A photograph of three people sitting around a table, looking at and discussing documents. A woman on the left is wearing a grey cardigan over a blue top. A man in the center is wearing a dark grey t-shirt and glasses. A person on the right is wearing a red and white plaid shirt. They are all focused on the papers in front of them. The background is a wooden floor and a red wall.

Epilepsy Awareness & Seizure Management Training

Epilepsy awareness and seizure management:

- an introduction to epilepsy
- causes and diagnosis
- types of seizures (including management and first aid)
- status epilepticus
- treatments – medication and sides effects
- risk management and support needs

OBJECTIVES

At the end of the session the delegates will be able to:

- give examples of how epilepsy can affect a person physically
- give examples of how epilepsy can affect a person socially and psychologically
- briefly describe how epilepsy is diagnosed and treated
- list the actions you would take to support someone during a seizure

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The National Society for the Employment of Epileptics (NSEE) was launched in 1892 by a group of London philanthropists and medical men. The aim of the Society was to establish a 'colony' for people with epilepsy who were capable of work but couldn't find employment due to their condition and the prevailing social attitudes of the time. At that time, many people with epilepsy were confined to workhouses or asylums due to difficulties in finding work and lodgings.

Once sufficient money had been raised, the Society bought Skippings Farm near Chalfont St Peter. The first home was a temporary iron building and water was supplied through a horse driven pump. In 1894 the first patients (or colonists, as they were called) were admitted; they were all men and were charged 10 shillings a week, although financial help was provided from an annuity fund for those who couldn't afford the full amount. The original staff consisted of a lady superintendent, a bailiff, a male attendant, a nurse and a female servant.

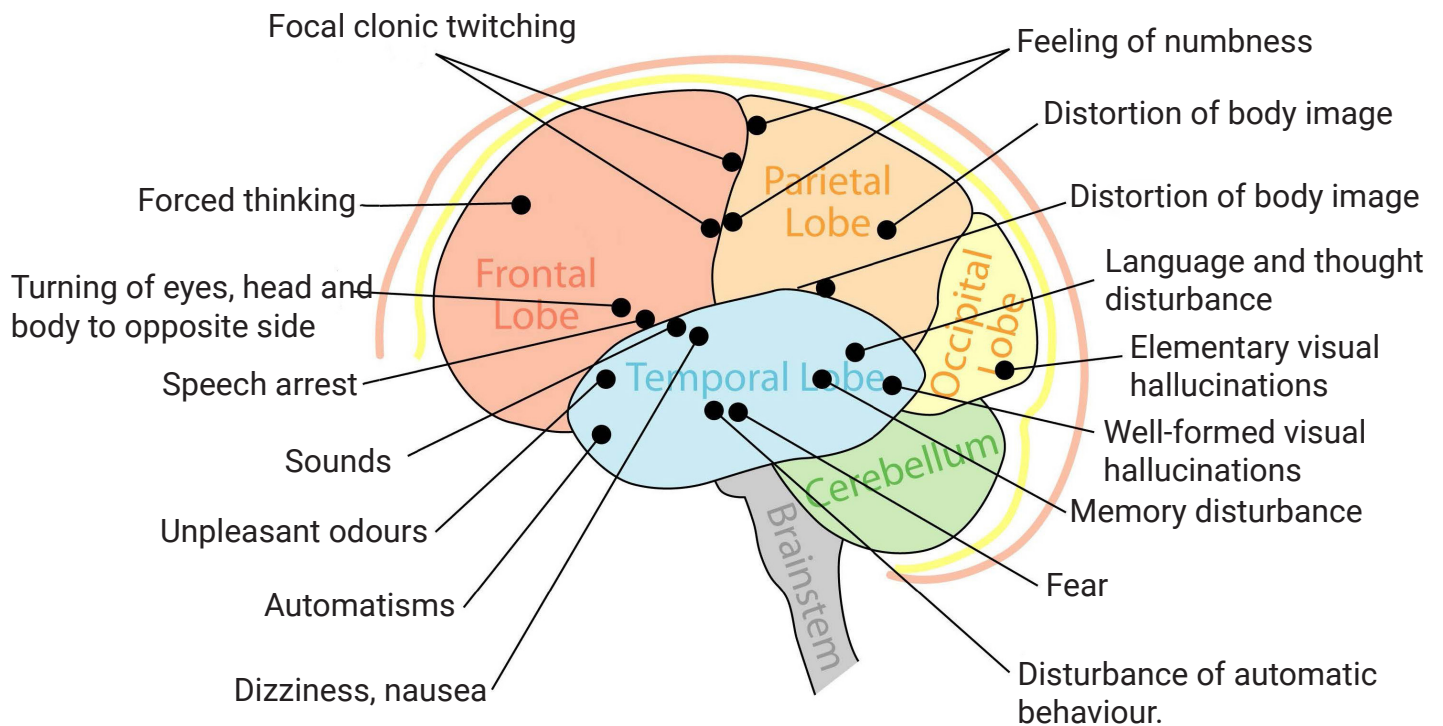
Only people considered to be of 'reasonable behaviour and mental ability' were admitted to the colony. They worked six days a week on the land or did domestic work in the home. Later on the men undertook other work such as carpentry, plumbing, painting and bricklaying. It was believed that the fresh air and hard work was beneficial to the patients' health and well-being - perhaps more so than drugs and doctors. However the men were visited regularly by medical staff from the National Hospital for the Paralysed and Epileptic in London, some of whom had been responsible for the founding of the NSEE. At this time, the headquarters of the Society were in London and the colony was planned and run from there.

