Medicare
Training

Manual for Epilepsy Care

During this module you will be asked some questions to simply provoke thought and test your current knowledge please have a note pad or supervision workbook to hand to make notes. Your performance will only be measured on the answers you select when completing the knowledge test at the end of the module.

Contents

Learning Outcomes

- Knowing the treatment and management options for individuals with epilepsy
- Understanding how to respond to seizures
- Knowing your role in supporting people with epilepsy
- Knowing about epilepsy
- Understanding possible factors that trigger seizures
- Recognizing signs and symptoms of different types of seizures

Complementary Manuals

- Basic First Aid
- Record Keeping
- Person-centred Approaches
- Care and Administration of Medication

Chapter One

Introduction to Epilepsy

Under the Health and Social Care Act 2008 your employer has a duty to make sure that you and your colleagues are given appropriate information, support and training to understand the differing needs of clients with chronic health issues. (Regulation 23. Supporting staff).

When they assess your care The Care Quality Commission will look for evidence of the following;

People using services are safe and their health and welfare needs are met by competent staff because employers:

- Ensure that staff are properly supported to provide care and treatment
- Ensure that staff are properly trained, supervised and appraised
- Enable staff to acquire further skills and qualifications that are relevant to the work they undertake

(Essential Standards of Quality and Safety, October 2010)

Epilepsy Definition

Seizures can happen to anyone, they may be isolated incidents which never happen again or they may be the first of many. Epilepsy is a condition which causes people to have repeated seizures; it is rare for a person who has only had one seizure to be treated for epilepsy. There are around 600,000 people with epilepsy in the UK and between 60 and 70% of these will have good control of their condition so it will not have a major effect on their day to day life. When the cause of epilepsy is identifiable the condition is known as secondary epilepsy; causes include brain injury, illnesses such as meningitis, and events which affect the flow of oxygen to the brain including strokes and birth trauma.

However, the majority of cases (around 60%) have no known cause; these are referred to as primary epilepsy. Although several types of epilepsy begin in childhood, and some people will grow out of it; the risk of developing the condition increases with age. Therefore, like many other age related health conditions, more people are being diagnosed with epilepsy than ever before.

The type of epilepsy a person has will be defined by their age and the type and frequency of their seizures.

Seizure definition

It is important for you to know what to expect when clients have a seizure; how to care for them before, during and after; and how, if at all, you can reduce the likelihood of seizures occurring. There are around 40 different types of seizure; people with epilepsy may experience more than one type. In Chapter 4 we will look at how people might be affected and how you should deal with seizures when they occur.

A seizure is the result of a surge of electrical activity which affects the functioning of the brain; the type of seizure a person experiences will depend on the part of the brain which is affected, the extent to which it is affected and the amount of time this ‘electrical interference’ lasts.

To manage their condition people should be educated about treatment options and medications; we will look at what’s available and why it’s important to follow doctors’ advice.

It is not always possible to prevent seizures altogether but individuals can minimise their risk; certain behaviours can make seizures more likely, these are referred to as triggers and they include; stress; lack of sleep; alcohol and drugs; poor medication compliance; stimuli such as flashing lights; infections and missing meals

In the next Chapter we will look at how you can support people with epilepsy to identify and avoid their own personal triggers; this will help them to feel in control of their condition.

Epilepsy and client care needs

The first book on epilepsy ‘On the Sacred Disease’ was written by the Greek physician Hippocrates around 400 BC.

Hippocrates recognized that epilepsy was a brain disorder, and he spoke out against the ideas that seizures were a curse from the gods and that people with epilepsy held the power of prophecy.

What a pity it took over 2,000 years for the rest of the world to catch up! People with epilepsy have been accused of witchcraft and of possession by demons and until last century were routinely confined to mental institutions.

Epilepsy is not a mental illness, it’s a physical illness that affects brain functions. People with epilepsy will not necessarily be disabled by it; they may have other conditions such as learning disabilities which have increased their risk of seizures, or they may have completely unrelated health conditions but many people with epilepsy live completely normal lives.

