

# **EPILEPSY12**

**National Clinical Audit of Seizures and  
Epilepsies for Children and Young People**

**2024 report; Glossary and useful resources**

# Glossary of terms and abbreviations

<b>Absence seizure</b>	A type of generalised seizure where the person briefly loses awareness and becomes blank or unresponsive. Absences often last a few seconds, and the person is unconscious. If they are walking, they might carry on walking.
<b>Acute assessment</b>	Inpatient review, or paediatric review in emergency department, or other clinical assessment in an acute paediatric setting.
<b>Adherence</b>	When someone takes their medication as they have agreed with their doctor. This is a more modern term than 'compliance' (doing what your doctor tells you to) and implies that there has been some discussion between the individual and their doctor to agree upon a plan of treatment. Whether someone is adherent or not is a measure of how closely they adhere (or 'stick to') taking their medication or treatment as agreed.
<b>Adverse events</b>	Another term for 'side effects'. These are unwanted symptoms caused by medical treatments. Side effects can range from mild, to life-threatening (although the latter are rare).
<b>AED (Anti-epileptic drug)</b>	Anti-epileptic drugs (AEDs) are the main type of treatment for most people with epilepsy. AEDs are a type of medication that aims to stop seizures. There are many different AEDs, and they work in different ways and stop different types of seizures. Up to 70% of people with epilepsy could have their seizures stopped with the right AEDs.
<b>Atonic or atonic seizure</b>	A type of seizure where the person's muscles suddenly lose tone, go floppy, and they fall down (usually forwards) if they are standing up. Although the seizures themselves don't hurt, the person might hurt themselves, especially their head and face, when they fall. These seizures are usually very brief, and the person becomes conscious again very quickly. This is sometimes called a 'drop attack'.
<b>BPT/BPC</b>	Best Practice Tariff / Best Practice Criteria are payment incentives designed to encourage best practice care and reduce variation in the quality of care.
<b>Children's Epilepsy Specialist Nurse</b>	A children's nurse with a defined role and specific qualification and/or training in children's epilepsies.
<b>Childhood epilepsy syndrome</b>	A type of epilepsy that happens in children and young people, and follows a particular, typical pattern: the age that the seizures start, the type of seizures, the EEG recording and the progression or outcome. Some syndromes are benign and either go away or have little impact on the child. Others are severe and can affect the child's behaviour, learning and life expectancy. This is sometimes just referred to as a 'syndrome'.
<b>Clonic seizures</b>	These are seizures where the person convulses (jerks or shakes). Unlike tonic clonic seizures, the person does not go stiff at the start of the seizure.
<b>Clusters</b>	When a series or group of seizures happen close together in time, with gaps between each cluster. For example, in catamenial epilepsy, a woman might have a cluster of seizures around ovulation and no seizures at other times.
<b>Focal onset impaired awareness seizures</b>	These are seizures of focal onset <b>and</b> the person has a change in their level of awareness during some or all of it. These seizures used to be called 'complex partial seizures' or 'CPS'. The person will not be fully conscious, and they are often very confused and may not remember what happens during the seizure. During CFS the person may behave strangely or make repetitive movements called automatisms.