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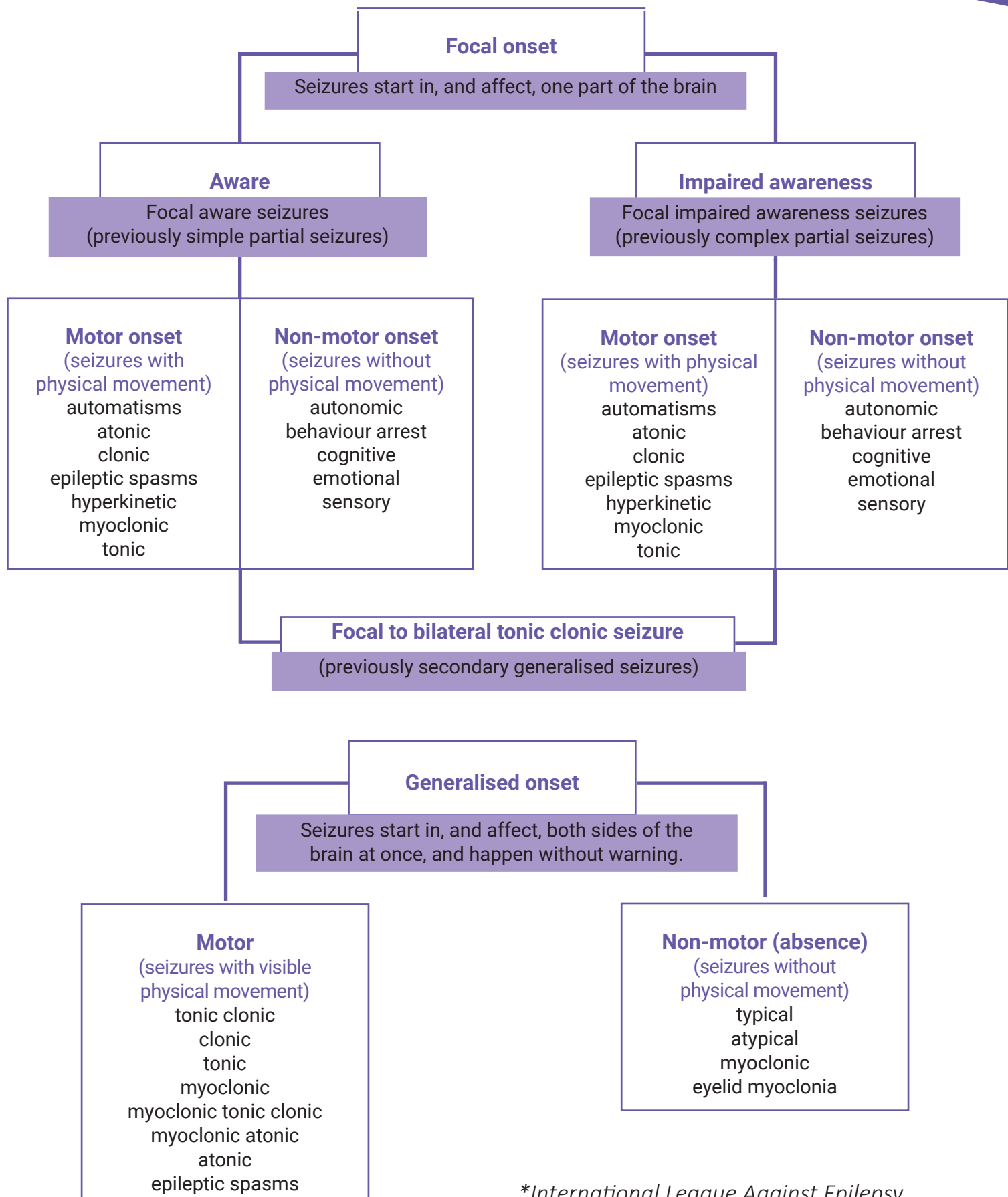


