptic Disorders." Epilepsia **42**(3): 316.

EpilepsyAction (2005). Seizure map. Seizures Explained**:** 2.

Faircloth, C. A. (1998). "Epilepsies, Identities, and Difference: Horizons of Meaning for Individuals With an Epilepsy." Qualitative Health Research. **8**(5): 602 - 617.

Fastenau, P., S, , J. Shen, et al. (2008). "Academic Underachievement Among Children With Epilepsy: Proportion Exceeding Psychometric Criteria for Learning Disability and Associated Risk Factors." Journal of Learning Disabilities **41**(3): 195 - 208.

Featherstone, V. A. (2004). What is it like to live with epilepsy?
An exploratory phenomenological study. Psychology. London, City University.
Master of Science (Health Psychology).

Fisher, R. S., B. Vickrey, G, et al. (2000). "The impact of epilepsy from the patient's perspective 1. Descriptions and subjective perception." Epilepsy Research **41**: 39 - 51.

Frueh, E. (2007). "Seizure managemetn of School-Age Children." Epilepsy Foundation **40**: 7 - 11.

Galletti, F., A. Rinna, et al. (1998). "An insight into children's and adolescents' experience of seizures and epilepsy." Seizure **7**: 309 - 316.

Gallop, K., D. Wild, et al. (2009). "Impact of Lennox-Gastaut Syndrome (LGS) on health-related quality of life (HRQL) of patients and caregivers: Literature review." Seizure **18**: 554 - 558.

Galvin, R. (2002). "Disturbing notions of chronic illness and individual responsibility: towards a genealogy of morals." Health **6**(2): 107 - 137.

Goldstein, L. H., M. McAlpine, et al. (2003). "Cognitive behaviour therapy with adults with intractable epilepsy and psychiatric co-mobidity: preliminary observations on changes in psychological state and seizure frequency." Behaviour Research and Therapy **41**: 447 - 460.

Goodman, S. (2008). "Epilepsy: diagnosis and management." Practice Nurse **35**(1): 18 - 21.

Griffiths, J. L. (1990). "The Mind/Body Problem Revisited: Pseudoseizure Patients." Family Systems Medicine **8**(1): 71 - 89.

Guerinni, R. (2006). "Epilepsy in children." Lancet **367**: 499 - 524.

Guerinni, R. and L. Parmeggiani (2006). "Practitioner Review: Use of antiepileptic drugs in children." Journal of Child Psychology and Psychiatry **47**(2): 115 - 126.

Hamiwka, L., D, C. Yu, G, et al. (2009). "Are children with epilepsy at greater risk for bullying than their peers?" Epilepsy and Behaviour **15**: 500 - 505.

Hargreaves, S. (2002) "Shortcomings in care" to blame for avoidable epilepsy deaths. bmj.com **Volume**, 1237 DOI: doi:10.1136/bmj.324.7348.1237/b

Hermann, B. P., M. Seidenberg, et al. (2002). "The neurodevelopmental impact of childhood onset temporal lobe epilepsy on brain structures and function and the risk of progressive cognitive effects." Progress in Brain Research **135**: 429 - 438.

Hingley, A. T. (1999). "Epilepsy: taming the seizures, dispelling the myths." FDA Consumer **33**(1): 6 - 12.

Holmes, G., L (2009). "The 2008 Judith Hoyer Lecture: Epilepsy in children: Listening to mothers." Epilepsy & Behavior **16**: 193 - 202.

ILEA (2005). Epilepsia **46**(4): 470 - 472.

Jacobs, M., P., Lebland, Gabrielle, G., Brooks-Kayal, Amy, Jensen, Frances, E., Lowenstein, Dan, H., Noebels, Jeffrey, L., Spencer, Dennis, D., & Swann, John, W. (2009). "Curing epilepsy: Progress and future directions." Epilepsy & Behavior **14**: 438 - 445.

Jakovljević, V. and M. Žarko (2006). "Social competence of children and adolescents with epilepsy." Seizure **15**: 528 - 532.

JEC (nodate). Epilepsy syndromes of childhood and adolescent, Joint Epilepsy Council.

Johanson, M., A. Revonsuo, et al. (2003). "Level and contents of consciousness in connection with partial epileptic seizures." Epilepsy and Behaviour **4**: 279 - 285.