Clients must never be described as ‘epileptics’; epilepsy is not a label to sort people. Care must be person-centred and planned around the diverse needs, wants and beliefs of the individual. Some people with epilepsy have complex needs and require 24 hour support; others live independent lives in the community. Be careful not to develop low expectations; epilepsy is not always accompanied by a reduction in physical or mental function.

The abilities of people with epilepsy are as varied as any other randomly selected group of people. Many people with epilepsy work, raise families and hold driving licenses (if their seizures are under control) but there is such fear and ignorance about seizures that people with this condition can be discriminated against.

Chapter Two

Controlling Epilepsy

In this Chapter we're going to look at how people with epilepsy can take control of their illness and what your role is in supporting them to do this.

Clients should take their prescribed medication and follow their doctor's advice, but there are also psychological and social elements to good seizure management and this is where you can make a real difference to your clients' lives.

To safeguard your clients' health you should be supporting them to make 'good' lifestyle choices and helping them to access advice and information.

Outcome 1 of the Care Quality Commission's essential standards of quality and safety requires that 'people who use services must be given relevant information to encourage them to change lifestyle behaviours that are placing their health at risk, so they can make an informed choice about whether they wish to lead a healthier life.'

The Mental Capacity Act 2005

The Mental Capacity Act 2005 was designed to protect the rights of potentially vulnerable adults who might otherwise be prevented from making their own choices and decisions.

The Act is based on five key principles which together ensure that individuals are respected as competent adults; given every opportunity to make their own decisions and choices; treated fairly without prejudice or discrimination and supported to be as independent as possible.

The statutory principles

1. A person must be assumed to have capacity unless it is established that he lacks capacity
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action (Mental Capacity Act 2005 Code of Practice)

For further information about mental capacity go to www.publicguardian.co.uk and download a copy of the Mental Capacity Act 2005 code of practice. When you are working you must comply with the Mental Capacity Act and CQC guidance, therefore, it is up to your individual clients to decide whether to make changes or not. Even if you have to make decisions on a client's behalf you must base your decisions on your knowledge of their personal values, beliefs etc.

If you feel that individuals could benefit from changes in their lifestyle and behaviors you must find appropriate ways to encourage and support them. Your methods need to be gently persuasive without restricting people's rights and freedoms or overstepping the professional boundaries of your relationship.

Here are some examples of good and bad practice:

Good Practice:

- Make sure you are acting in the individual's best interests
- Use a person-centred approach based on fairness, respect and partnership
- Respect the individual's cultural and religious identity
- Identify benefits that mean something to the individual
- Educate, inform and empower

Bad Practice:

- Taking actions which restrict the individual's freedoms or rights
- Making assumptions about individual's knowledge or motivations
- Dismissing any fears or anxiety related to change
- Putting pressure on individuals to follow your values and beliefs

It is important that clients are given the information necessary to make their own minds up about health risks; it's also vital that their freedoms are not unnecessarily restricted in the interests of 'health and safety'.

How to control and avoid triggers

To help clients and their doctors and carers to work out circumstances which make their seizures more likely they should be supported to keep a seizure diary. This diary should be completed by witnesses to be as accurate as possible a record of the number, type and duration of an individual's seizures. Having identified possible factors increasing the likelihood of seizures you can then work with your client to reduce their exposure.

As we identified in Chapter 1 common triggers include:

- Stress
- Lack of sleep

- Alcohol and drugs
- Poor medication compliance
- Stimuli such as flashing lights
- Infections
- Missing meals

Stress can cause physical changes in the brain as well as affecting individuals' likelihood of remembering their medication and being motivated to take it. Increasing the individual's medication will not help, their stress must be treated by either dealing with the source or finding ways to help them relax.

Lack of sleep affects the brain's electrical activity; sleep deprivation is used as a form of torture because it can induce symptoms including seizures in people who do not have epilepsy. People who do have epilepsy have a lower tolerance or 'seizure threshold' and may be significantly affected if they don't get adequate sleep.