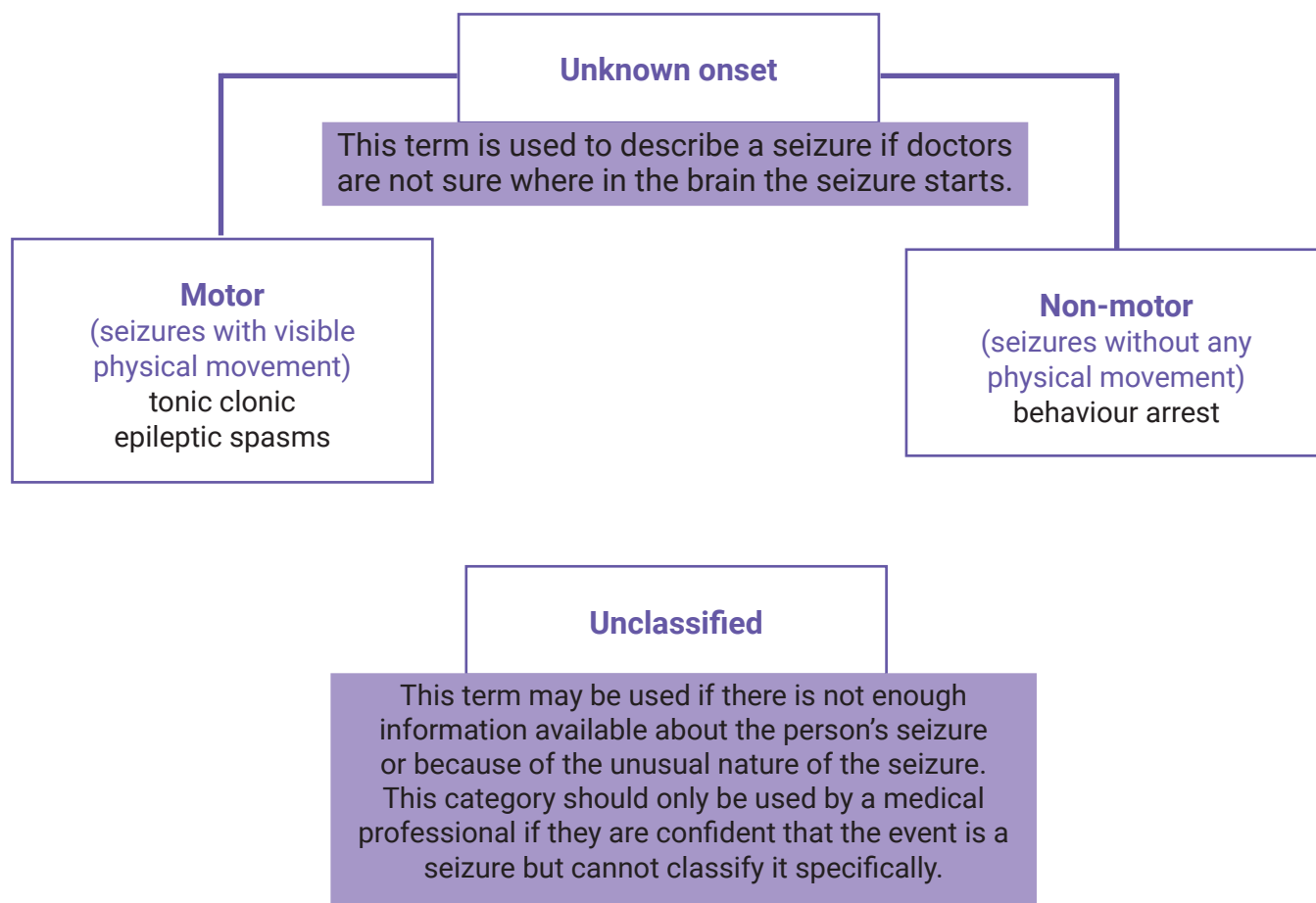
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***ILAE 2017 Classification of seizure types****International League Against Epilepsy*



