



The
Queen's
Nursing
Institute



Working with Epilepsy and Homelessness

Guidance for Community Nurses





Introduction

This guidance aims to improve knowledge, confidence and practice for community nurses supporting people with epilepsy experiencing homelessness.

Research evidence shows that people who are homeless are at increased risk of epilepsy than the housed population. In landmark research from France, even discounting the presence of alcohol-related seizures, 8% of a population of people who are homeless had active epilepsy (Laporte, 2006). This is at least 8 times the prevalence within the general population. Subsequent research conducted in the UK in 2013 found an epilepsy prevalence of 12% (Story, 2013).

However, epilepsy in this group is often difficult to manage. This is in part due to the fact that excessive alcohol use and brain injury are common precursors of homelessness, which also contribute to this higher prevalence of epilepsy (Lewer, 2019). In addition, people without a home often struggle to access primary care (Hodson et al, 2019) and specialist services for a variety of reasons including stigma. Stigma is related to both homelessness (Rae and Rees, 2015), and the condition itself (Laporte et al, 2006).

Many people experiencing homelessness suffer seizures, and these do not always result in an epilepsy diagnosis. However, anyone who experiences seizures should be assessed by a specialist to identify the cause, and any treatment that is required. This guidance helps nurses to understand what clinical steps to take when they identify that someone is experiencing seizures, and what care is needed. It also provides advice on basic safety and first aid, and where to get further help and support.

“Homelessness is associated with increased morbidity and mortality compared with the general population, and some medical problems are particularly prevalent such as seizures.” (Laporte et al, 2006)

Definition and prevalence of epilepsy?

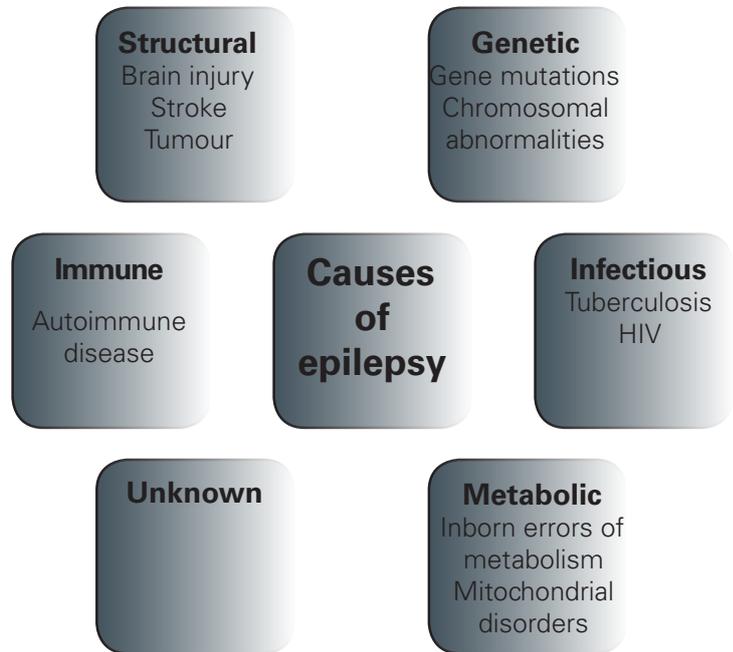
Epilepsy is considered to be an ongoing disorder of the brain and is diagnosed by having two unprovoked seizures more than 24 hours apart, or one unprovoked seizure with an increased risk of further unprovoked seizures. Some people may have an identifiable epileptic ‘syndrome’ – a group of signs and symptoms that are classed as a unique medical condition.

It is estimated that within the UK there are approximately 600,000 people with epilepsy equating to approximately 1% of the population. However, epilepsy is more prevalent in areas of greater socioeconomic deprivation (Steer et al, 2014).

The prevalence of active epilepsy in people who are homeless is estimated to be 12 times higher than the general population (Story, 2013).

Causes of epilepsy

The causes of epilepsy can be complex, and sometimes hard to identify. They can be divided into five main known areas but often the cause is unknown.



We found a markedly higher prevalence of seizures among people who are homeless than that estimated in the general population, with a large majority of non-alcoholic etiology. (Laporte, 2006)

There are other causes for seizures that are not epilepsy related such as alcohol withdrawal, drugs, cardiac events, diabetic hypoglycaemia, stress on-epileptic attack disorder (NEAD) etc.

If you meet someone who tells you they have epilepsy or seizures / fits it is important to find out if the cause has been identified. If they have, it is also important to understand whether their condition remains stable, or is changing.

In 46.5% of cases the frequency of seizures increased following the onset of homelessness; the principal stated reasons were alcohol (75%), sleep deprivation (42.5%), anxiety (32.5%), and stress (27.5%) (Laporte 2006)

Diagnosis of epilepsy

The diagnosis of epilepsy is based on clinical judgement, and supported by investigations. However, it can be diagnosed by a neurologist in the absence of investigations, which may be the case if a person is homeless. Epilepsy is not always easy to detect and should be considered as a possibility for people who experience unexplained blackouts etc.

It may help to identify the type of seizure and the



cause for epilepsy. Routine investigations may include Electroencephalography (EEG), Magnetic Resonance Imaging (MRI), Electrocardiography (ECG) and blood tests. However, the most important element of diagnosis is a detailed seizure history, and seizure description.

Obtaining a seizure description

The essential information required to make the clinical diagnosis involves obtaining as much detail as possible about the seizure event from the patient and/or any witnesses.

