



Cerebra

Positively Different

Epilepsy in children and young people.

Background

The cause of epilepsy in children can be genetic, developmental or related to an abnormality acquired early in life and may be associated with learning difficulties and impairments.

- 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 drug 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.

Some difficulties children with epilepsy and their families may encounter are:

- Learning difficulties
- Depression
- Sleep problems
- Diminished quality of life
- Parental stress and its effects on children
- The need for support

Valerie Featherstone

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- Problems with school
- Lack of hope for the future

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Any feelings the child has before a seizure should be noted.

Videotaping the seizure on a mobile phone, for example, is very useful, as is acting them out for the doctor.

What is epilepsy?

Epilepsy is one of the most common serious, chronic central nervous system neurological disorders in children.¹ It is a disorder of the central nervous system, which results in seizures.² It is the overall diagnosis given to people who have two or more unprovoked seizures.³

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 diagnosed⁴ equating to almost 1% of the UK population.⁵

Seventy per cent of people diagnosed with epilepsy are seizure-free within five years from beginning of treatment.⁶ This leaves about one third of people with epilepsy who require services for complex epilepsy.¹

Epilepsy in children

Epilepsy is the most commonly encountered neurological condition in children. Half a 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.⁷ There are around 7 to 8 cases per 1000 children, under the age of 11 every year.⁸

Diagnosis

A specific diagnosis is important for children. Most children are diagnosed within 2 years. Detailed history taken from family and carers helps greatly in diagnosis.⁷

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 may exclude other diagnoses), and neuropsychological assessment.¹⁰

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.¹¹

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.¹²

Childhood epilepsies and their prognoses

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

- i) Some are benign, for example, benign rolandic epilepsy¹³ and simple febrile convulsions,¹⁴ which can have an excellent outcome.¹⁵
- 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 atstatic epilepsy and symptomatic focal epilepsy.
- iv) others are resistant to AEDs and their prognosis is poor.⁷ Temporal lobe epilepsy, for example, is chronic and associated with reduced intellectual and memory capacity.¹⁶

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National guidelines recommend that children with epilepsy should be managed by paediatricians with expertise in epilepsy but there is a lack of nurses, psychologists, psychiatrists and allied health professionals specialising in epilepsy in the UK.

Complex febrile convulsions are more serious, however, they are prolonged and occur more than once in the same illness.¹⁵

Status epilepticus 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.⁷

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.⁸

Childhood surgery should be seriously considered for those whose seizures do not respond to AEDs¹⁸ as 'refractory' seizures can lead to major neurological impairments.¹⁹

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Additional treatments can include:

- Cognitive behavioural therapy for help with strategies to reduce seizure frequency, stress and seizure management.²⁰ Behaviour therapy can be useful for sleep problems in children.²¹
- Biofeedback can help with depression and how much people feel in control of their condition.²²
- Speech therapy, psychomotor therapy and psychotherapy are available.¹⁸

Difficulties children having epilepsy may encounter

Seventy-five percent of children with epilepsy will achieve seizure control and /or experience minimal side-effects with their medication.⁸ Sixty-four percent 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.³

However, AEDs not only can significantly affect cognitive function but can also increase aggression and hyperactivity.²² 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.³

Children with epilepsy are an 'at risk' population, they have a chronic condition and need to be screened for any special health care they require.²⁴

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.¹¹ Although AEDs can suppress and/or decrease seizures, the way in which they do this is complex and can interfere with cognitive functioning.²⁵ Children with epilepsy can also have higher rates of ADHD and behavioural problems such as disruptive behaviour and aggression.²⁶

Having seizures can affect school performance and children can need special assistance at school, possibly quite early on.²⁷ 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.²⁸ Children can be sleepy at school, again putting their learning at risk.²¹

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.²⁷

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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,²⁹ in that it can alert teachers to the potential mental health needs of children with epilepsy.³⁰ Parents of children with epilepsy advocate that school is the place for education about epilepsy for both pupils and teachers.³⁰

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.^{29,30}

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.¹⁸ Seizures can delay sleep, lead to waking during the night, bad quality sleep, decrease in sleep time,^{18,31} and can lead to memory problems.¹⁸ A lack of sleep can trigger seizures.²¹

Young people with epilepsy have reported feeling tired, their need for more sleep interfering with joining in with their peers in social pursuits.²³ 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.³¹ 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.²¹

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.²¹

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.^{32,31} Parents may be anxious about their child's diagnosis,^{31,23} seeing them as different from other children.