People with epilepsy should aim to maintain regular habits that allow for plenty of sleep. They should be discouraged from 'overdoing' it i.e. staying up late and then having to get up early.

Alcohol and drugs, including prescribed, may affect the way that medications work. Doctors should provide information about interactions. Some people with epilepsy will be unaffected by alcohol, others will not be able to tolerate it.

Clients should be encouraged to follow government guidelines for safe alcohol intake. Doctors should check for safe alternatives when prescribing drugs but if there are none close monitoring may be necessary.

It should also be noted that the use of alcohol (or recreational drugs) may also be associated with chaotic lifestyles and disrupted sleeping patterns potentially leading to an increased risk of seizures.

Poor medication compliance reduces people's control of their seizures. GPs who take a person-centred approach to prescribing; information and support increase the likelihood that medications will be taken correctly. Discreet monitoring may be necessary and reviews should be carried out if people are refusing medication or not taking it regularly.

Stimuli such as flashing lights may trigger seizures in a small percentage of people with epilepsy (5% of these have photosensitive epilepsy). Affected individuals should be supported to avoid the stimulus and to take appropriate medication.

Infections increase individuals' risk of seizure; the infection should be treated quickly and the person's condition should be monitored to maintain their safety.

Missing meals may lead to an increased risk of seizures in affected individuals; generally speaking people with epilepsy should try to maintain regular habits with a routine for eating and sleeping. People in your care should be monitored to ensure that they eat and drink regularly and in adequate amounts.

General Safety measurements

Risk assessments must be carried out for each individual client; you cannot have a generic one for everybody with epilepsy as the risks for each will be very different. Never generalize, always get to know individual clients' personal strengths and weaknesses.

People with epilepsy often suffer unfair discrimination from people and organisations who fail to recognise that their rights are the same as anyone else's. There are very few things which people with epilepsy are absolutely unable to do and they are generally extreme sporting activities. Risk should be assessed based on the reality of the individual's condition, not on a stereotypical view of what epilepsy is. For example as many people with epilepsy are perfectly adequate parents there is no reason why they can't be teachers or child carers but many people seem to find this hard to understand.

Avoid being condescending to people; if they have previously been independent without coming to any harm it's unlikely that they will suddenly need to be showering with the door open or staying away from sharp objects unless a significant health event such as a stroke has suddenly disabled them.

Good sources of safety advice and information are given at the end of this manual.

Depression

Mental and physical health are very closely linked; people with epilepsy are more prone to depression than the general population so it is important that you look out for the signs and symptoms and can offer support for clients to cope with poor mental health.

If you suspect that a client may be depressed refer them to their GP for further investigation. It is important that their treatment is closely monitored as anti-depressants may increase the frequency of seizures but anti-epilepsy drugs can help to stabilise mood.

Complementary therapies and herbal medications can interact with epilepsy medication so the GP should be consulted if these options are being considered.

Signs and symptoms of depression include:

- Feeling tired or having little energy
- Crying all or some of the time

- Lack of concentration
- Sleep problems
- Avoiding social contact
- Having little interest or pleasure in doing things
- Finding it hard to function
- Loss of appetite or overeating
- Physical aches and pains
- Feelings of despair and hopelessness

Chapter Three

Caring Epilepsy

If you suspect that one of your clients has had a seizure you must refer them to their GP who can investigate possible causes. Unless they are in a high risk group, for example if they have an existing brain injury, this will not result in a diagnosis of epilepsy.

If the client has further seizures they should then be referred to a specialist, usually a neurologist, for more detailed investigations such as scans and blood tests.

Other possible causes of seizures or their symptoms include:

- Fainting
- Transient Ischaemic Attack (mini stroke)
- Migraine
- Narcolepsy
- Hyperventilation
- Pseudo epilepsy

A wrong diagnosis of epilepsy can result in a person's lifestyle being unnecessarily restricted as well as putting them at risk of side effects from long term medication. When someone experiences seizures it is essential to get an accurate diagnosis and to identify appropriate treatment.

