



Epilepsy

What it is, Diagnosis, Investigations and Treatment

An information booklet for parents/carers on Epilepsy

What is Epilepsy?

Epilepsy is currently defined as a tendency to have recurrent seizures (sometimes called fits). It is a neurological disorder and there is often no known cause.



A seizure is caused by a sudden burst of excess electrical activity in the brain, causing a

temporary disruption in the normal message passing between brain cells. This disruption results in the brain's messages becoming halted or mixed up.

Diagnosis

The diagnosis of epilepsy is mainly based on the description of the seizure given by the person themselves and any eye witness accounts. At the moment, there is no single test available that can say if someone does or does not have epilepsy.

Because there are so many different seizure types and symptoms, epilepsy can be a difficult condition to diagnose. It is important for doctors to know what type of seizure a person has, so they can decide on the most suitable course of treatment. This is why it is so helpful to keep a diary and even take a video, when someone has a seizure.

Investigations

Electroencephalogram (EEG)

The EEG is a painless investigation that tells doctors about the activity of the brain. During an EEG, electrodes are placed on the scalp using a special glue or sticky tape. These electrodes are connected to the EEG machine that records - on paper or computer - the electrical signals from the brain. It is important to remember that an EEG only shows what is happening in the brain at the time it is being carried out. An abnormal EEG does not necessarily mean that someone has epilepsy and a normal EEG does not necessarily mean that someone does not have epilepsy. However, it is a common test in investigating epilepsy and can be very helpful to doctors.

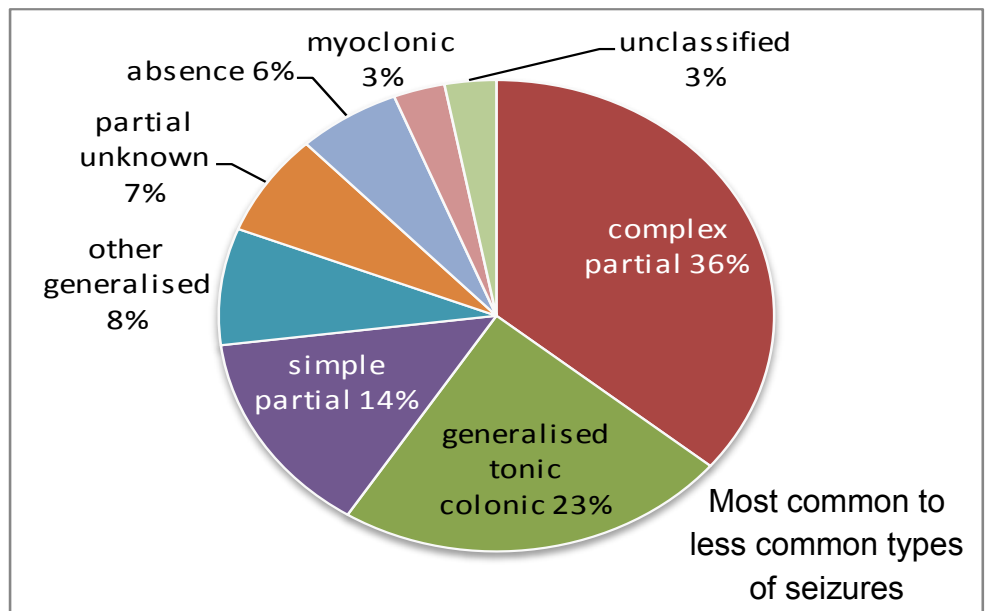


CT Scan

This scan is a type of X-ray that looks at the structure of the brain. It does not show if someone has epilepsy but it may show if there is an abnormality that could cause epilepsy. It will not be appropriate or necessary for everyone to have a CT scan.

MRI Scan

Like the CT scan, the MRI can show if there is a structural cause for a person's epilepsy. However, the MRI is a more powerful machine, so it may pick up abnormalities that the CT scanner may not detect. The MRI uses radio waves and a magnetic field, rather than X-rays.