<b>Consultant General Paediatrician</b>	A paediatric consultant (or associate specialist) with a role that includes seeing children or young people in a general outpatient or community clinic setting. They may or may not have other specialty or acute roles. They are likely to receive referrals directly from primary care. Neonatologists would not be included in this definition unless they also fulfil general paediatric roles
<b>Consultant Paediatrician with 'Expertise in Epilepsy'</b>	A paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having: <ul style="list-style-type: none"> <li>• Training and continuing education in epilepsies</li> <li>• And peer review of practice</li> <li>• And regular audit of diagnosis (e.g. Participation in epilepsy12)</li> <li>• Epilepsy must be a significant part of clinical workload.</li> </ul> <p>A paediatric neurologist is also defined as a 'paediatrician with expertise'</p>
<b>Convulsive seizure</b>	A seizure where the person's body jerks or shakes, such as tonic clonic or clonic seizures.
<b>Data completeness</b>	The percentage of clinical audit records within a defined cohort with a submitted first year of care form.
<b>Deprivation Index</b>	This is calculated using the English Indices of Multiple Deprivation (Ministry of Housing, Communities & Local Government, 2019) and Welsh Index of Multiple Deprivation (Welsh Government, 2019). Deprivation is determined using information regarding income, employment, crime, health, education, housing, and physical environment. <p>In England, each postcode is assigned to its Lower-layer Super Output Area (LSOA). LSOAs are ranked 1 to 32,844, from most-deprived to least deprived. In Wales, LSOAs are ranked 1 to 1,909. We collate the LSOAs into five quintiles, where quintile 1 is most deprived and quintile 5 is least deprived.</p>
<b>Diazepam</b>	A type of sedative medication that is given to someone in status epilepticus to stop the seizures. Diazepam is given rectally (up the bottom). This is sometimes referred to as a type of 'emergency' or 'rescue' medication.
<b>Electrocardiogram (ECG)</b>	An electrocardiogram (ECG) is a simple test that can be used to check your heart's rhythm and electrical activity. Sensors attached to the skin are used to detect the electrical signals produced by your heart each time it beats.
<b>ED</b>	Emergency Department
<b>Electroencephalogram (EEG)</b>	An electroencephalogram (EEG) is a recording of brain activity. During the test, small sensors are attached to the scalp to pick up the electrical signals produced when brain cells send messages to each other. These signals are recorded by a machine and are looked at by a doctor later to see if they're unusual.
<b>Emergency medication</b>	Medication that is given to stop prolonged or repeated seizures (to stop status epilepticus from happening).
<b>Epilepsy</b>	A chronic neurological condition characterised by two or more epileptic seizures (International League Against Epilepsy, ILAE). A pragmatic definition for epilepsy in this audit is 2 or more epileptic seizures more than 24 hours apart that are not acute symptomatic seizures or febrile seizures.
<b>Epilepsy surgery</b>	Different types of surgery on the brain to try to reduce or stop seizures. Some people with epilepsy, whose seizures are not controlled or significantly reduced with medication, are able to have epilepsy surgery. Also called neurosurgery.

<b>Epilepsy syndrome</b>	A complex of clinical features, signs and symptoms that together define a distinctive, recognizable clinical disorder (ILAE)
<b>'Epilepsy syndrome category'</b>	A group of epilepsies described using the terms idiopathic primary, symptomatic, probably symptomatic and cryptogenic and focal, partial, multifocal or generalised
<b>Epileptic seizure</b>	Seizures that start due to interrupted electrical activity in the brain but can affect the body in many different ways.
<b>Febrile convulsions</b>	Convulsive seizures that can happen in young children (from about six months to six years of age) when they have a high temperature or fever. Febrile convulsions happen because very young children cannot control their body temperature very well. Although they can look like epileptic seizures they are not: they are caused by high temperatures, not interrupted brain activity.
<b>First paediatric assessment</b>	A 'face to face' assessment by a secondary level/tier doctor in a paediatric service occurring in any non-acute or acute setting. Assessment within emergency department (ED) counts if performed by paediatric team rather than an ED team. Some paediatric neurologists see referrals direct from GP or ED and these would count as both a first paediatric assessment and tertiary input.
<b>Focal seizures (also called partial seizures)</b>	These are seizures that happen in, and affect, only part or one side of the brain (not both sides of the brain) and start from a 'focal point' in the brain. What happens in focal seizures varies depending on which part of the brain is affected and what that part of the brain normally does. Some people may have seizures arising from multiple parts of the brain, called 'multifocal seizures'
<b>Frontal lobe seizures</b>	Focal seizures that start in the frontal lobe. Simple focal seizures from the frontal lobe include making strange movements or stiffness or jerking in part of the body such as the arm. Seizures with impaired awareness from this area include making strange postures with the arms or legs or making juddering movements.
<b>General examination</b>	Any evidence of a multisystem examination of the child other than neurological examination
<b>General practitioners (GP)</b>	A doctor based in the community who treats patients with all common medical conditions with minor or chronic illnesses and refers those with serious conditions to a hospital. for urgent and specialist treatment. They focus on the health of the whole person combining physical, psychological and social aspects of care.
<b>Generalised seizures</b>	Seizures that happen in, and affect, both sides of the brain from the start. There are many different types of generalised seizures, but they all involve the person becoming unconscious, even just for a few seconds, and they won't remember the seizure itself. The most well-known generalised seizure is the tonic clonic (convulsive) seizure.
<b>Genetic</b>	The information in the DNA in our cells that controls our characteristics, for example hair colour, sex and height.
<b>Handover clinic</b>	A clinic where a young people 'leaves the paediatric service and joins an adult service' and comprises both adult and paediatric health professionals.
<b>Infantile spasms (also called West Syndrome)</b>	A rare childhood epilepsy syndrome that starts in the first year of life. The child has brief jerks or spasms of the arms, legs or whole body, often in clusters. Some children have problems with learning or behaviour.
<b>Input</b>	Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact.