Epilepsy Diagnosing

As a first step doctors will want a detailed history of their patient; if your client is unable to communicate an appropriate person such as a relative or carer may have to provide information about the following:

- Medical history
- Medical history of close relatives
- Sleeping habits
- Alcohol consumption / illegal drug use
- Medication

There are a number of different types of epilepsy whose potential effects on the health and future of individuals can range from mild to severe. Some forms of epilepsy are temporary and will be outgrown and some will have such serious effects on the brain that the individual is likely to develop permanent mental and physical disabilities.

Note: If a person who has been diagnosed with epilepsy starts having more frequent or more serious seizures refer them to their GP for a review.

When diagnosing the type of epilepsy an individual has, doctors will look at factors such as their age and the type and frequency of seizures they experience. This information will help them to decide how best to treat the person's illness.

To aid diagnosis and treatment people who have seizures should be encouraged to keep a 'seizure diary' with as much detail as possible about the frequency, duration and effects of the seizures they have. These should be completed by witnesses to the events; if you are the witness try to time the seizure and note any defining features such as whether the person collapsed or maintained consciousness. (see Appendix A for a good example of a seizure record).

A properly completed seizure diary can be a helpful diagnostic tool as it should have been filled in soon after the event and is, therefore, likely to be more accurate than a person relying on memory. For doctors to give a proper diagnosis they will need to know as much as possible about the seizures the person has had. It may be necessary for them to talk to witnesses to get a clear picture of what happened as their patient will have had some loss of awareness even if they didn't lose consciousness.

Being diagnosed with a life altering condition can have a serious psychological affect; you should ensure that your client is offered both physical and emotional support in the time during and after diagnosis. For example:

- Someone they trust to accompany them to appointments
- Information in a suitable format that they can read at their leisure
- Help to understand complicated terminology; risks / benefits of treatment etc.
- Transport to and from appointments

Doctors may carry out various tests and examinations including blood tests, brain scans and physical examinations. Some tests will require a stay in hospital and many will involve specialised machinery which may be frightening for the individual. There is no single test to confirm or rule out a diagnosis of epilepsy.

Care and Treatment

By taking a person-centred approach to prescribing doctors can help to improve compliance; this is particularly important for the treatment of chronic conditions such as epilepsy when the medications can have unpleasant side effects and the benefits can be difficult to appreciate.

It's important that clients are given as much information as possible about their health and treatment options because for as long as they have capacity to make their own decisions it is entirely up to them whether they follow doctor's advice or not. Even if they lack capacity consideration must be given to the choices they would have made. It can be difficult to avoid interfering if someone is refusing to take vital medication but you have to respect their right to do so.

Carers should receive adequate information to understand what clients are taking and why so that they can promote compliance and monitor benefits and side effects effectively.
The way in which your clients' medication and treatment is prescribed and managed must meet the requirements of the Health and Social Care Act 2008 as regulated by the CQC.

Outcome 9: Management of medicines (Regulation 13) Health and Social Care Act 2008

Personalized care through effective medication

People who use services receive care, treatment and support that:

Ensures the medicines given are appropriate and person-centred by taking account of their:

- Age
- Choices
- Lifestyle
- Cultural and religious beliefs
- Allergies and intolerances
- Existing medical conditions and prescriptions
- Adverse drug reactions
- Recommended prescribing regimes

The aim of any treatment for epilepsy is to achieve control of seizures; for this reason you may see people's epilepsy being referred to as controlled or uncontrolled; these terms refer to the severity and frequency of their seizures.

Clients with epilepsy should be supported to follow any treatment regime developed for them; below are some of the medical options available to doctors.