Summary of terms

Focal onset – seizures that start in, and affect, just part of the brain, sometimes called the ‘focus’ of the seizure. May affect a large part of one hemisphere (side) of the brain or just a small area in one of the lobes. Sometimes a focal seizure can spread to both sides of the brain (see focal to bilateral tonic-clonic seizures below).

Focal aware seizure (previously simple partial seizures) – person is conscious (aware and alert), will usually know that something is happening, and will remember the seizure afterwards. Some people find these seizures hard to put into words. During the seizure they may feel ‘strange’ but not be able to describe the feeling afterwards. This may upset or frustrate them.

Focal impaired awareness seizure (previously complex partial seizures) – affects a bigger part of one hemisphere than focal aware seizures. Consciousness is affected and the person may be confused. They may be able to hear you, but not fully understand what you say or respond or react as they would normally. Afterwards they may be confused, sometimes called ‘post-ictal’ (after-seizure) confusion. It may be hard to tell when the seizure ends. They may be tired, want to rest, and may not remember the seizure afterwards.

Motor onset – focal seizures that involve movement. What happens during focal aware and focal impaired

awareness seizure depends on where in the brain the seizure happens and what that part of the brain normally does.

Terms used to describe seizures include:

- Automatisms – automatic movements that have no purpose. These often look strange or unusual and include lip-smacking, making chewing movements, repeatedly picking up objects or pulling at clothes.
- Atonic – opposite of tonic (below). Muscles suddenly lose tone and go floppy. The person will fall (usually forwards) if they are standing and may injure their head and face, when they fall. Seizures are usually very brief and the person regains consciousness very quickly.
- Clonic – rhythmic jerking of limbs on both sides of the body and often head, neck, face, and trunk.
- Epileptic spasms – muscles in the arms and legs suddenly bend and/or flex. Seizures usually happen in clusters (many happening close together in time) and last longer than myoclonic seizures (see below).
- Hyperkinetic – repeated movements such as, leg pedalling, or rocking.
- Myoclonic – meaning ‘muscle jerk’. Muscle jerks are not always due to epilepsy (for example, some people have them as they fall asleep). Seizures are brief but can happen in clusters.

- **Tonic** – muscles suddenly become stiff. The person will fall (usually backwards) if they are standing and may injure the back of their head. Tonic seizures tend to be very brief and happen without warning.

Non-motor onset – focal seizures that don't involve movements, but may involve unusual feelings or sensations.

Terms used to describe seizures include:

- **Autonomic** – unusual sensations such as, a 'rising' feeling in the stomach, feeling hot or cold, flushing of the skin, goose bumps, or a change in heart or breathing rate.
- **Behaviour arrest** – a brief pause in activity and responsiveness.
- **Cognitive** – difficulty remembering words, confusion, and déjà vu (feeling like you've 'been here before').
- **Emotional** – sudden intense feelings of fear or joy, anger, anxiety, laughing, or crying.
- **Sensory** – seeing coloured or flashing lights, hallucinations (seeing something that isn't actually there), getting an unusual smell or taste.

Focal to bilateral tonic-clonic (previously secondary generalised tonic-clonic seizure) – sometimes focal seizures spread from one side to both sides of the brain. The person becomes unconscious and will usually have a tonic-clonic (shaking) seizure. If this happens very quickly, they may not be aware that it started as a focal seizure.

Generalised onset – affects both sides of the brain at once and happen without warning. The person will be unconscious (except in myoclonic seizures), even if just for a few seconds and afterwards will not remember what happened during the seizure.