Kanner, A. M. (2003). "The Complex Epilepsy Patient: Intricacies of Assessment and Treatment." Epilepsia **44**(Supplement 5): 3 - 8.

Kokaia, M. (2009). "Novel perspectives in treatment of epilepsy." Epilepsy Research **85**: 129 - 130.

Kotsopoulos de Krom., M., F. Kessels, et al. (2005). " Incidence of epilepsy and predictive factors of epileptic and non-epileptic seizures." Seizure **14**: 175 - 182.

Krämer, G. (2003). "Broadening the Perspective: Treating the Whole Patient." Epilepsia **44**(Supplement 5): 16 - 22.

Lagae, L. (2006). "Cognitive side effects of anit-epileptic drugs. The relevance in childhood epilepsy." Seizure **15**: 235 - 241.

Lebrun, Y. (1992). "The language of epilepsy." Seizure **1**: 207 - 212.

Levisohn, P. M. (2002). "Understanding Stigma." Epilepsy and Behaviour **3**: 489 - 490.

MacDonald, B., K, A. Johnson, L, et al. (1999). "Febrile Convulsions in 220 Children - Neurological Sequelae at 12 years Follow up." European Neurology **41**: 179 - 186.

Mandelbaum, D., E, G. Burack, D, et al. (2009). "Impact of antiepileptic drugs on cognition, behaviour, and motor skills in children with new-onset, idiopathic epilepsy." Epilepsy & Behavior **16**: 341 - 344.

Mar, S., C. Dunkley, et al. (2005). "Comparison of a dedicated children's Seizure Clinic to mixed General Paediatric Clinics." Child: Care, Health and Development **31**(5): 597 - 602.

Martland, T. C., Helen, J., (2009). "Best clinical and research practice in pediatric neurology." Epilepsy & Behavior **15**: 551 - 554.

Mcewan, M., J, C. Espie, A, et al. (2004). "Quality of life and psychosocial development in adolescents with epilepsy: a qualitative investigation using focus group methods." Seizure **13**: 15 - 31.

Modi, A., C (2009). "The impact of a new pediatric epilepsy diagnosis on parents: Parenting stress and activity patterns." Epilepsy and behaviour **14**: 237 - 242.

Moore, P. M. and G. A. Baker (2002). "The neuropsychological and emotional consequences of living with intractable temporal lobe epilepsy: implications for clinical management." Seizure **11**: 224 - 230.

Nagai, T., T. Yamano, et al. (2007) Status epilepticus in infants and young children: Basic mechanisms, clinical evaluation, prognosis and treatment. Acta Neuroligica Scandinavica **Volume**, 5 DOI:

Neville, B., G, R, R. Chin, F, M, et al. (2007). "Childhood convulsive status epilepticus: epidemiology, managment and outcome." Acta Neuroligica Scandinavica **115**: 21 - 24.

NICE (2004). Guideline to improve care for children and adults with epilepsy: Press release. NHS.

NICE (2004a). The epilepsies: diagnosis and managment of the epilepsies in children and young people in primary and secondary care, National Institute for Clinical Excellence. **Clinical Guideline 20**.

Olson, A., L, A. Siedler, B, et al. (2004). "School professionals' perceptions about the impact of chronic illness in the classroon." Archives of Pediatrics and Adolescent Medicine **158**(1): 53.

Oostergard, J., R (2008). "Febrile seizures." Acta Pediatrica **98**(5): 771 - 773.

Oostrom, K., J, A. Smeets-Schouten, et al. (2003). "Not Only a Matter of Epilepsy: Early Problems of Cognition and Behaviour in Children With "Epilepsy only" - A Prospective Longitudinal, Controlled Study Starting at Diagnosis." Pediatrics **112**(6): 1338 - 1344.

Ottenberger, G., P, A. Byme, J, et al. (2005). "Assessment of the role of FDG PET in the diagnosis and management of children with refractory epilepsy." European Journal of Nuclear Medicine and Molecular Imaging **32**(11): 1311 - 1316.

Petitmengin, C. (2006). "Describing one's subjective experience in the second person: An interview method for the science of consciousness." Phemom Cogn Sci **5**.

