A brief of an original review entitled:

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

December 2009.

The main conclusions of the review were that;

- Two thirds of children with epilepsy manage it well with the other third needing extra help in their lives
- Causes include family history, brain abnormalities, infections and major head injuries.
- Treatment is an anti epileptic drugs and sometimes surgery
- Epilepsy can affect a child's quality of life, achievements and dreams
- An epilepsy diagnosis affects all the family
- Adolescents need help when moving to adult services
- Researchers are hopeful that epilepsy will be curable in the future

This briefing paper offers an overview of epilepsy and will outline some difficulties children with epilepsy and their families may encounter.

- Learning difficulties in children
- Depression in children
- Sleep problems in children
- Quality of life for children and adolescents with epilepsy
- Parental stress and its effects of children
- Support for children with epilepsy
- Children in school
- Hope for the future

What is epilepsy?

Epilepsy is one of the most common serious chronic central nervous system neurological disorders in the UK (Rajpura and Sethi 2004). It is a disorder of the central nervous system which results in seizures (Baxendale 2006). It is the overall diagnosis given to people who two or more unprovoked seizures (Guerinni 2006).

How many people have epilepsy?

Epilepsy affects, at any one time, 50 million people worldwide. In the UK, approximately 30,000 new cases per year are diagnosed (Duncan, Fairey et al. 2004) equating to almost 1% of this population (Elwyn, Todd et al. 2003).

70% of people diagnosed with epilepsy are seizure free within five years of onset of treatment (Stefan, Halász et al. 2001). This leaves about one third of people with epilepsy who require services for complex epilepsy (Rajpura and Sethi 2004).

Epilepsy in children

Epilepsy is also the most commonly encountered neurologically conditions in children. 0.5 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 live in developing countries (Guerinni 2006)

There are around seven to eight cases per 1000 children under the age of 11 every year (Dulac 2005).

◀ Diagnosis

A specific diagnosis is important for children. Most children are diagnosed within 2 years.

Detailed history taking from family and carers helping greatly in diagnosis (Guerinni 2006; Guerinni and Parmeggiani 2006).

Diagnosis consists of EEG (electroencephalogram), neuroimaging (MRI (Magnetic resonance imaging or CT (computed tomography) and possibly blood tests (which may indicate whether there are other reasons for the epilepsy and to exclude other diagnoses), and neuropsychological assessment (NICE 2004a).

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).

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 be at risk of seizures because it has not had time to develop networks to inhibit these (Holmes 2009).

Signs to look out for when your child has a seizure

It is important for parents to carefully document what happened when their child has a seizure. This means giving a detailed description of the seizures, the sequence of them, what happened just before and after a seizure occurred (Guerinni 2006; Guerinni and Parmeggiani 2006)..

Note any feelings your child has before a seizure (Romeo, Chifari et al. 2008).

Videotaping the seizure on a mobile phone for example is very useful or acting them out for a doctor.
Knowing your child's developmental milestones is also important.

Details of childhood and juvenile epilepsies are in the main review paper with details of their outcomes.

Complex febrile convulsions are more serious however, they are prolonged and occur more than once in the same illness (Oostergard 2008)

Status epilepticus

This is 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 10 minutes. This is more serious and more common in children and requires urgent medical treatment (Nagai, Yamano et al. 2007)

Additional treatments can include;

Cognitive Behavioural Therapy for help with strategies to reduce seizure frequency, stress and seizure managment (Goldstein, McAlpine et al. 2003). Behaviour therapy can be useful for sleep problems in children (Dorriss, Scott et al. 2008).

Biofeedback can help with depression and how much people feel in control of their condition (Uhlmann and Froscher 2001).

Speech therapy is available as is psychomotor therapy and psychotherapy (Soria, Callu et al. 2008)

◀ Some childhood epilepsies and their prognoses

Childhood epilepsies fall into four main groups in terms of outcome:

i) some are benign for example Benign Rolandic Epilepsy (JEC nodate) and simple febrile convulsions (BMJ 2009) which can have an excellent outcome (Oostergard 2008).

ii) some are very responsive to anti epileptic drugs (AEDs) and will go into remission in time. For example, Idiopathic generalised epilepsies.

iii) some require AEDs for life, for example Myoclonic astatic epilepsy and Symptomatic focal epilepsy.

iv) others are resistant to AEDs and their prognosis is poor (Guerrini 2006). Temporal lobe epilepsy, for example, is chronic (Hermann 2007) and associated with reduced intellectual and memory capacity (Hermann 2007).