<b>Juvenile myoclonic epilepsy (JME)</b>	A type of childhood epilepsy syndrome that starts between the ages of 11 and 18 years. The person usually has myoclonic seizures when they are waking up and might also have absences and tonic clonic seizures. This syndrome usually responds well to medication.
<b>Ketogenic diet</b>	A high fat, controlled protein, low carbohydrate diet that helps control seizures in some children with epilepsy. The diet works by encouraging the body to get energy from fat (rather than from carbohydrates). When this happens, the body produces chemicals called ketones which, for some children, help prevent seizures from happening.
<b>Ketosis</b>	The process of producing ketones in the body, when the body uses fat for energy.
<b>Learning disability (also called intellectual disability)</b>	A learning disability affects the way a child learns and understands things when compared to other children of the same age. Some children may have both epilepsy and learning disabilities, and they may or may not be caused by the same underlying problem. Around 20% of people with epilepsy also have a learning disability.
<b>Magnetic resonance imaging (MRI)</b>	A type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body. An MRI scanner is a large tube that contains powerful magnets.
<b>Mental Health Provision</b>	Co-located mental healthcare within paediatric epilepsy services. For example, this may take the form as a mental health professional attending MDT meetings or epilepsy clinic appointments.
<b>Mental Health Screening</b>	Routine, formal assessment of mental health issues within paediatric epilepsy services. For example, a screening questionnaire or clinical enquiry.
<b>Midazolam</b>	A type of medication that is given to someone who is having prolonged or repeated seizures, to stop status epilepticus from happening. Buccal means it is given into the mouth between the teeth and the cheek. Midazolam is a type of 'emergency' or 'rescue' medication.
<b>Multidisciplinary team</b>	A group of healthcare staff of different professions or disciplines that work together to make decisions regarding the treatment of individual patients.
<b>Myoclonic seizure</b>	A type of generalised seizure where just part of the body (for example, a leg or an arm) suddenly jerks. Myoclonic jerks often happen in clusters (several happening in a row) and often early in the morning.
<b>Neurodisability</b>	<p>Documented diagnosis including any of the following phrases indicating the diagnosis made by the assessing team:</p> <ol style="list-style-type: none"> <li>1. Autistic spectrum disorder</li> <li>2. Moderate, severe (or profound) learning difficulty or global development delay</li> <li>3. Cerebral palsy</li> <li>4. Neurodegenerative disease or condition</li> <li>5. An identified chromosomal disorder with a neurological or developmental component</li> <li>6. Attention deficit hyperactivity disorder (ADHD)</li> </ol> <p>Exclusions e.g. hypermobility, dyspraxia, specific learning difficulties e.g. (dyslexia, dyscalculia)</p>
<b>Neurological examination</b>	Any assessment of sensory and motor responses, especially reflexes, to determine if the nervous system is impaired. This can include a physical exam and a review of the child's medical history.