Terms used to describe generalised seizures that involve visible signs of movement include:

- **Tonic-clonic** – person becomes rigid and falls. During the seizure the limbs jerk and shake as the muscles relax and tighten rhythmically. Breathing may become difficult or sound noisy, and skin may change colour and become very pale or bluish.

They may wet themselves. Tonic-clonic seizures are the seizures most people think of as epilepsy.

- **Clonic** – rhythmic jerking of all limbs and often

head, neck, face, and trunk.

- **Tonic** – muscles suddenly become stiff. The person will fall if they are standing (usually backwards), and may injure the back of their head. Seizures tend to be very brief and happen without warning.

- **Myoclonic** – meaning 'muscle jerk'. These are not always due to epilepsy (for example, some people have them as they fall asleep). Seizures are brief but can happen in clusters.

- **Myoclonic-tonic-clonic** – seizures begin with a few myoclonic jerks followed by tonic-clonic activity. These seizures are common in people with Juvenile myoclonic epilepsy (JME).

- **Myoclonic-atonic** – brief jerking of arms, legs or trunk, followed by a limp drop. Common in Doose syndrome, Lennox-Gastaut, and other syndromes.

- **Atonic** – muscles suddenly relax and become floppy. If the person is standing they often fall, usually forwards, and may injure the front of their head or face. Like tonic seizures (above), atonic seizures tend to be brief and happen without warning.

- **Epileptic spasms** – muscles in the arms and legs suddenly bend and/or flex. Seizures usually happen in clusters and last longer than myoclonic seizures.

Terms used to describe absence seizures that do not involve any physical movement, but that start with a change in awareness include:

- **Typical absence** – the person becomes blank and unresponsive for a few seconds. Because seizures are brief, they may not be noticed. The person may stop what they are doing, look blank and stare, or their eyelids might blink or flutter. They will not respond to what is happening around them. If they are walking they may carry on walking, but will not be aware of what they are doing.

- **Atypical absence** – similar to typical absences but start and end more slowly, and last a bit longer than typical absences. Because they also include a change in muscle tone, where the limbs go limp some people may fall.

- **Myoclonic absence** – similar to typical absence seizures, but these seizures also involve repetitive myoclonic jerks.

- **Eyelid myoclonia** – repetitive, very brief movements of the eyelids. The person will stare upwards at the same time.

Unknown onset – this term is sometimes used to describe a seizure if doctors are not sure where in the brain the seizure starts. This may happen if the person was asleep, alone or the seizure was not witnessed.

Unclassified – if there is not enough information about a person's seizure, or if it is unusual, doctors may call it an unclassified seizure.

For more information about the ILAE classification of seizure types visit ilae.org/guidelines/definition-and-classification/operational-classification-2017

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Focal onset seizures

Focal onset seizures start in, and affect, one part of the brain: either a large part or just one small area.

Focal onset seizures are divided into two main categories:

- **aware** - the person is aware of the seizure and what is happening around them (their level of awareness); and
- **impaired awareness** - the person's consciousness is affected and they may be confused. They might be able to hear you, but not fully understand what you say or be able to respond to you.



Focal onset seizures

and.....

two sub-categories:

- **motor** – seizures with visible signs of physical movement; and
- **non-motor** – seizures which don't involve any physical movement and may be difficult to detect, for example changes in sensation, or emotion.



Focal aware seizures

Previously called 'simple partial seizures'

During a focal aware seizure the person is conscious, will usually know that something is happening and will remember the seizure afterwards. They may experience unusual smell or taste, a twitching of an arm or hand, a strange feeling such as a 'rising' feeling in the stomach or a sudden feeling of joy or fear.

How to help:

- as the person might feel 'strange' or be upset, reassuring them might be helpful.



Focal impaired awareness seizures

Previously called 'complex partial seizures'

During a focal impaired awareness seizure the person's consciousness is affected and they may be confused. They might be able to hear you, but not fully understand what you say or be able to respond to you.

How to help:

- do not restrain the person as this may upset or confuse them;
- gently guide them away from any danger, for example from walking into the road; and
- speak gently and calmly as they may be confused. If you speak loudly or grab them they might not understand and get upset or respond aggressively.



Focal to bilateral tonic-clonic seizures

Previously called 'secondary generalised seizures'

Focal seizures may spread from one side to both sides of the brain. The person will become unconscious and will usually have a tonic-clonic ('convulsive' or shaking) seizure.

