East of England
Community Health and Care
NHS Trust

Seizure Information and First Aid

Patient details:

Name:

Date of birth:

NHS No:

Address:

Tel no:

Mobile:

Email:

Family/carer contact details:

Name:

Relationship:

Tel no:

Mobile:

Email:

Healthcare professional contact details:

GP: Tel no:

Consultant: Tel no:

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A - Tonic-clonic (convulsive) seizures
Tonic-clonic seizures are the type of epileptic seizure most people recognise. In the past they were called grand-mal seizures. Tonic-clonic seizures can have a generalised onset, meaning they affect both sides of the brain from the start. Or they can start in one side of the brain and then spread to affect both sides. When this happens it's called a focal to bilateral tonic-clonic seizure.

What happens during a tonic-clonic seizure?
There are 2 phases in a tonic-clonic seizure: the 'tonic' phase, followed by the 'clonic' phase.

During the tonic phase:
You lose consciousness, so you won't be aware of what's happening
All your muscles go stiff, and if you're standing you fall to the floor
Air might push past your voice box, which can make a sound like you're crying out
You may bite down on your tongue or inside your mouth
During the clonic phase:
Your limbs jerk quickly and rhythmically
You may lose control of your bladder and/or bowels
Your breathing may be affected, causing a blue tinge around your mouth

Focal to bilateral tonic-clonic seizures
If the seizure starts on one side of the brain and spreads to affect both sides, it's called a focal to bilateral tonic-clonic seizure. If you have this type of seizure, you might get the symptoms of a focal seizure immediately before you lose consciousness. Examples of these symptoms are feeling frightened, having a rising sensation in your stomach or smelling something that's not there. This can act as a warning that you're about to have a tonic-clonic seizure. Some people call this warning an aura.

How long do tonic-clonic seizures last?
Most tonic-clonic seizures last between one and 3 minutes. If a tonic-clonic seizure lasts longer than 5 minutes you may need emergency medical treatment.

What happens after a tonic-clonic seizure?
After a tonic-clonic seizure, you might have a headache and feel sore, tired and very unwell. You might feel confused, or have memory problems. You might go into a deep sleep. When you wake up, minutes or hours later, you might still have a headache, feel sore and have aching muscles.
The length of time it takes to recover after a tonic-clonic seizure is different from one person to the next. Some people feel better after an hour or 2, but for some people it can take several days to feel 'back to normal'.

Some people find they have temporary weakness or can't move part of their body after they've had a seizure. This is called Todd's paresis or Todd's paralysis. It can last from a few minutes up to 36 hours, before going away.

How to help if you see someone having a tonic-clonic seizure.
Do:
Protect them from injury (remove harmful objects from nearby)
Cushion their head
Look for an epilepsy identity card or identity jewellery – it may give you information about their seizures and what to do
Time how long the jerking lasts
Aid breathing by gently placing them in the recovery position once the jerking has stopped (see picture)
Stay with the them until they are fully recovered
Be calmly reassuring

Don't:
Restrain their movements
Put anything in their 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 999 for an ambulance if:
You know it is their first seizure or
The jerking continues for more than five minutes or
They have one tonic-clonic seizure after another without regaining consciousness between seizures or
They are injured during the seizure or
You believe they need urgent medical attention

B – Tonic Seizure
When someone has a tonic seizure the persons muscles will stiffen, this can happen on one or both sides of the body depending on the part of the brain effected. If they are not sitting or lying down, they may fall. Their lips may turn blue, and they may appear to stop breathing, this is because their chest muscles stiffen. The persons neck will extend, their eyes open wide and roll upwards, their arms may raise upwards, and legs may stretch or contract. These seizures are more likely to happen during sleep.

How long do tonic seizure last?
Tonic seizures are usually short-lasting up to 60 seconds, some people can have clusters of tonic seizure where they have several seizures, in a short space of time.