◀ Treatment

A low dose of one AED is advocated initially to test out seizure control and minimise side effects and this is achieved in nearly 75% of children (Dulac 2005).

Childhood surgery should be seriously considered for those whose seizures do not respond to AEDs (Soria, Callu et al. 2008) as 'refractory' seizures can lead to major neurological impairments (Ottenberger, Byme et al. 2005).

National guidelines recommend that children with epilepsy should be

	managed by paediatricians with expertise in epilepsy (NICE 2004; Mar, Dunkley et al. 2005) but there is a lack of nurses, psychologists, psychiatrists and allied health professionals specialising in epilepsy in the UK (Martland 2009).

Some difficulties children with epilepsy may encounter.

75% of children with epilepsy will achieve seizure control and /or experience minimal side effects with their medication (Dulac 2005). 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 (Guerinni 2006).

However, AEDs not only can significantly affect cognitive function but can also increase aggression and hyperactivity (Wagner, Sample et al. 2009). Epilepsy puts children more at risk of accidents, with some epilepsies having more risk attached to them. Kitchen and bathrooms are particularly dangerous places for children putting them at risk of burning or drowning (Guerinni 2006).

Children with epilepsy are 'at risk' population, they have a chronic condition and need to be screened for any special health care they require (Schmidt, Thyen et al. 2009). Some difficulties children may encounter are described below.

Learning difficulties

Many epilepsies directly impact on a child's brain and, therefore, on their cognitive development, language and social skills (Martland 2009). Although AEDs can suppress and/or decrease seizures, the way in which they do this is complex and can interfere with cognitive functioning (Mandelbaum, Burack et al. 2009). Children with epilepsy can also have higher rates of ADHD and behavioural problems such as disruptive behaviour and aggression (Fastenau, Shen et al. 2008; Jacobs 2009).

Having seizures can affect school performance and children can need special assistance at school, possibly quite early on (Oostrom, Smeets-Schouten et al. 2003; Jacobs 2009). Children having absence seizures where consciousness is impaired for a few seconds at a time, for example, will miss things in class and this can affect their educational outcome (Blumenfeld 2005). Children can be sleepy at school, again putting their learning at risk (Dorriss, Scott et al. 2008).

Children may not be able to remember what happened at school the previous day or immediately after a seizure. Their medication can affect their attention span and ability to concentrate.

However, learning and behavioural difficulties are not always due directly to their epilepsy. If children are ashamed of their condition or parents and others exhibit negative emotions and reactions this can affect their academic skills, learning and attention and, ultimately, how they adapt to their condition (Oostrom, Smeets-Schouten et al. 2003; Jacobs 2009)**.**

Ideas for making school life easier

Knowledge about epilepsy in school is scarce and educating parents and teachers goes a long way to putting in place appropriate help and support (Sillanpää and Cross 2009) in that it can alert teachers to the potential mental health needs of children with epilepsy (Vona, Siddarth et al. 2009). Parents of children with epilepsy suggest that school is the place for education about epilepsy for both pupils and teachers (Vona, Siddarth et al. 2009; Wagner, Sample et al. 2009).

For teachers and other school staff, epilepsy is rated as serious in terms of children needing extra attention and they have concerns about emergencies and legal liability issues (Olson, Siedler et al. 2004 ; Sillanpää and Cross 2009) (Vona, Siddarth et al. 2009).

It is a good idea for parents to meet teachers and other staff such as school nurses (as they administer the medication), on a regular basis in order to discuss their children’s seizures, the implications of them in the classroom and how to respond to them and the child.

The epilepsy foundation offer ideas for helping parents prepare action plans for staff for potential seizure occurrence and how to record them. www.epilepsyfoundation.org

Sleep difficulties

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, decrease total sleep time (Soria, Callu et al. 2008; Modi 2009) and can lead to memory problems (Soria, Callu et al. 2008).   A lack of sleep can trigger seizures (Dorriss, Scott et al. 2008).