How to help:

- if the person is aware of a warning, they may need help to get to a safe place before the generalised seizure happens. Follow directions for managing generalised seizures.



Generalised onset seizures

Tonic-clonic and clonic (convulsive) seizures

During a tonic-clonic seizure the person goes stiff ('tonic' phase), usually falls to the ground, and shakes or makes jerking movements ('clonic' phase).

- breathing may be affected and they may go pale or blue, particularly around their mouth.
- they may bite their tongue.
- some people have clonic seizures without going stiff to start with.



Generalised onset seizures

Tonic-clonic and clonic (convulsive) seizures

How to help:

- try to stay calm
- check the time to see how long the seizure goes on for (because there may be a risk of status epilepticus)
- only move the person if they are in a dangerous place, for example in the road.
- move any objects, such as furniture, away from them so that they don't hurt themselves
- put something soft (such as a jumper) under their head, or cup their head in your hands, to stop it hitting the ground
- do not restrain them or hold them down - allow the seizure to happen
- do not put anything in their mouth - they will not swallow their tongue
- try to stop other people crowding around.

Generalised onset seizures

Absence seizures

Absence seizures can be confused with daydreaming. However, unlike daydreaming, someone who is having an absence seizure will not usually respond. Also, if blank spells happen when someone is doing something that they enjoy, such as talking or playing a game, then this is less likely to be daydreaming.

During a typical absence seizure the person becomes unconscious for a short time. Because the seizures are brief, they may not be noticed.

- they may look blank and stare, or their eyelids might flutter.
- they will not respond to what is happening around them. If they are walking they may carry on walking but will not be aware of what they are doing.

An atypical absence seizure is similar to typical absence, but last a bit longer. It can include a change in muscle tone, where limbs go limp or floppy.

How to help: gentle reassurance may be helpful.

Generalised onset seizures

Tonic and atonic seizures

- **During a tonic seizure** the person's muscles suddenly become stiff and if they are standing they often fall backwards and may injure the back of their head.
- **During an atonic seizure** the person's muscles suddenly relax and become floppy. If they are standing they often fall forwards and may injure their face or head.
- Both these seizures are brief and happen without warning. Most people usually recover quickly.
- **How to help:** reassurance may be helpful. If they are injured they may need medical help.

Generalised onset seizures

Myoclonic seizures

- **During a myoclonic seizure** a limb or part of a limb will jerk. These seizures often happen shortly after waking up, are brief and can happen in clusters (many happening close together in time).
- **How to help:** you don't need to do anything to help during the seizure other than make sure that the person has not hurt themselves.



1. Kneel on the floor to one side of the person.



2. Place the person's arm that is nearest to you at a right angle to their body, so that it is bent at the elbow with the palm facing upwards. This will keep it out of the way when you roll them over.



3. Gently pick up their other hand with your palm against theirs (palm to palm). Turn any rings inward to avoid scratching their face. Now place the back of their hand onto their opposite cheek (for example, against their left cheek if it is their right hand). Keep your hand there to guide and support their head as you roll them over.



4. Use your other arm to reach across to the person's knee that is furthest from you, and pull it up so that their leg is bent and their foot is flat on the floor.

See next page for steps 5 to 7.

The recovery position can help someone recover after a tonic clonic seizure. These steps should be followed once the shaking has stopped.

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5. Gently pull their knee towards you so that they roll over onto their side, facing you. Their body weight should help them to roll over quite easily.



6. Move their bent leg that is nearest to you, in front of their body so that it is resting on the floor. This position will help to balance them.



7. Gently raise their chin to tilt their head back slightly, as this will open up their airway and help them to breathe. Check that nothing is blocking their airway. If there is an obstruction, such as food in their mouth, remove this if you can do so safely. Stay with them, giving reassurance, until they have fully recovered.

For our video of how to put someone into the recovery position visit epilepsysociety.org.uk/recovery-position-video recovery position.



Call for an ambulance if:

- it is the person's first seizure;
- they have injured themselves badly;
- they have trouble breathing after the seizure has stopped;
- one seizure immediately follows another with no recovery in between;
- the seizure lasts 2 minutes longer than is usual for them; or
- the seizure lasts for more than 5 minutes.

For a printed copy of this information contact our helpline (details above).