How to help if you see someone having a tonic seizure:
Start timing the seizure
Do not try to stop the seizure
Try to protect their head if they fall
Check for any injuries and administer first aid as required
Be understanding and talking reassuringly throughout the seizure
Repeat any information the person may have missed
Note length of time of seizure and record

Call 999 for an ambulance if:
The person has sustained an injury that requires more than first aid. You should consider calling 999 if you have concerns for any other reason.

C – Atonic Seizure
When someone has an atonic seizure the person will lose all muscle tone, and they will fall the floor. Falls can result in injury often to face, nose, or head. Sometimes the person will not completely fall (wheelchair bound) but their head may drop forward, or they may sag at the knees.

How long do atonic seizure last?
Atonic seizures are usually very short, and the person is usually able to get up again straight away.

How to help if you see someone having an atonic seizure
You should call an ambulance if an injury is sustained due to falling or more than first aid is required. You should consider calling 999 if you have concerns for any other reason.

Call 999 for an ambulance if:
The person has sustained an injury that requires more than first aid. You should consider calling 999 if you have concerns for any other reason.

D – Myoclonic seizures
Myoclonic seizures are also called myoclonic jerks. They can be generalised onset, meaning both sides of the brain are affected from the start, or they can be focal onset, meaning just one side is affected. Myoclonic seizures are sudden, short-lasting jerks that can affect some or all of your body. They are usually too short to affect your consciousness. The jerking can be very mild, like a twitch, or it can be very forceful. Sometimes if the jerk is very forceful it can make you throw something you're holding, or make you fall over. After a myoclonic seizure you're usually able to get back to what you were doing straight away.

How long do myoclonic seizures last?
Myoclonic seizures usually only last for a fraction of a second. However, some people have them in clusters of several seizures over a period of time.

How to help if you see someone having a myoclonic seizure:
Start timing the seizure and if appropriate consider videoing
Do not try to stop the seizure
Check for any injuries and administer first aid as required
Be understanding and talk reassuringly throughout the seizure
Repeat any information missed during episode
Note length of seizure and record

Call 999 for an ambulance if:
Any injury is sustained which required more than basic first aid or you have concerns for any other reason.

E - Focal seizures

When an epileptic seizure starts in one side of the brain, it's called a focal onset seizure or a focal seizure. Both terms mean the same thing. Until recently these seizures were called partial seizures. There are 2 main types of focal seizures:

Focal aware seizures - During a focal aware seizure, you stay fully aware of what's happening around you. This type of seizure used to be called a simple partial seizure. During a focal aware seizure, awareness is maintained even if you can't move or respond. Some people with epilepsy use the word 'aura' to describe the feeling they get that warns them they're about to have a tonic-clonic seizure. The aura is in fact the seizure starting in a single part of the brain as a focal aware seizure, before spreading to affect both sides of the brain. Focal aware seizures can also happen on their own, without developing into another seizure type.

Focal impaired awareness seizures - If your awareness of what's happening around you is affected at any time during your seizure, it's called a focal impaired awareness seizure. This type of seizure used to be called a complex partial seizure.

What happens during a focal seizure?

What happens to you during a focal seizure depends on which part of the brain the seizure happens in. This is because different areas of the brain control movements, body functions, feelings and reactions. Some people experience just one symptom during a focal seizure, while others experience several. The symptoms of focal seizures can be split into 2 groups. Symptoms that involve movement are called motor symptoms. Symptoms that don't involve movement are called non-motor symptoms. Here are some examples:

Motor symptoms	Non-motor symptoms
Part of your body, for example one arm, going stiff	Feelings of fear, anxiety, anger or pleasure
Part of your body going limp or 'floppy'	Changes to vision, hearing, smell or taste
Rhythmic jerking in part of your body	Sensations of being hot or cold
Brief, irregular jerks in part of your body	Seeing or hearing things that aren't there (hallucinations)
Your head and eyes turning to one side	Feeling like your body is distorted
Lip smacking, repeated swallowing or chewing	Feeling like part of your body is missing or doesn't belong to you
A jerking movement that starts in one part of your body – usually your hand or face – and then spreads bit by bit to other parts of your body	Feeling or being sick

Having repeated movements such as rocking, pedalling or pelvic thrusting	Changes to breathing, heart-rate or skin tone
Undressing	Feeling like what's happening has happened before (deja vu)
Running or walking	Difficulty processing language

How long do focal seizures last?
Most focal aware seizures are brief, lasting between a few seconds and 2 minutes. Focal impaired awareness seizures usually last between one and 2 minutes.

