Epilepsy in Children and Young People

Children and young people may present with similar types of seizures and in similar ways to adults with epilepsy (see the separate Epilepsy in Adults article). However, this article focuses on the forms of epilepsy and aspects of management which apply to children and young people. Status epilepticus is also dealt with in the separate Status Epilepticus Management article.

Epileptic seizures and epilepsy syndromes should be classified according to the description of seizure, the seizure type, the epilepsy syndrome and the aetiology. The seizure type(s) and epilepsy syndrome, aetiology, and comorbidity should be determined, because failure to classify the epilepsy syndrome correctly can lead to inappropriate treatment and persistence of seizures. Children and young people with epilepsy and/or their family/carers should be given information about their seizure type(s) and epilepsy syndrome, and the likely prognosis.\(^1\)

Prevalence

- Epilepsy is a common neurological disorder in childhood. Seizures and epilepsy affect infants and children more than any other age group.\(^2\)
- Epilepsy is about twice as common in children as in adults (about 700 per 100,000 in children under the age of 16 years compared to 330 per 100,000 in adults).
- The incidence of status epilepticus in developed countries is between 17 and 23/100,000 with a higher incidence in younger children.\(^3\)
- There is an increased risk of seizures in children of parents with epilepsy. The probability that a child will be affected is generally low but will depend on the family history.\(^1\)

Causes

- Malformations - eg, tuberous sclerosis and other hamartomas.
- Infections: meningitis and encephalitis; parasitic infections, particularly cysticercosis, are common causes of epilepsy in Third World countries.
- Electrolyte disturbances - eg, hypernatraemia, hyponatraemia, hypoglycaemia, hypocalcaemia, hypomagnesaemia, toxins.
- Trauma.
- Metabolic disorders.

Trigger factors

- Watching television and lack of sleep are two common triggers.
- It has been shown that observing the set with one eye covered prevents the occurrence of these seizures.

Presentation

When a child or young person presents with a seizure, a thorough physical examination should be performed, including cardiac, neurological and mental state. An assessment of development is important for children presenting with a seizure.\(^1\)

Presenting features in children are similar to those in adults. However, these subtypes are more common, or occur exclusively, in childhood:
Typical absences ('petit mal' seizures): petit mal epilepsy is manifest by frequent (as many as 100 times per day or more) episodes of brief staring spells (lasting seconds at a time):
- Onset in childhood; attacks continuing into adult life are rare.
- A typical absence attack lasts only a few seconds. The onset and termination are abrupt. The child ceases what he or she is doing, stares, looks a little pale and may flutter the eyelids.
- Sometimes more extensive bodily movements occur (such as dropping the head forwards) and there may be a few clonic movements of the arms.
- The interruption of the normal stream of consciousness is very brief and the child may be unaware of the attacks, as indeed may be the parents for some time after onset, assuming that the child is just day-dreaming.
- About one third of all children with petit mal will have one or more tonic-clonic convulsions.

Infantile spasms:
- Occur in infants aged 4-8 months.
- Consist of clusters of myoclonic spasms that occur when waking up.

Dravet's syndrome:
- Dravet's syndrome includes severe myoclonic epilepsy of infancy with the onset of recurrent febrile and/or afebrile hemiclonic or generalised seizures, or status epilepticus, in a previously healthy infant.
- Multiple seizure types develop which are generally resistant to AEDs. There is also developmental arrest or regression.
- Onset up to 15 months of age may occur.
- Mortality may be up to 15% by age 20 years.

Lennox-Gastaut syndrome.

Juvenile myoclonic epilepsy:
- Occurs in the teen years.
- Early morning sudden myoclonic jerks, especially of the arms and shoulders.
- Often later develop generalised tonic-clonic (GTC) seizures.
- May be inherited as autosomal dominant.

Panayiotopoulos syndrome:
- Panayiotopoulos syndrome is a common multifocal autonomic childhood epileptic disorder.
- Affects otherwise normal children with onset at around 3-6 years.
- Seizures are often prolonged, with predominantly autonomic symptoms and mainly ictal vomiting.
- Electroencephalogram (EEG) shows shifting and/or multiple foci, often with occipital dominance.
- Often confused with occipital epilepsy and acute non-epileptic disorders - eg, encephalitis, syncope, cyclical vomiting or atypical migraine.