<b>Non-epileptic seizure</b>	Also called dissociative seizures (these used to be called pseudoseizures). An episode that appears similar to an epileptic seizure, but not caused by unusual electrical activity in the brain. This may involve convulsions, stiffening, behavioural arrest, loss of awareness, and other symptoms. This is often linked to stress or trauma. Some people may have both epilepsy and non-epileptic seizures.
<b>OPEN UK</b>	The Organisation of Paediatric Epilepsy Networks in the UK. A clinical network connecting NHS Health Boards and Trusts that provide care for children with epilepsies with regional epilepsy networks and a UK Working Group.
<b>Paediatrician with expertise</b>	A paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having: <ol style="list-style-type: none"> <li>1. training and continuing education in epilepsies</li> <li>2. AND peer review of practice</li> <li>3. AND regular audit of diagnosis (e.g. participation in Epilepsy12)</li> </ol> <p>(Consensus Conference on Better care for children and adults with epilepsy- Final Statement, Royal College of Physicians of Edinburgh, 2002). A paediatric neurologist is also defined as a 'paediatrician with expertise'.</p>
<b>Parietal lobe seizures</b>	Focal seizures that start in the parietal lobe. Simple focal seizures from the parietal lobe include feeling numb or tingling in part of the body, a burning sensation or feeling of heat, or feeling that parts of the body are bigger or smaller than they really are. Seizures with impaired awareness from this area are rare.
<b>Paroxysmal episodes</b>	This is the term chosen in this audit to represent the events causing concern. It includes all epileptic and non-epileptic seizures and also seizures of uncertain in origin.
<b>Participation</b>	In the clinical audit, defined as locking at submitting at least one First Year of Care form by the audit deadline. In the organisational audit, defined as completing the organisational audit form by the audit deadline.
<b>Prolonged seizure</b>	Any convulsive seizure that continues for more than 2 minutes longer than a person's usual seizure. If the seizure continues for a total of 5 minutes or more, it is considered convulsive status epilepticus.
<b>Psychiatrist</b>	A medically trained doctor who specialises in mental health problems. Psychiatrists are medically qualified and can prescribe medications.
<b>Psychologist</b>	Someone who studies the way the mind works and how people behave. Clinical psychologists are trained to help people manage mental health and social problems and they cannot prescribe medications.
<b>Refractory epilepsy</b>	Epilepsy that does not respond to AEDs (AEDs do not stop the seizures). This is also called intractable, drug-resistant or difficult to control epilepsy.
<b>Rescue medication</b>	Medication that is given to a person when they are having prolonged or repeated seizures to stop status epilepticus from happening. It is usually either rectal diazepam or buccal midazolam. These are only given in an emergency: they are not the same as AEDs, which are taken every day to prevent seizures.
<b>Risk assessment</b>	An assessment of someone's safety and possible risks. This might be at work, at home or any other area. Assessments look at risks to health and safety as well as ways to reduce risk, such as making reasonable adjustments or taking safety measures.