What happens after a focal seizure?
What happens after a focal seizure varies from person to person. You might feel fine after a focal seizure and be able to get back to what you were doing straight away. Or you might feel confused or tired for some time afterwards. You might need to sleep. Some people find they have temporary weakness or can't move part of their body after they've had a seizure. This is called Todd's paresis or Todd's paralysis. It can last from a few minutes up to 36 hours, before going away.

How to help if you see someone having a focal seizure.

Do:
Guide them away from danger (such as roads or open water)
Stay with them until recovery is complete
Be calmly reassuring and explain anything that they may have missed
Start timing the seizure
Start timing the seizure and if appropriate consider videoing

Don't:
Restrain them
Act in a way that could frighten them, such as making abrupt movements or shouting at them
Assume they are aware of what is happening, or what has happened
Give them anything to eat or drink until they are fully recovered
Attempt to bring them round
Try to stop the seizure

Call 999 for an ambulance if:
You know it is their first seizure or
The person is having a focal unaware seizure that continues for more than ten minutes
They are injured during the seizure or you believe they need urgent medical attention

G - Absence seizures

Absence seizures are a type of generalised onset seizure, meaning both sides of your brain are affected from the start. In the past absence seizures used to be called petit-mal seizures. The 2 most common types of absence seizure are typical and atypical.

What happens during an absence seizure?

Typical absences

If you are having a typical absence seizure, you will be unconscious for a few seconds. You will suddenly stop doing whatever you were doing before it started, but will not fall. You might appear to be daydreaming or 'switching off' or people around you might not notice your absence. Your eyelids might flutter and you might have slight jerking movements of your body or limbs. In longer absences, you might have some brief, repeated actions. You won't know what is happening around you, and can't be brought out of it.

Some people have hundreds of absences a day. They often have them in clusters of several, one after another, and they are often worse when they are waking up or drifting off to sleep. Typical absence seizures usually start in childhood or early adulthood.

Atypical absences

These absences are similar to, but not the same as, typical absences. They last longer, and they start and end more slowly. You might be able to move around, but your muscles might go limp or 'floppy', making you clumsy. You may be able to respond to someone during an atypical absence seizure. People who have atypical absences usually have learning disabilities or other conditions that affect the brain. Atypical absences can happen at any age.

How long do absence seizures last?

A single typical absence seizure usually lasts less than 10 seconds. But some people have clusters of absences one after another.
Atypical absence seizures last longer, up to 30 seconds.

What happens after an absence seizure?

After an absence seizure, you're normally able to go straight back to what you were doing beforehand. If you've had a cluster of several absence seizures you might feel confused.

How to help if you see someone having an absence seizure:

During the absence (especially if they are having a repeated absence) you may need to guide the person away from any danger. It is also important:
Stay with them until they are fully recovered

Be calm and reassuring
Explain anything they may have missed
If any injury has occurred medical help may be needed e.g. calling 999, attending A&E

Call 999 for an ambulance if:
If the the absence continues for more than 10-15 minutes, it can be regarded as abnormally prolonged

Special considerations:
Discussed the risks associated with seizures and general health and safety considerations relevant to living with epilepsy. Relevant QR codes are listed at the end of the care plan.