Young people with epilepsy have reported feeling tired, their need for more sleep interfering with joining in with their peers in social pursuits (Wagner, Sample et al. 2009). A combination of AEDs and seizures can produce excessive day time sleepiness.

Parents can also suffer from sleep deprivation as they often regularly wake to check on their children during the night (Modi 2009). It is important for parents and other family members to have enough sleep. Mothers, in particular can feel stressed and less able to cope with their child’s sleep issues if they themselves are tired (Dorriss, Scott et al. 2008).

There are various ways to help parents induce or encourage sleep including; not giving children any drinks containing caffeine before going to bed, or by discouraging play in the bedroom prior to going to sleep. Behavioural therapy can also be effective (Dorriss, Scott et al. 2008).

Parental and family stress

The way parents feel about their child's diagnosis can affect the way they behave towards their child, affect their adaptation to the condition and to 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 still encourage independence so that children develop their own competencies rather than being overprotective (Wagner, Sample et al. 2009). A new diagnosis of childhood epilepsy is significant for a whole family and time is needed for everyone to adjust to this (Modi 2009). Parents should seek and accept both support both social and professional support for themselves and their children. They can then voice their concerns and realise that not every concern will resolve itself straightaway (Chiou and Hsieh 2008).

Sisters and brothers of children with epilepsy have less time with their parents and feel a sense of responsibility for their sisters or brothers. This can result in stress, anxiety, behavioural and emotional problems (Tsuchie, Guerreiro et al. 2006)**.**

The 'sources of help' document related to this briefing paper is aimed at helping parents gain support.

Quality of life for children and adolescents with epilepsy

Epilepsy can still be stigmatised (Wagner, Sample et al. 2009) and attitudes of others can cause low self esteem in children with epilepsy, more so than those with asthma or diabetes, as it can be a very obvious condition and difficult for children to cope with (Soria, Callu et al. 2008). Children with epilepsy have to cope with unpredictable seizures losing control over their mind and body. This can result in children being vulnerable, feeling 'different' to their peers (Verhey, Kulik et al. 2009)(p410) and potential victims of bullying (Hamiwka, Yu et al. 2009).

These issues can trigger mental health problems in children and adolescents and reduce their quality of life (Vona, Siddarth et al. 2009).

Depression in children

For children and adolescents with epilepsy there is an element of grief when given a diagnosis of epilepsy as their expectations of their life may not be fulfilled (Wagner, Sample et al. 2009). This carries a high risk of depression and anxiety developing and this carries life threatening risks such as attempted suicide (Ekinci 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) and remain undetected (Fastenau, Shen et al. 2008).

From child to adolescent services

Adolescence is a time when major biological changes take place and children develop their own identities and having epilepsy can impact on this process especially in terms of how independent a young person can be (Mcewan, Espie et al. 2004). Adolescents are concerned for their future as adults, their employment, and whether they will be able to live alone or have children (Mcewan, Espie et al. 2004).

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 (Tsuchie, Guerreiro et al. 2006)..

Adolescents are a vulnerable group of epilepsy patients having the task of moving from child to adult services, no longer being under the official watchful eye of their parents (Smith, Myson et al. 2002). Establishing good relationships with family doctors and specialists early on can help adolescents move successfully from child to adult services (Galletti, Rinna et al. 1998).

Hope for the future

There is hope for a future cure for epilepsy as scientists come to know more about the mechanics of epilepsy. Uncovering these mechanisms can assist in the development of drugs to prevent epilepsy rather than just managing the condition (Spinney 2004). During the last ten years with the completion of the human genome project, the brain processes involved in epilepsy have become clearer and there is hope for a cure for epilepsy during the next decade (Jacobs 2009).

Newer AEDs for children seem to be safer now in that they may not affect a child's cognitive abilities so much and newer drug trials are designed to address this (Lagae 2006). There is now a Task Force of European Drug Development for the Young – TEDDY - which aims to improve the regulation and research into medications for children, including AEDs for epilepsy (Ackers 2006). Clinical trials specifically for children are advocated now when new drugs are being developed (Dulac 2005).

The full review: An overview of epilepsy with a focus on the effects and implications of the condition for children and their families. Valerie A. Featherstone, C Psychol. A freelance Health Psychology researcher in East Yorkshire.

Specific services for children with epilepsy in the Yorkshire area and beyond are noted in a separate briefing paper.

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