Benign Rolandic epilepsy:
- Also known as benign focal epilepsy.
- It occurs in children aged 4-10 years and is more common in boys.
- Nocturnal seizures that are characterised by facial twitching and aphasia.
- Some children with benign Rolandic epilepsy may also have GTC seizures.

Benign childhood epilepsy with centrotemporal spikes:
- Some older children may have focal or generalised seizures.
- The interictal EEG is characterised by large spike discharges over the Rolandic area of one hemisphere.
- Is not associated with any structural lesion and has an excellent prognosis.
Differential diagnosis

Non-epileptic attacks include: [1]

- **Syncope**: loss of consciousness occurring in crowded trains, waiting at bus stops, or in school assembly; should always be presumed to be syncopal in nature unless there is clear-cut evidence to the contrary.
- **Night terrors**: these affect children aged between about 6 and 8 years, who suddenly awaken from a sound sleep, wide-eyed, screaming, and inconsolable. They are amnesic for the events the following morning. They seem to occur just as often in happy children as in children who are not doing well at school or in the family. Fortunately, they too pass quickly.
- **Reflexic anoxic seizures**: affect younger children, aged between 1 and 2 years. A typical story is of a child who has some minor injury, or who is crossed in some way so that he or she becomes suddenly angry, upset or frightened. Such attacks terminate spontaneously without treatment.
- **Febrile convulsions**.
- **Fabricated or induced illness by carers**.
- **Cardiac arrhythmias**.
- **Migraine**.
- **Sleep apnoea**.
- **Narcolepsy**.

Investigation [1]

- **EEG**:
  - An EEG should be performed only to support a diagnosis of epilepsy where the clinical history suggests that the seizure is likely to be epileptic in origin. The EEG should not be used in isolation to make a diagnosis of epilepsy.
  - If an EEG is considered necessary, it should be performed after the second epileptic seizure but may, in certain circumstances as evaluated by the specialist, be considered after a first epileptic seizure. Following a first unprovoked seizure, unequivocal epileptiform activity shown on EEG can be used to assess the risk of seizure recurrence.
  - Photic stimulation and hyperventilation should remain part of standard EEG assessment. The child, young person and family and/or carer should be made aware that such activation procedures may induce a seizure.
  - An EEG should not be performed in the case of probable syncope because of the possibility of a false positive result.
  - An EEG may be used to help to determine seizure type and epilepsy syndrome.
  - Repeated standard EEGs may be helpful when the diagnosis of the epilepsy or the syndrome is unclear. However, if the diagnosis has been established, repeat EEGs are not likely to be helpful. Repeated standard EEGs should not be used in preference to sleep or sleep-deprived EEGs.
  - When a standard EEG has not contributed to diagnosis or classification, a sleep EEG should be performed. In children and young people, a sleep EEG is best achieved through sleep deprivation or the use of melatonin.
  - Long-term video or ambulatory EEG may be used in the assessment when there are diagnostic difficulties after clinical assessment and standard EEG.

- **Neuroimaging**:
  - Neuroimaging should be used to identify structural abnormalities that cause certain epilepsies. MRI is the imaging investigation of choice. MRI is particularly important in those:
    - Who develop epilepsy before the age of 2 years.
    - Who have any suggestion of a focal onset on history, examination or EEG (unless there is clear evidence of benign focal epilepsy).
    - In whom seizures continue in spite of first-line medication.
Neuroimaging should not be routinely requested when a diagnosis of idiopathic generalised epilepsy has been made.
CT should be used to identify underlying gross pathology if MRI is not available or is contraindicated and for children or young people in whom a general anaesthetic or sedation would be required for MRI but not CT. CT may be used to determine whether a seizure has been caused by an acute neurological lesion or illness.

Other tests:
- Other investigations, including blood and urine biochemistry, should be undertaken at the discretion of the specialist, to exclude other diagnoses and to determine an underlying cause of the epilepsy.
- A 12-lead ECG should be considered in cases of diagnostic uncertainty. In cases of diagnostic uncertainty, a referral to a cardiologist should be considered.

Neuropsychological assessment

Neuropsychological assessment should be considered when it is important to evaluate learning disabilities and cognitive dysfunction, particularly in regard to language and memory. Referral for a neuropsychological assessment is indicated:

- When the child or young person with epilepsy is having educational difficulties.
- When an MRI has identified abnormalities in cognitively important brain regions.
- When there are reported memory or other cognitive deficits and/or cognitive decline.