Parents can still encourage independence, rather than being overprotective, so that children develop their own competencies.²³ A new diagnosis of childhood epilepsy is significant for the whole family and time is needed for everyone to adjust to this.³¹ Parents should seek and accept 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.³²

Siblings 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.³³

Quality of life for children and adolescents with epilepsy

Epilepsy can still be stigmatised²³ 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 handle.¹⁸ 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' from their peers³⁴ and becoming potential victims of bullying.³⁵

These issues can trigger mental health problems in children and adolescents and reduce their quality of life.³⁰

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Teenagers have been found to perceive epilepsy as more stigmatising a condition than, asthma, diabetes, arthritis, migraine, leukaemia and even HIV.

Depression in children

For children and adolescents with epilepsy, there is an element of grief when they are given a diagnosis of epilepsy, as their expectations of their life may not be fulfilled.²³ This carries a high risk for developing anxiety or depression.³⁶ Children with epilepsy are at risk of not receiving adequate mental health assessments and care, because psychological and psychiatric symptoms can be missed²³ and remain undetected.²⁶

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.³⁷ Adolescents are concerned for their future as adults, their employment, and whether they will be able to live alone or have children.³⁷

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.³³

When epilepsy patients reach adolescence they are more vulnerable, and have the additional task of moving from child to adult services, no longer being under the official watchful eye of their parents.⁴⁰ Establishing good relationships with family doctors and specialists early on can help adolescents move successfully from child to adult services.³⁸

Hope for the future

There is hope for a future cure for epilepsy as scientists come to know more about the mechanics of the condition. Uncovering these mechanisms can assist in the development of drugs to prevent epilepsy, rather than just managing the condition.⁴¹ 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.⁴²

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. 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. Clinical trials specifically for children are advocated, when new drugs are being developed.⁸

The full report, 'Epilepsy in children and young people', Valerie Featherstone, 2010, is available from the Research and Education Department at Cerebra on request.

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References

- ¹ Rajpura, A. and S. Sethi (2004). "Evidence-based standards of care for adults with epilepsy-a literature review." *Seizure* 13: 45 - 54
- ² Baxendale, S. (2006). *Epilepsy: An approach to case formulation. Formulation and treatment in Clinical Health Psychology*. V. Nikcevic Ana, A. Kuczmierczyk, R and M. Bruch. Hove, Routledge
- ³ Guerinni, R. (2006). "Epilepsy in children." *Lancet* 367: 499 - 524
- ⁴ Duncan, J. S. (2004). *Clinical update: Epilepsy in Adults*. The Royal Society of Medicine Symposia The Royal College of General Practitioners, London
- ⁵ 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)
- ⁶ Stefan, H., P. Halász, et al. (2001). "Recent advances in the diagnosis and treatment of epilepsy." *European Journal of Neurology* 8: 519 - 539
- ⁷ Guerinni, R. and L. Parmeggiani (2006). "Practitioner Review: Use of antiepileptic drugs in children." *Journal of Child Psychology and Psychiatry* 47(2): 115 - 126
- ⁸ Dulac, O. (2005). "Issues in paediatric epilepsy." *Acta Neurologica Scandinavica* 112 (Suppl. 182): 9 - 11
- ⁹ 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
- ¹⁰ NICE (2004a). *The epilepsies: diagnosis and management of the epilepsies in children and young people in primary and secondary care*, National Institute for Clinical Excellence. Clinical Guideline 20
- ¹¹ Martland, T. C., Helen, J., (2009). "Best clinical and research practice in pediatric neurology." *Epilepsy & Behavior* 15: 551 - 554