Treatment

At the moment there is no cure for epilepsy. However, with the right type and dosage of anti-epileptic medication, about 70 per cent of people with epilepsy could have their seizures completely controlled. All medication can have side effects, although the majority of people will experience few or relatively mild side effects. If you are concerned about any possible side effects then it is important to talk to the doctor who may suggest changing either the dosage or the drug itself.

Other Treatments

- Vagal nerve stimulation
- Surgery
- Ketogenic diet



Lobes of the brain

The Frontal lobe

Because the frontal lobe of the brain deals primarily with movement, the symptoms are sometimes called 'motor seizures'. The person may feel their head drawn to one side. Sometimes their arm or hand becomes stiff and is drawn upwards. Some people then experience some jerking movements in that limb.

Because this lobe also controls part of our speech, some people experience 'speech arrest', resulting in an inability to talk or not being able to be understood. After this type of seizure, which again is usually only brief, the person can experience a short period of weakness. In rare instances people can be briefly paralysed and this is known as 'Todd's paralysis'.

The Occipital lobe

This area is responsible for vision. The symptoms of seizures in this area are to do with the way we see things. Flashing lights, balls of light or strange colours are typical symptoms, affecting half of the vision.

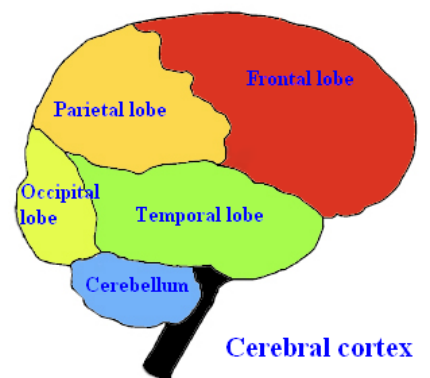
The Parietal lobe

The parietal lobe deals with our bodily sensations and simple partial seizures beginning in this part of the brain cause strange physical sensations. A tingling or warmth down one side of the body is typical. Because the parietal lobe is closely associated with the frontal lobe, people sometimes experience movement too. Known as 'sensory seizures' the after effect can be a period of numbness which wears off after a while.

The Temporal Lobe

The temporal lobe is involved in memory, speech, auditory and visual perception.

Typical symptoms of epileptic activity in the temporal lobe area are flushing or sweating, going very pale, or a churning feeling in the stomach. People's perceptions can be changed: some think things are bigger or smaller than they really are or experience hallucinations.



Other symptoms can be intense feelings of fear, panic, sadness or happiness, or feeling detached from one's environment. A common symptom is the experience we all know as *déjà vu*, when we are convinced we have been somewhere or witnessed something before. Conversely, some people find very familiar things become unrecognisable - *jamais vu*.

Types of Seizures

Complex Partial Seizures

In these types of seizures a person's consciousness is altered. This alteration of consciousness during a complex seizure does not mean the person falls to the floor but it does mean they will not remember the seizure or their memory of it will be distorted. However, to onlookers it may seem that the person is fully aware of what they are doing.

Complex partial seizures can take the form of 'automatisms' such as chewing and swallowing, repeatedly scratching the head or searching for an object. Some people may even undress. Occasionally, a person may wander off, recovering full awareness minutes or even hours later, unable to remember anything.

Complex partial seizures can spread to the rest of the brain. When this happens the resulting seizure is called a secondary generalised tonic-clonic seizure. If the spread of activity happens quickly it may appear to be a straightforward tonic-clonic seizure.

Simple Partial Seizures

The difference between complex partial and simple partial seizures is that, during simple partial seizures, the person remains conscious and fully aware. However, this does not mean that the person experiencing this type of seizure is able to stop or control the symptoms. Simple seizures can affect movement, emotion and sensations.

The electrical activity which causes a simple partial seizure is confined to one small part of the brain. What a person experiences during one of these seizures depends on which part of the brain is affected.