Management

Diagnosing epilepsy can be complex, and it has been estimated that misdiagnosis occurs in 5-30% of people. It is therefore essential that specialists are involved early in diagnosing epilepsy and that they take great care to establish the correct diagnosis. Therefore children and young people presenting with a suspected seizure should be seen by a specialist in the diagnosis and management of the epilepsies within two weeks of presentation.

Essential information on how to recognise a seizure, reducing the risk of severe trauma during a seizure, appropriate first aid measures and the importance of reporting further attacks should be provided to a child or young person who has experienced a possible first seizure and to their family/carer/parent as appropriate. This information should be provided while awaiting a diagnosis.

Young people with epilepsy: healthcare professionals should adopt a consulting style that allows the young person with epilepsy to participate as a partner in the consultation. The diagnosis and management of epilepsy should be reviewed during adolescence.

The diagnosis of epilepsy in children and young people should be established by a specialist paediatrician with training and expertise in epilepsy.

Provide regular structured review by a specialist at least once a year but probably more frequently (every 3-12 months) depending on need.

Although a review of the impact of four different education and counselling programmes for children, children and parents, or teenagers and parents showed some benefit to children with epilepsy, their impacts were extremely variable.

Sudden death: information provided to children and young people with epilepsy and their carers should take account of the small but definite risk of sudden death. The risk of sudden unexpected death can be minimised by optimising seizure control and being aware of the potential consequences of nocturnal seizures.

Drug treatment

See also the separate Anticonvulsants used for Generalised Seizures, Anticonvulsants used for Focal Seizures and Epilepsy in Adults articles.

- Use monotherapy whenever possible. The formulation or brand of AED should not be changed (variations in bioavailability or different pharmacokinetic profiles may increase the potential for reduced effect or excessive side-effects).
- Anti-epileptic treatment is associated with a small risk of suicidal thoughts and behaviour. The increased risk applies to all AEDs and is seen as early as one week after starting treatment.
Initiation of drug treatment

- AED therapy should only be started once the diagnosis of epilepsy is confirmed, except in exceptional circumstances. AED therapy should be initiated by a specialist.
- Treatment with AED therapy is generally recommended after a second epileptic seizure. AED therapy should be considered and discussed after a first unprovoked seizure if:
  - The child or young person has a neurological deficit.
  - The EEG shows unequivocal epileptic activity.
  - The child or young person and/or their family and/or carers consider the risk of having a further seizure unacceptable.
  - Brain imaging shows a structural abnormality.

Continuation of drug treatment

- Maintain a high level of vigilance for adverse effects of treatment.
- Continuing AED therapy should be planned by a specialist but part of an agreed treatment plan and the needs of the child or young person and their family and/or carers as appropriate should be taken into account.
- If management is straightforward, continuing AED therapy can be prescribed in primary care if local circumstances and/or licensing allow.
- Adherence to treatment can be optimised with the following:
  - Educating children, young people and their families and/or carers in the understanding of their condition and the rationale of treatment.
  - Reducing the stigma associated with the condition.
  - Using simple medication regimens.
  - Positive relationships between healthcare professionals, the child or young person and their family and/or carers.
- Regular blood test monitoring is not recommended as routine and should be done only if clinically indicated. Indications for monitoring of AED blood levels are:
  - Detection of non-adherence to the prescribed medication.
  - Suspected toxicity.
  - Adjustment of phenytoin dose.
  - Management of pharmacokinetic interactions (eg, changes in bioavailability, changes in elimination, and co-medication with interacting drugs).
  - Specific clinical conditions - eg, status epilepticus, organ failure and certain situations in pregnancy.
- Examples of blood tests include clotting studies before surgery in those on sodium valproate.