Rajpura, A. and S. Sethi (2004). "Evidence-based standards of care for adults with epilepsy-a literature review." Seizure **13**: 45 - 54.

Rantanen, K., S. Timonen, et al. (2009). "Social competence of preschool children with epilepsy." Epilepsy and behaviour **14**: 338 - 343.

Reuber, M. and R. Mackay (2008ii). "Epileptic automatisms in the criminal courts: 13 cases tried in England and Wales between 1975 and 2001." Epilepsia **49**(1): 138 - 145.

Romeo, A., R. Chifari, et al. (2008). "Ictal impending danger - "sixth sense seizures" - in patients with benign focal epileptic seizures of adolescence." Epilepsy Research **79**: 90 - 96.

Ryvlin, P. (2003). "Beyond Pharmacotherapy: Surgical Management." Epilepsia **44**(Supplement 5): 23 - 28.

Sbarra, D., A, S. Rimm-Kaufman, E, et al. (2002). "The behavioural and emotional correlates of epilepsy in adolescence: a 7-year follow up study." Epilepsy & Behavior **3**: 358 - 367.

Schneider, J. W. and P. Conrad (1981). "Medical and sociological typologies: the case of epilepsy." Social Science and Medicine. **15A**: 211 - 219.

SIGN (2005). Diagnosis and management of epilepsies in children and young people: National clinical guideline number 81. I. Scottish, Guidelines, Network. Edinburgh.

Sillanpää, M. and H. Cross, J (2009). "The psychological impact of epilepsy in childhood." Epilepsy & Behavior **15**: S5 - S10.

Smith, P., E, M, V. Myson, et al. (2002). "A teenager epilepsy clinic: observational study." European Journal of Neurology **9**: 373 - 376.

Soria, C., D. Callu, et al. (2008). "Parental report of cognitive difficulties, quality of lie and rehabilitaiton in children with epilepsy or treated for brain tumour." Developmental Neurorehabilitation **11**(4): 268 - 275.

Spinney, L. (2004). "New Models for Epileptogenesis." The Scientist **November 22**: 16 - 17.

Stefan, H., P. Halász, et al. (2001). "Recent advances in the diagnosis and treatment of epilepsy." European Journal of Neurology **8**: 519 - 539.

Stefan, H. and E. Pauli (2002). "Progressive cognitive decline in epilepsy: an indication of ongoing plasticity." Progress in Brain Research **135**: 409 - 417.

Taylor, M. P. (2000). Managing Epilepsy. A Clinical Handbook. Oxford., Blackwell Publishing.

Thompson, N., C, I. Osorio, et al. (2005). "Nonepileptic Seizures: Reframing the Diagnosis." Perspectives in Psychiatric Care **41**(2): 71 - 78.

Tourniaire, D. (2007). "L'Anniversaire des 150 ans de la Teppe." Épilepsies **19**(2).

Trimble, M. R. (2001). "Psychiatric Issues in Epilepsy: A practical Guide to Diagnosis and Treatment." The New England Journal of Medicine **345**(24): 1783 - 5.

Tsuchie, S., Y, M. Guerreiro, M, et al. (2006). "What about us? Siblings of children with epilepsy." Seizure **15**: 610 - 614.

Uhlmann, C. and W. Froscher (2001). "Biofeedback treatment in patients with refractory epilepsy: Changes in depression and orientation." Seizure **10**: 34 - 38.

Verdru, P. (2005). "Epilepsy in children: the evidence for new epileptic drugs." Acta Neuroligica Scandinavica **112** (suppl 181): 17 - 20.

Verhey, I., H, D. Kulik, M, et al. (2009). "Quality of life in childhood epilepsy: What is the level of agreement between youth and their parents?" Epilepsy and Behaviour **14**: 407 - 410.

Vona, P., P. Siddarth, et al. (2009). "Obstacles to mental health care in pediatric epilepsy: Insight from parents." Epilepsy and Behaviour **14**: 360 - 366.

Wagner, J., L, P. Sample, L, et al. (2009). "Impact of pediatric epilepsy: Voices from a focus group and implications for public policy change." Epilepsy & Behavior **16**: 161 - 165.

Wolf, P. (2005). "Determinants of outcome in childhood epilepsy." Acta Neuroligica Scandinavica **112**(Suppl. 182): 5 - 8.