- **Bathing** – It is advised that having a shower is safer due to the risk of drowning if a seizure occurs whilst in the bath.
- **Driving** – Made aware of DVLA driving regulations regarding epilepsy and signposted to government website. If you are informed not to drive, it is your responsibility to notify the DVLA and voluntarily surrendered your driving license.
- **Cooking**: Using a kettle tipper, and wire baskets inside saucepans, to avoid lifting containers of hot water can help to reduce injuries. Use the hob rings at the back of the hob and turning pan handles to the side. Use a microwave or steamer rather than an oven and using plastic containers rather than glass ones.
- **Working/School/College/University** – Colleagues and friends must be aware of what to do in the event of you having a seizure.
- **Preconception counselling** - If you are thinking of starting a family, it is essential to talk to your neurologist about planning your epilepsy treatment in preparation for your pregnancy.
- **Contraception** - Some methods of contraception may be less effective in preventing pregnancy and some contraception methods may affect the levels of epilepsy medications. Please talk to your GP or local iCaSH regarding contraception.
- **Entitlements** – You may be entitled to a concessionary bus pass, disabled rail card and cinema card. We can provide supporting letter for these if you are experiencing on-going seizures
- **Assistive technology –** Advice provided on seizure alarms. You can self-refer by calling 0344 800 8020 or emailing information@norfolk.gov.uk
  Information also available through Epilepsy Action website:
  https://www.epilepsy.org.uk/living/safety-equipment
- **Apps –** What 3 words, MediSafe and ICE contacts.

Common seizure triggers

- **Medication** – Take medication as prescribed, missed doses can lead to seizure breakthrough. If a dose is forgotten there is a four-hour window to take the medication, after this time you will need to wait until your next dose. If you run out of medication, out of GP hours, you can call 111 who will be able to issue an emergency prescription. Discuss repeat prescription options with the pharmacist. You are entitled to free prescriptions, request exemption form FP92A from your GP.
- **Feeling unwell/high temperature –** Looking for the signs of an infection early to try and prevent seizures
- **Constipation -** constipation can lead to a build-up of toxins in the system and may lead to an increase in seizures
- **Sleeping** – It is important to have a good sleeping pattern as tiredness can be a trigger for a seizure.
- **Alcohol** – Be aware that drinking alcohol can trigger seizures this is more likely to happen when the alcohol is leaving the body, this could be up to a day later.
- **Stress** – Stress can cause you to have more seizures.
- **Flashing and flickering lights –** Lights can trigger a seizure in some patients it is important to look away from the light source
- **Menstrual cycle –** Seizures can increase at the time of ovulation as the oestrogen rises in the body
- **Missing meals** – It is important to eat regular meals to avoid fluctuations in your blood sugar levels which can impact on seizure.

Living with epilepsy;

The Epilepsy Nursing Team has a website which provides lots of helpful information about living with epilepsy. This can be found on the following link or via the QR code below;

https://www.eastofenglandcommunityhealthandcare.nhs.uk/our-services/norfolk-communityhealth-and-care-services/norfolk-adult-epilepsy-specialist-nurse-team/

Specific advice given as appropriate on:

- SUDEP (Sudden Unexpected / Unexplained Death in Epilepsy) is a rare risk, there are changes that you can make to reduce the risk further as explained above. For information about how to reduce your risks and take control; Tel 01235 77285 or visit SUDEP Action at www.sudep.org You can also download a free App for smart phones; EpSmon this helps you assess your personal risk factors and tells you how to reduce risk

Additional areas of support from the epilepsy charities helplines;

- Epilepsy Action, www.epilepsy.org.uk Helpline 0808 800 5050 is very good for advice on benefits, driving and employment, Monday - Saturday
- The Epilepsy Society, www.epilepsysociety.org.uk Helpline 01494 601 400 Monday, Tuesday and Wednesday, provides more of a listening service providing more emotional support.

Useful QR Codes

DVLA

Epilepsy Action – Contraception

MHRA (Medicines and Healthcare Products Regulatory Agency) epilepsy medications and pregnancy

Disabled Rail Card

Concessionary Bus Pass

CEA Card

Norfolk County Council Assistive Technology Team

To find out how we use what we know about you (Privacy Notice) and the services we provide please visit https://eastofenglandcommunityhealthandcare.nhs.uk and follow the links or contact us.