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Some people cannot remember what happened to them during a seizure and may not be aware that they have even had one. This can make it difficult for them to describe their seizures to their specialist. If you have witnessed a seizure, the questions below may be helpful for the person to share with the specialist.

How did the seizure start?

If known, when the seizure started, was the person awake ☐ or asleep? ☐

Was the person restless or did they cry out before the seizure started?

Was there any trigger for the seizure (such as feeling tired, stressed, excited, or unwell)?

What position were they in when the seizure happened or when they were found?

Standing ☐ lying on front ☐ lying on back ☐ lying on side ☐ sitting ☐ other

Did they appear to have any warning beforehand? If so, what did you notice?

Did they have any unusual sensations, such as a taste or smell, a rising feeling in the stomach, numbness, or pins and needles? When did they experience this?

Was there any change in muscle tone (did they become stiff or floppy)?

Did they fall down and, if so, forwards or backwards?

Did they lose awareness, appear dazed or confused or lose consciousness?

This factsheet lists what can be useful to know about someone's epilepsy, and what to look out for and note, before, during, and after a seizure. This may help a doctor to confirm a diagnosis or identify the type of seizures someone is having.

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for opening hours.

Was there any change in their breathing pattern? Did they have difficulty breathing?

Did their face change colour? Did they become pale, blue around the mouth, or flushed?

Were their eyes open or closed during the seizure? If open, were their eyes turned to one side (which side)?

Was there any movement, such as jerking or twitching? If so, was this rhythmical? Was it on both sides of the body or on one side only and, if so, which side? Was it symmetrical (exactly the same on both sides) or not symmetrical?

Were there any automatisms (automatic behaviours) such as wandering around, chewing or lip-smacking, making strange movements or postures with their limbs, picking up objects for no reason, or fiddling with clothing?

Did they make any noises, such as mumbling, not making sense, or repeating words or phrases?

How long did the seizure last?

Were they incontinent (did they wet themselves)?

Did they bite the inside of their cheek or their tongue?

How were they afterwards? Were they confused or sleepy? If they slept afterwards, for how long? Or were they immediately back to their normal selves?

How long did it take for them to fully recover and return to normal activities?

Epilepsy Society is grateful to Dr F J Rugg-Gunn, Consultant Neurologist & Honorary Associate Professor Clinical Lead, Chalfont Centre for Epilepsy, who reviewed this information.

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Contact our Helpline on **01494 601400** or email **helpline@epilepsysociety.org.uk**

ESNA - Epilepsy Specialist Nurses Association

[esna-online.org](https://www.esna-online.org)

NICE - National Institute for Health and Care Excellence, Epilepsies: diagnosis and management

[nice.org.uk/guidance/cg137](https://www.nice.org.uk/guidance/cg137)

CQC – Care Quality Commission

[cqc.org.uk/content/controlled-drugs](https://www.cqc.org.uk/content/controlled-drugs) **[cqc.org.uk](https://www.cqc.org.uk)**

MHRA – Medicines and Healthcare products Regulatory Agency

[gov.uk/government/publications/supply-unlicensed-medicinal-products-specials](https://www.gov.uk/government/publications/supply-unlicensed-medicinal-products-specials)

ILAE – International League Against Epilepsy

[ilae.org](https://www.ilae.org)

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Epilepsy awareness follow-up questions



Your name: Date:.....

1. Give two examples of how epilepsy can affect a person physically.

2. Give two examples of how epilepsy can affect a person socially and psychologically.

3. How is epilepsy diagnosed?

4. Name some of the treatments for epilepsy.

5. List three actions you would take to support an individual experiencing a seizure.

Tell us what you think



We really welcome your feedback on today's course, so we can make sure future courses are as informative and helpful as possible for all who attend. **Please take a few moments to complete this form and hand it to your trainer before you leave.**

Thank you.

Date..... Trainer

Please rate the following statements:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Training objectives were clearly described.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interaction and participation were encouraged.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Topics covered were relevant to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The content of the course was easy to follow.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The delegate pack and handouts were helpful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The training will be useful for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The trainer was knowledgeable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The trainer was well prepared.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Training objectives were met.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient time was allowed for Q&A.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What have you learnt from attending this training?

What will you do differently as a result of this training?

What could be done to improve this training?

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