Anti-Epilepsy Drugs (AEDs)

Anti-epilepsy drugs are intended to be taken daily to reduce the frequency and severity of seizures; they are not a cure for epilepsy and they are not for controlling seizures in an emergency. Ideally control will be achieved by a low dose of one type of medication thus minimising the likelihood of side effects; in practice doctors will often have to find the combination of drugs which best suits their patient.

The prescribing doctor must explain that these drugs might be a lifelong necessity and that an absence of seizures may be a sign that they are working well, not an indication that the person no longer has epilepsy.

Other options to choose

Anti-epilepsy drugs do not work for everyone so doctors may have to find other options. In some cases surgery may be considered; this can involve quite brutal sounding operations to disconnect parts of the brain. Doctors will only recommend surgery when the benefits and chances of success significantly outweigh the risks involved.

When clients cannot make decisions for themselves their family and carers may be involved in discussions with medical professionals to agree on a course of action that is in the client’s best interests. Particular care must be taken if invasive treatment is being considered or if there may be a need for medication to be given covertly.

Pseudo Epilepsy

Some people who have seizures do not have epilepsy but do have a psychological condition called pseudo epilepsy; to further complicate things, some people who do have epilepsy may also have pseudo epileptic seizures.

Your treatment of the individual should be the same regardless of their diagnosis but their medical treatment may need to be very different. Epilepsy medication will not work for pseudo epilepsy, the condition requires psychiatric treatment.

Chapter Four

Seizure classifications

There are nearly 40 different types of seizure; the seizures a person has may be similar in type and duration or may be a combination of different types. People may have several seizures a day, a couple a year, or none since they were prescribed appropriate medication.

The International League Against Epilepsy (ILAE), a world-wide organisation of epilepsy professionals, has compiled a list of names of different seizure types. This is called the ILEA seizure classification. The names given here to different types of seizures are based on this classification.

Currently agreed terms for seizures aim to define how much of the brain is affected and which part. Old fashioned terms such as ‘minor’ and ‘major’ or ‘grand mal’ and ‘petit mal’ are no longer in use as they are not descriptive of what actually happens.

Giving seizures the right names is important for doctors. This is because some drugs and treatments can help some seizure types but not others (ref www.epilepsy.org.uk)

Types of seizure are split into 2 main groups; focal (partial) affecting one side of the brain (cerebral hemisphere) or generalized affecting both sides of the brain and characterized by loss of consciousness. Individuals may have a generalized seizure after experiencing a focal one so appropriate monitoring is vital to maintain their safety.

Simple Focal Seizures (SFS)

Simple focal seizures affect a small part of one of the lobes of the brain; the effects will depend on which lobe of the brain these occur in. The person having the seizure will be conscious and may know that something is happening. Often people with these types of seizure find it hard to put their experience into words and this can be both frustrating and upsetting.

A simple focal seizure may cause:

- Stiffness or twitching in parts of the body
- An odd feeling like a wave going through the head
- Déjà vu
- An unusual smell or taste
- A sudden intense feeling of fear or joy
- Numbness or tingling

- A sensation that an arm or a leg is bigger or smaller than it is
- Visual disturbances such as colours or flashing lights
- Hallucinations

Complex Focal Seizures (CFS)

Complex focal seizures affect a bigger part of one hemisphere (side) of the brain than a simple focal seizure.

The person's consciousness will be affected and they may be confused. They might be able to hear you, but not fully understand what you say. They may not be able to respond to you and their reactions may seem abnormal.

Common symptoms include:

- Picking up objects for no reason or fiddling with clothing
- Chewing or lip-smacking movements
- Muttering or repeating words that don't make sense
- Wandering around in a confused way
- Making a loud cry or scream
- Making odd movements such as cycling or kicking

Focal Seizures Caring

- gently guide the person away from any dangers
- calm and reassure them
- remain with them until they fully recover
- monitor appropriately in case a generalised seizure follows
- if necessary call an ambulance

Common Generalized Seizures

All generalized seizures cause temporary loss of consciousness.

Absences

1-30 seconds of unresponsiveness; these may go unnoticed as they are of such short duration.