Tonic-Clonic Seizures

Tonic-clonic seizures are the most common form of generalised seizures. In a tonic-clonic seizure, the person loses consciousness, the body stiffens, and then they fall to the ground. This is followed by jerking movements. After a minute or two, the jerking movements usually stop and consciousness slowly returns.

Tonic Phase

This is the part of the seizure when the person goes stiff, because all the body's muscles contract. The person may appear to cry out, because the muscles in the lungs contract and force air out. Breathing becomes irregular, resulting in a lack of oxygen in the lungs. This can cause the skin (especially around mouth) to look blue, a condition called cyanosis. Occasionally, the person may lose control of their bladder or bowels.

Clonic Phase

This phase of the seizure follows the tonic phase. This is when the limbs jerk, caused by the muscles contracting and relaxing in quick succession. During this period, the person may bite their tongue and the inside of their cheeks. It is not possible to stop the seizure and nobody should try to restrict the person's movements – this could cause damage to their limbs.

Recovery

After a minute or so, the muscles relax and the person's body goes limp. At this stage the person is deeply unconscious and nothing will rouse them. Slowly they will regain consciousness, but may be groggy and confused. Gradually they will return to normal, but may not be able to remember anything for a while. The person will not remember anything about the seizure when they come round and they will need time to recover. Recovery time varies from minutes to hours. Many people will have a headache and aching limbs, which may last for hours or days after the seizure.

Absence Seizures

Absence seizures are generalised seizures, affecting both sides of the brain at once. However, they do not affect the entire brain. This type of seizure usually affects children, most commonly beginning between the ages of six and twelve. It is very rare in adults.

During an absence seizure the child stops what they are doing, loses awareness of their surroundings and stares. It can appear to onlookers that they are daydreaming or switching off. However, the child cannot be alerted or woken up, because they are momentarily unconscious. Around half of children who have absences may also display other symptoms during the seizure, such as smacking their lips, chewing, swallowing repeatedly or fiddling with their clothes. Their eyelids may also flicker slightly.

When an absence is over, the child is unlikely to be aware of what has happened, but may have the feeling that they have 'missed' something. Most children do not feel tired or ill after this type of seizure. Absence seizures generally only last for a few seconds. They can happen several times a day. Some children may have hundreds of them during a day, although this is rare. However, if the seizures are very brief they can be difficult to spot.

What to do if someone is having a Seizure

- Protect the person from injury - remove harmful objects from nearby
- Cushion their head
- Look for an epilepsy identity card or identity jewellery
- Aid breathing by gently placing them in the recovery position once the seizure has finished
- Stay with the person until recovery is complete

Don't:

- Restrain the person's movements
- Put anything in the person's mouth
- Try to move them unless they are in danger
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

Call for an ambulance if:

- You know it's the person's first seizure
- The seizure continues for more than 5 minutes
- One tonic-clonic seizure follows another without the person regaining consciousness between seizures
- The person is injured during the seizure
- You believe the person needs urgent medical attention



Epilepsy in Schools

If your child has epilepsy, it is important that you feel confident that they are safe when they are at school. You should also be confident that if your child has a seizure at school, they will be given the appropriate first aid or emergency medicine.

In September 2014, new guidance came into effect, placing a legal requirement on schools in England to support children with medical conditions.



This guidance means that children with epilepsy should have full access to education. They should have the support they need to do as well as they possibly can with their studies. They should also enjoy the same opportunities at school as any other child, which includes PE and school trips.

They should not send your child home frequently, or prevent them from staying at lunch time, unless there is a good reason for this.

If your child needs their emergency medicine during school time, it should only be administered by a named person. They should have been trained how to do this by a professional, such as an epilepsy specialist nurse. The people who can administer it will be named in your child's individual healthcare plan (IHP).

Useful Contacts

Epilepsy Action

They are the main UK epilepsy organisation and their role is improve the lives of everyone affected by the condition. They are a member-led association, who represent people with epilepsy, their friends, families and healthcare professionals.

The logo for Epilepsy Action, featuring the words "epilepsy action" in white lowercase letters on a red rectangular background.