¹² Holmes, G., L (2009). "The 2008 Judith Hoyer Lecture: Epilepsy in children: Listening to mothers." *Epilepsy & Behavior* 16: 193 - 202

¹³ JEC (nodate). *Epilepsy syndromes of childhood and adolescent*, Joint Epilepsy Council

¹⁴ BMJ (2009) Febrile convulsions. BMJ Group Volume, DOI: http://clinicalevidence.bmj.com/ceweb/conditions/chd/0324/febrile-seizures-standard-ce_patient_leaflet.pdf

¹⁵ Oostergard, J., R (2008). "Febrile seizures." *Acta Paediatrica* 98(5): 771 - 773

¹⁶ 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

¹⁷ Nagai, T., T. Yamano, et al. (2007) Status epilepticus in infants and young children: Basic mechanisms, clinical evaluation, prognosis and treatment. *Acta Neurologica Scandinavica* Volume, 5 DOI

¹⁸ Soria, C., D. Callu, et al. (2008). "Parental report of cognitive difficulties, quality of life and rehabilitation in children with epilepsy or treated for brain tumour." *Developmental Neurorehabilitation* 11(4): 268 - 275

¹⁹ Ottenberger, G., P, A. Byrne, 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

²⁰ Goldstein, L. H., M. McAlpine, et al. (2003). "Cognitive behaviour therapy with adults with intractable epilepsy and psychiatric co-morbidity: preliminary observations on changes in psychological state and seizure frequency." *Behaviour Research and Therapy* 41: 447 - 460

²¹ Dorriss, L., N. Scott, et al. (2008). "Sleep problems in children with neurological disorders." *Developmental Neurorehabilitation* 11(2): 95 - 114

²² Uhlmann, C. and W. Froscher (2001). "Biofeedback treatment in patients with refractory epilepsy: Changes in depression and orientation." *Seizure* 10: 34 - 38

- ²³ 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
- ²⁴ Schmidt, S., U. Thyen, et al. (2009). "The performance of a screener to identify children with special health care needs in a European sample of children with chronic conditions." *Eur J Pediatrics* 163: 517 - 523
- ²⁵ 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
- ²⁶ 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
- ²⁷ Ostrom, 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
- ²⁸ Blumenfeld, H. (2005). "Consciousness and epilepsy: why are patients with absence seizures absent?" *Progress in Brain Research* 150: 271 - 286
- ²⁹ Sillanpää, M. and H. Cross, J (2009). "The psychological impact of epilepsy in childhood." *Epilepsy & Behavior* 15: S5 - S10
- ³⁰ Vona, P., P. Siddarth, et al. (2009). "Obstacles to mental health care in pediatric epilepsy: Insight from parents." *Epilepsy and Behaviour* 14: 360 - 366
- 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
- ³² 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
- ³³ Tsuchie, S., Y. M. Guerreiro, M., et al. (2006). "What about us? Siblings of children with epilepsy." *Seizure* 15: 610 - 614

³⁴ 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

³⁵ 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

³⁶ 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

³⁷ 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

³⁸ Galletti, F., A. Rinna, et al. (1998). "An insight into children's and adolescents' experience of seizures and epilepsy." *Seizure* 7: 309 - 316

³⁹ SIGN (2005). *Diagnosis and management of epilepsies in children and young people: National clinical guideline number 81. I. Scottish, Guidelines, Network. Edinburgh*

⁴⁰ Smith, P, E, M, V. Myson, et al. (2002). "A teenager epilepsy clinic: observational study." *European Journal of Neurology* 9: 373 - 376

⁴¹ Spinney, L. (2004). "New Models for Epileptogenesis." *The Scientist* November 22: 16 - 17

⁴² 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

The Cerebra In-house Research Team carries out desk-based research into a number of areas, based upon parent and professional requests, new scientific evidence and issues raised by our staff. We aim to provide information that is relevant to parents and carers of children with disabilities as well as the professionals who come into contact with them. By empowering parents and professionals with knowledge, we can help them to improve the lives of the children they care for and support.

If you require further information or would like to suggest avenues for further research, please get in touch.

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