Myoclonic Seizures

Myoclonic seizures are more likely in the period after a person wakes up and they may cause minor accidents such as spilt drinks. People who experience these may need more support when they get up in the morning or after a nap.

These seizures are characterised by muscle jerks which can affect the whole body, but more usually affect the arms and head; they are similar to the jerks you may feel when falling asleep (but these are not related to epilepsy).

Tonic and Atonic Seizures

Tonic seizures are usually brief and happen without warning. The person's muscles stiffen and it is likely that they will fall.

Like tonic seizures, atonic seizures are usually sudden and short lasting. In an atonic seizure (or 'drop attack') the person's muscles suddenly relax, and they become floppy.

Tonic-Clonic

Tonic-clonic seizures involve:

- Sudden loss of consciousness
- General stiffening (tonic phase)
- Jerking of body (clonic phase)
- Possible incontinence
- Relaxation after stiffness and jerking stop

These are the types of seizure that everyone thinks of when they are asked what a seizure is.

Recovery should be quick but the experience may leave the individual fatigued and confused, they may also need treatment for a headache or injuries suffered during the seizure

Emergency aid during and after a tonic–clonic seizure (it will be best if the person responsible for this has first aid training)

Ensure the person's safety by moving objects that may injure them; if the ground is hard try to get something soft, like a jumper, under their head. Do not physically restrain or move the person unless they are at immediate risk of harm e.g. because they are lying in the road and traffic cannot be controlled.

Any physical restraint introduces a risk of harm; during this type of seizure the person's muscles tighten uncontrollably so they can be injured if their movement is restricted.

Protect the person's dignity by asking bystanders to leave the area and by covering the person's legs to hide evidence of any incontinence. Time the seizure and monitor the individual for signs of breathing difficulties.

When the seizure ends place the person in the recovery position and remain with them while they return to normal. Monitor their breathing, colour and responsiveness and be prepared to act if they become unconscious or stop breathing.

Call an ambulance:

- if you think this is a first seizure
- if the person is injured in any way
- if they have further seizures without regaining consciousness
- if the seizure lasts longer than 5 minutes or is unusual for this person
- if the person wants you to

Status Epilepticus

Status epilepticus in a tonic-clonic (convulsive) seizure is a medical emergency and the person will need urgent medical help. Call for an ambulance after five minutes.

An individual's seizures usually last the same length of time each time they happen, and stop by themselves. However, sometimes seizures do not stop, or one seizure follows another without the person recovering in between. If this goes on for 30 minutes or more it is called 'status epilepticus'. This is not common but it can happen in any type of seizure and the person may need to see a doctor.

Urgent Medication

Clients who are prone to prolonged seizures may be prescribed emergency medication to be injected, used as a suppository or dissolved in the mouth. If this is the case there must be detailed policies and procedures covering the following issues:

- who will administer the medication – the person must have specific training
- when medication is to be given
- when reviews are to be carried out

Sudden Unexpected Death in Epilepsy (SUDEP)

SUDEP kills around 500 people a year in the UK alone. Doctors do not know exactly why these deaths happen but risk factors include:

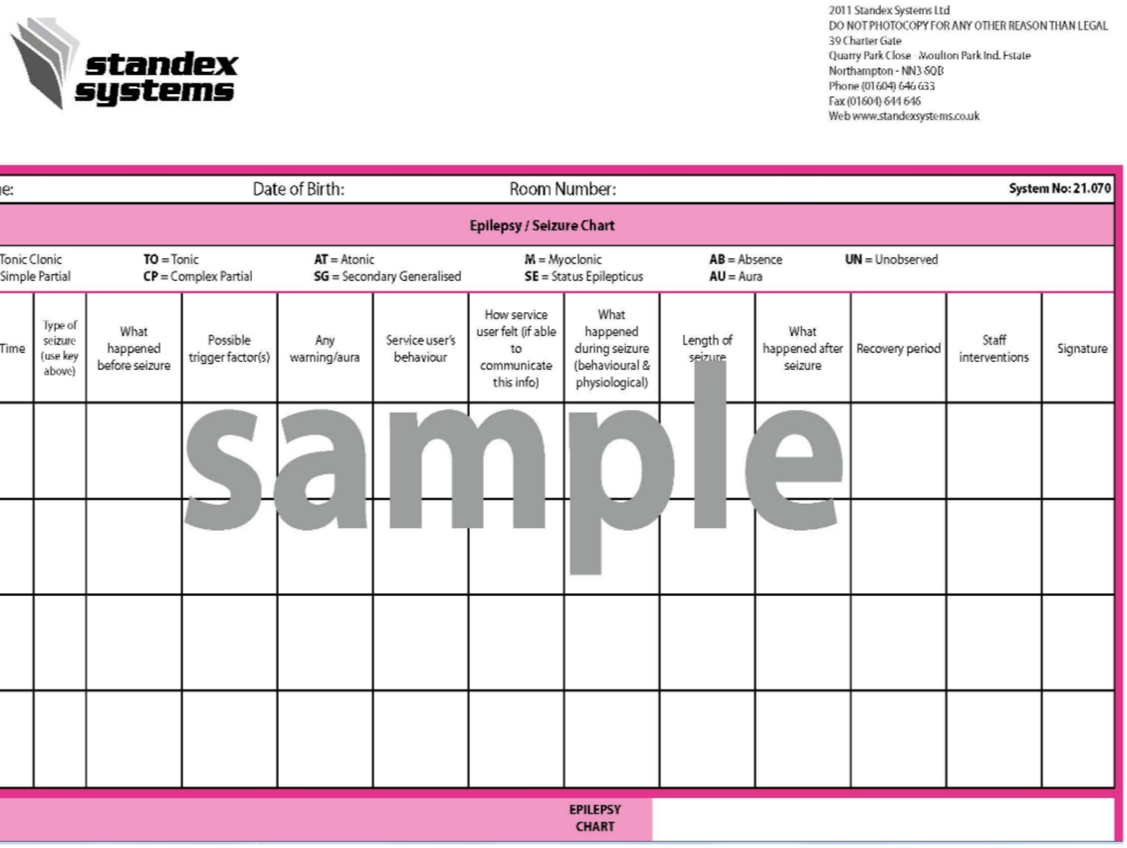
- poor control over seizures
- generalised nocturnal seizures
- learning disability
- being a young male
- not taking medication
- frequently or suddenly changing medication

If you identify clients as being at risk of SUDEP they may require discreet monitoring particularly at night; options should be discussed with the client, their GP and anyone else involved in their care.

Nocturnal Seizure

Despite the name these don’t always occur at night; nocturnal seizures are any type of seizure that occur while a person is asleep. Individuals who experience nocturnal seizures may be at increased risk of life threatening complications.

Useful Contacts	
National Society for Epilepsy	www.epilepsysociety.org.uk
01494 601400	
Epilepsy Action	www.epilepsy.org.uk
0808 8005050	
Epilepsy Research UK	www.epilepsyresearch.org.uk
0208 9954781	
Epilepsy Cymru / Epilepsy Wales	www.epilepsy-wales.co.uk
0800 2289016	
Joint Epilepsy Council	www.jointepilepsycouncil.org.uk



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Epilepsy / Seizure Chart

TC = Tonic Clonic
SP = Simple Partial
TO = Tonic
CP = Complex Partial
AT = Atonic
SG = Secondary Generalised
M = Myoclonic
SE = Status Epilepticus
AB = Absence
AU = Aura
UN = Unobserved

Date/Time	Type of seizure (use key above)	What happened before seizure	Possible trigger factor(s)	Any warning/aura	Service user's behaviour	How service user felt (if able to communicate this info)	What happened during seizure (behavioural & physiological)	Length of seizure	What happened after seizure	Recovery period	Staff interventions	Signature

EPILEPSY CHART