Provides information about coping with epilepsy and seizures. They provide free help and advice through email and telephone helplines.

Email: helpline@epilepsy.org.uk

Web: www.epilepsy.org.uk

Helpline: 0808 800 5050 (free UK calls)

Epilepsy Action Tyneside

The logo for Epilepsy Action Tyneside, featuring the words "epilepsy action" in white lowercase letters on a red rectangular background, with "Tyneside" written in smaller white lowercase letters below "action".

Epilepsy Action Tyneside (EAT) is a local branch of the national charity Epilepsy Action which aims to provide an information and support service to those affected by epilepsy in Tyneside and surrounding regions. Contact them for more information about epilepsy and the service they provide.

They hold a monthly support group in the centre of Newcastle, which is suitable for anyone aged 18 years and over affected by epilepsy, including parents of young children with epilepsy. The meetings are unsuitable for children themselves.

Tel: 07756 721 831

(please leave a voicemail message, including your name and contact number, and they will get call you back as soon as possible)

Email: epilepsyactiontyneside@gmail.com

Web: www.epilepsyactiontyneside.webs.com

Epilepsy Society

The logo for Epilepsy Society, featuring the words "epilepsy society" in a stylized, lowercase font.

Works towards a full life for everyone affected by epilepsy.

Web: www.epilepsysociety.org.uk

Email: fromthehelpline@epilepsysociety.org.uk

National Helpline: 01494 601400

(Mon, Tue, Thu, Fri, 9.00am - 4.00pm & Wed 9.00am - 8.00pm)

Young Epilepsy

A national charity working with children/young people aged 25 and under with epilepsy and associated conditions.

The logo for Young Epilepsy, featuring a green star icon to the left of the words "Young Epilepsy" in a bold, sans-serif font.

They provide a range of support and advice for parents, children and young people.

Helpline: 01342 831342 (Mon - Fri 9am - 1pm)

Email: helpline@youngepilepsy.org.uk

Web: www.youngepilepsy.org.uk

Newcastle Special Educational Needs and Disabilities Information, Advice and Support Service



This service provides information specialising in education matters and includes information and signposting on social care and health issues.

Contact: Judith Lane

Tel: 0191 284 0480

Contact

The logo for Contact, featuring the word "contact" in a lowercase, rounded, sans-serif font.

(New name for Contact a Family)

Helping families in the North East who care for disabled children.

Tel: 0191 213 6300

Email: northeast.office@contact.org.uk

Web: www.contact.org.uk

Look for advice in your area - select North East

Local Offer

The Local Offer describes the services available for children/young people with special educational needs or disabilities (SEND) aged 0 - 25 and their families.



Email: localoffer@newcastle.gov.uk

Web: www.newcastlesupportdirectory.org.uk

Select SEND Local Offer

Skills for People

This booklet is produced by the Skills for People, a charity run by disabled people. We are based in Newcastle upon Tyne and for over 25 years we have been helping disabled people to speak up for themselves and make their own choices about their lives. Our work is led by disabled people and their experiences are at the heart of all we do.

Our Family Advice Workers support families with disabled children/young people up to the age of 25. They help families by giving practical advice, appropriate to their needs and working across all agencies such as education, social care, health, benefits, leisure and voluntary services. Their services are free to parents/carers.

We produce a range of information booklets, factsheets and "How To" guides. Visit our website to see the full range: www.nsn.org.uk/resources

How to get in touch

Skills for People
Key House
Tankerville Place
Newcastle upon Tyne
NE2 3AT

Telephone: 0191 281 8737

Fax: 0191 212 0300

Email: info@skillsforpeople.org.uk

Website: www.skillsforpeople.org.uk

Facebook: facebook.com/skillsforpeople

Twitter: [@skillsforpeople](https://twitter.com/skillsforpeople)



Facebook: on.fb.me/1istYKg



Newcastle parents of children with disabilities
and special needs working together

Facebook: Pass it on Parents Newcastle

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