<b>'School age'</b>	Child 4 years and older (past their 5 <sup>th</sup> birthday).
<b>School Individual Healthcare Plan</b>	A written plan of care regarding health needs coordinated and held by a patient's school, with input and agreement from parents and relevant healthcare professionals.
<b>Secondarily generalised seizures</b>	Seizures that start as a focal seizure (in part of the brain) but the seizure activity spreads and affects the whole of the brain. In simple terms these are 'small seizures' that become 'big seizures'. The focal seizure start is sometimes called an 'aura' or 'seizure warning', and the seizure usually spreads to become a tonic clonic seizure.
<b>Seizure</b>	A sudden, short-lived event that causes a change in the person's behaviour, awareness or consciousness. There are lots of different causes and types of seizures including epileptic seizures, hypoglycaemic (diabetic) seizures, non-epileptic seizures, syncope (fainting), and seizures caused by a heart problem.
<b>Seizure control</b>	When seizures are completely stopped, and the person experiences no seizures anymore. This is usually achieved by taking AEDs.
<b>Seizure formulation</b>	<p>A classification of epileptic seizures and epileptic syndromes based on the following axes:</p> <ol style="list-style-type: none"> <li>1. Description of seizure (ictal phenomenology)</li> <li>2. Seizure type (e.g. tonic, absence, myoclonic)</li> <li>3. Syndrome (e.g. Dravet syndrome, West syndrome)</li> <li>4. Aetiology (e.g. generalised, frontal lobe, multifocal)</li> </ol> <p>A patient may have multiple seizure classifications within their formulation. A seizure may be unclassified.</p>
<b>Seizure-free</b>	When a person's seizures are fully controlled and stop happening (they don't have seizures anymore).
<b>Severe Myoclonic Epilepsy in Infancy (SMEI)(also called Dravet Syndrome)</b>	A rare childhood epilepsy syndrome that starts in a child's first few years of life. The child has jerking seizures, usually on one side of the body. They may also be photosensitive. Learning, speech and general development may be affected.
<b>Sodium valproate</b>	An anti-epileptic drug taken regularly to treat epilepsy, among other conditions. If taken during pregnancy, sodium valproate can cause problems for a baby's development.
<b>Sudden Unexpected Death in Epilepsy (SUDEP)</b>	When a person with epilepsy suddenly dies and no reason for their death can be seen.
<b>Symptomatic epilepsy</b>	Epilepsy where there is a known physical cause of the person's seizures. This could be due to a scar on the brain, an accident or head injury, or a stroke or brain tumour. Structural causes can often be seen on an MRI.
<b>Syncope</b>	When someone loses consciousness and collapses because the oxygen getting to their brain temporarily stops. This can be because of a drop- in blood pressure, a change in the heartbeat (and not enough blood is pumped through the heart), or because of a reduced amount of oxygen in the blood. Syncope is also another word for 'faint'.
<b>Status epilepticus</b>	A seizure that lasts longer than 5 minutes, or more than one seizure within a 5 minute period without recovery in between seizures. This is a life threatening condition and can be convulsive or nonconvulsive.

<b>Temporal lobe seizures</b>	Focal seizures that start in the temporal lobe. Simple focal seizures from the temporal lobe include an epigastric rising sensation, a sudden feeling of fear or joy or a funny taste or smell.
<b>Tonic clonic seizure</b>	A type of generalised seizure where the person stiffens (the 'tonic' part), falls down if they are standing, and then shakes, jerks or convulses (the 'clonic' part).
<b>Tonic seizure</b>	These are seizures where muscles in the body become stiff. Unlike tonic clonic seizures, the person does not experience any convulsions.
<b>Transition</b>	When the management of someone's epilepsy moves ('transfers') from a paediatrician to an adult neurologist. Transition usually happens at around 13 – 18 years of age.
<b>Treatment plan</b>	A record of the number and types of AED taken, when to take them and what to do if they do not work or need adjusting or changing. This is also called a drug plan
<b>Vagus nerve</b>	The vagus nerves connect to many different parts of the body and passes messages between the brain and various organs, including the throat, the heart, organs in the chest and abdomen.
<b>Vagus Nerve Stimulation (VNS)</b>	A type of treatment for epilepsy. It involves having a generator implanted in the chest wall attached to electrical wires around the vagus nerve in the neck. The generator sends regular electrical signals through the vagus nerve into the brain. For some people, this prevents or reduces the brain activity that causes seizures, and can reduce the number, length or severity of seizures they have.
<b>Video telemetry</b>	A test which involves having an EEG and being videotaped at the same time. This means that the EEG recording of a seizure can be compared to what is seen happening to the person. This can help to diagnose epilepsy and non-epileptic seizures.
<b>Whole Time Equivalent (WTE)</b>	A way of indicating staffing availability, where 1 WTE is equivalent to one full time staff member. For example, a staff member working 3 out of 5 weekdays would total 0.6 WTE.