Withdrawal of drug treatment

- The decision to continue or withdraw medication should be taken after a full discussion of the risks and benefits of continuing or withdrawing AED therapy. Withdrawal of AEDs must be managed by, or be under the guidance of, the specialist.
- The risks and benefits of continuing or withdrawing AED therapy should be discussed when the person with epilepsy has been seizure-free for at least two years.
- There is evidence to support waiting for at least two seizure-free years before discontinuing AEDs in children, particularly if individuals have an abnormal EEG or focal seizures, or both.\(^9\)
- There is insufficient evidence to establish when to withdraw AEDs in children with generalised seizures.\(^9\)
- Withdrawal of AED treatment should be carried out slowly (at least 2-3 months) and one drug should be withdrawn at a time.
- Particular care should be taken when withdrawing benzodiazepines and barbiturates (may take up to six months or longer) because of the possibility of drug-related withdrawal symptoms and/or seizure recurrence.
- There should be an agreed plan that if seizures recur, the last dose reduction is reversed and medical advice is sought.
Other interventions

Ketogenic diet

- A ketogenic diet is high in fat but low in carbohydrates and protein.
- Refer children and young people with epilepsy whose seizures have not responded to appropriate AEDs to a tertiary paediatric epilepsy specialist for consideration of the use of a ketogenic diet.

Vagus nerve stimulation (VNS) and deep brain stimulation (DBS)

- VNS is indicated for use as an adjunctive therapy in reducing the frequency of seizures in children and young people who are refractory to anti-epileptic medication but who are not suitable for resective surgery. This includes children and young people whose epileptic disorder is dominated by focal seizures (with or without secondary generalisation) or generalised seizures.\(^1\)
- The National Institute for Health and Care Excellence (NICE) states that the evidence on the efficacy of DBS for refractory epilepsy is limited and that there are potentially serious side-effects. Therefore, DBS is currently not recommended.\(^10\)

Surgery

The introduction of newer AEDs with better tolerability and fewer drug-drug interactions has made a significant impact on the treatment of epilepsy. However, a significant proportion of patients still have intractable epilepsy. Epilepsy surgery is an effective way to control seizures in patients with drug-resistant focal epilepsy, often leading to improvements in cognition, behaviour and quality of life.\(^11, 12, 13\)

- Modern techniques for the accurate localisation of epileptic discharge and the recognition of specific seizure patterns have increased the role of surgery in the management of drug-resistant epilepsy.\(^12\)
- Surgical operations for epilepsy include anteromedial temporal resection (the most frequently performed operation for medial temporal lobe epilepsy), corpus callosotomy (for generalised epilepsy syndromes), functional hemispherectomy and multiple subpial transection.

Review

- Children and young people with epilepsy should have a regular structured review and be registered with a general medical practice.
- Children and young people should have a regular structured review with a specialist.
- The maximum interval between reviews should be one year but the frequency of review will be determined by the patient's epilepsy and their wishes. The interval is usually between 3 and 12 months.
- Treatment should be reviewed at regular intervals to ensure that the patient is not maintained for long periods on treatment that is ineffective or poorly tolerated and that concordance with prescribed medication is maintained.
- Annual review should include an enquiry about side-effects and a discussion of the treatment plan to ensure concordance and adherence to medication.
- At the review, there should be access to written and visual information, counselling services, information about voluntary organisations, epilepsy specialist nurses, appropriate investigations and referral to tertiary services including surgery, when indicated.

Prognosis

Although overall mortality in children with epilepsy is higher than would be expected in the general paediatric population, one large study found that death occurred significantly more in children with neurological impairment and poorly controlled epilepsy. Epilepsy-related death was rare and similar to the expected mortality in the general population. Most children died of complications of the underlying neurological disease or unrelated disease rather than as a result of epilepsy.\(^14\)

- Although for most children epilepsy is a relatively benign disorder, for some, epilepsy can be designated as 'catastrophic' because the seizures are so difficult to control and because they are strongly associated with general learning disability.
Continuing epilepsy is more likely in those with neurological impairment, frequent seizures, many types of seizures or other additional medical conditions.

Conditions associated with epilepsy identified by a prospective UK study included Lennox-Gastaut syndrome, Addison’s disease, hearing loss, deaf mutism after meningitis, and congenital heart disease. [1]

After age 16 there is a high death rate in young people with epilepsy. This emphasises the importance of maintaining supportive relationships between healthcare professionals and people with epilepsy as they become independent adults.

In many children the seizures remit but can have a major impact on a child’s education and development and therefore affect adult life.

Further reading & references

- Transient loss of consciousness ('blackouts') management in adults and young people; NICE Clinical Guideline (August 2010)
- Epilepsy Action
- Epilepsy Society
- Epilepsy Scotland
- Epilepsy Wales

1. Epilepsies: diagnosis and management; NICE Clinical Guideline (January 2012)
2. Epilepsy; NICE CKS, December 2014 (UK access only)
6. The epilepsies in children and young people; NICE Quality Standard, February 2013

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