# Useful resources

## The Royal College of Paediatrics and Child Health (RCPCH)

The Royal College of Paediatrics and Child Health (RCPCH) was founded in 1996. We play a major role in postgraduate medical education, professional standards, research and policy. The RCPCH has a number of useful resources, including:

- **British Paediatric Surveillance Unit** [rcpch.ac.uk/work-we-do/bpsu](http://rcpch.ac.uk/work-we-do/bpsu)

The BPSU is a world leading centre for rare paediatric disease surveillance. It enables doctors and researchers to investigate how many children in the UK and Republic of Ireland are affected by particular rare diseases, conditions or treatments each year.

- **Courses and continuing professional development** [rcpch.ac.uk/education/courses](http://rcpch.ac.uk/education/courses) and [rcpch.ac.uk/education/continuing-professional-development](http://rcpch.ac.uk/education/continuing-professional-development)

The following pages describe the audit's reports and resources, and other related outputs from the College.

- **Epilepsy12 Reports and resources** [rcpch.ac.uk/work-we-do/clinical-audits/epilepsy12/reports-resources](http://rcpch.ac.uk/work-we-do/clinical-audits/epilepsy12/reports-resources)
- **Epilepsy 12 Frequent reporting dashboard** <https://www.rcpch.ac.uk/resources/epilepsy12-audit-dashboard>
- **Epilepsy12 Youth Advocates** [rcpch.ac.uk/resources/epilepsy12-youth-advocates](http://rcpch.ac.uk/resources/epilepsy12-youth-advocates)

A group of epilepsy experienced or interested children, young people and families who volunteer together to improve care for epilepsy patients and their families. Established in 2018, the Epilepsy12 Youth Advocates formed to support the Epilepsy12 national audit programme.

- **Invited reviews** [rcpch.ac.uk/invitedreviews](http://rcpch.ac.uk/invitedreviews)

We support healthcare organisations, commissioners and clinical teams to resolve concerns about paediatric service provision, safety, training, compliance with standards, and proposals for paediatric reconfiguration or service design. Our service is confidential, established and influential, and tailored to each organisation's needs.

- **Medicines for children** [medicinesforchildren.org.uk](http://medicinesforchildren.org.uk)

The Medicines for Children website provides parents and carers with free information they can trust on over 200 medicines commonly prescribed to children; specifically developed to advice parents and carers how to give medicine to their child

- **MedsIQ** [qicentral.rcpch.ac.uk/medsiq](http://qicentral.rcpch.ac.uk/medsiq)

Medication errors are a significant but preventable cause of harm to children and young people.

- **Research activities** [rcpch.ac.uk/work-we-do/research-activities](http://rcpch.ac.uk/work-we-do/research-activities)

We aim to improve children's health outcomes through supporting high quality and trusted research. Let's share our expertise, collaborate with others and promote the evidence to drive forward improvements in child health.

- **RCPCH EQIP** [rcpch.ac.uk/eqip](http://rcpch.ac.uk/eqip)

The first paediatric epilepsy QI collaborative in England and Wales, supporting epilepsy service teams to identify sustainable improvements within their services for children and young people with epilepsy.

- **RCPCH Child Protection portal** [childprotection.rcpch.ac.uk](http://childprotection.rcpch.ac.uk)

RCPCH Child Protection portal is an online resource to help inform clinical practice, child protection procedures, and professional and expert opinion in the legal system.

- **RCPCH QI Central** [qicentral.org.uk](http://qicentral.org.uk)

QI Central is a free online resource open to all child health professionals. As an online repository of peer-reviewed tools and projects, healthcare professionals are also able to submit their own projects and resources to share their experiences with others and propagate knowledge in quality improvement.

- **Workforce and service design** [rcpch.ac.uk/workforce](http://rcpch.ac.uk/workforce)

We play a key role in workforce planning to ensure there is an appropriately trained paediatric medical workforce to deliver safe and sustainable services for children in the UK - in the present and in the future.