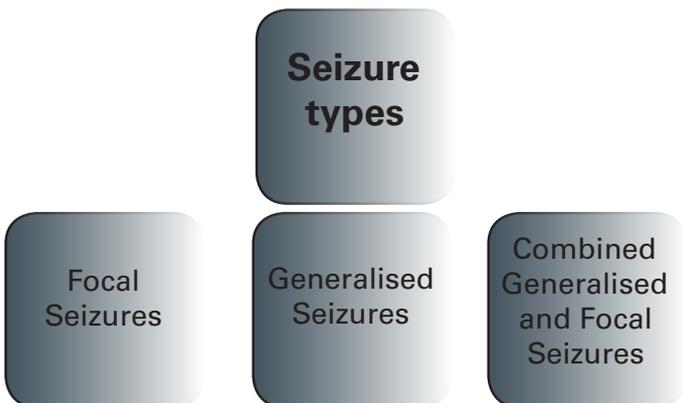
Key components of a seizure description include:

- Date and time of seizure
- Triggers such as alcohol, drugs, missed medication, illness, stress, lack of sleep etc
- Seizure description – a detailed step by step description of the event including the nature of the movements involved, tongue biting, incontinence etc
- Timing – how long did the event last?
- Recovery - How long was it before they were back to their usual self?

Please see attached Appendix which provides a form for to assist in the documentation of key information. The attached Appendix can be given to any witness to complete.

Seizures

Seizures are characterised by excessive discharges of neurons. This may affect changes in awareness, behaviours, emotions, motor functions or sensations.



Seizures are classified as focal or generalised. In focal seizures people may retain a level of awareness during the seizure, and in generalised seizures there is a loss of consciousness. Some seizures can start as focal seizures and develop into a generalised seizure.

Focal Seizures

During a focal seizure the person may become blank and generally unresponsive with repetitive actions, confusion and possible behavioural changes for a few seconds or minutes. During a focal seizure some people may retain full awareness. They may also experience déjà vu, or changes in smell, taste or perception, which can be a warning or aura that the seizure may progress into a generalised seizure. Other people may have reduced awareness, or even be unconscious during a focal seizure. Sometimes people in this state are incorrectly thought to be drunk or have been taking drugs.

Generalised seizures

Generalised seizures always involve a loss of consciousness, however brief that might be. There are a number of different types of generalised seizures but tonic clonic seizures (convulsions) carry a high risk.

In a tonic clonic seizures the person may cry out - suddenly going stiff with eyes open, and have a change in breathing and colour. This is quickly followed by bilateral synchronous muscles jerking. The person may bite the side of their cheek or tongue, have excess salivation and may be incontinent. Tonic clonic seizures on average last 2-3 minutes. Other generalised seizures include, atonic, myoclonic and absences.

For further information on seizures: https://learn.epilepsy.org.uk/wpcontent/uploads/articulate_uploads/What-to-do-if-someone-has-a-seizure-live/story_html5.html

Convulsive tonic clonic seizures lasting longer than 5 minutes are a medical emergency and require 999 support.

Generally, it is not thought that seizures cause brain damage however there is risk of brain damage if a tonic clonic seizure is prolonged longer than 30 minutes which is defined as status epilepticus

Treatment

'When you are homeless, you are not thinking about your medication, but your food, shelter or heat for the night.' (Paudyal et al, 2017)

Anti-epileptic drugs (AEDs) are the main form of treatment for people with epilepsy. Prescribing for epilepsy should be by a specialist or on the advice of an epilepsy specialist. It is important that medication prescribed is for the person's seizure type and suits a person's individual social circumstances and current lifestyle. For example, there are a number of drugs that have long half-lives and can be administered once a day. This may be more beneficial to somebody who is homeless.



SEIZURE FIRST AID

Call 999 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 two minutes longer than is usual for them; or
- the seizure lasts for more than five minutes.

First aid for a tonic clonic seizure

- Allow the person to have their seizure, making sure that they are not at risk of injury or harm.
- Only move them during a seizure if they are at risk (e.g. on a road).
- Do not put anything in their mouth.
- Put something soft behind their head if they are likely to injure it on a hard floor.
- Gently put them into the recovery position after the seizure and check their breathing.
- Be aware that they may be tired, confused and may not want people crowding them when they come out of a seizure.
- Ensure that they get good rest after the seizure and they are with someone who can care for and monitor them.

For other seizure types ensure the person is safe, time the event, reassure and check for injuries.

Free seizure first aid guides are available from <https://www.epilepsy.org.uk/info/firstaid/what-to-do> <https://www.epilepsysociety.org.uk/seizure-first-aid#.Xd6XLTP-7TIU>

If there are concerns about compliance with medication it is possible to monitor blood serum concentrations of AEDs. Ask the prescriber if blood levels have been done. Dossett boxes and verbal prompts may be helpful. If the person's day/night routine is chaotic it may be better to suggest they take their medications on waking or going to sleep rather than morning/evening.

If you are aware compliance is poor (taking medications less than 80% of the time), request a review with the epilepsy specialist. It may be possible to adjust dosing regimes, use long acting medications or different formulations to achieve better seizure control.

'Given the higher morbidity and mortality rates amongst the population that is homeless, adherence to prescribed medicines is imperative in achieving optimum health benefits.' (Paudyal et al 2017)

There are some drugs that may be less appropriate to use when people are vulnerable such as Benzodiazepines, Gabapentin and Pregabalin, which have addictive properties and street value.

Some AEDs may also be prescribed for other conditions such as anxiety, depression, migraines and pain.

There is a major challenge in ensuring people who are homeless receive the care they need for their epilepsy. Community nurses should liaise with epilepsy specialist nurses, neurology services or epilepsy charities to investigate what help is available and accessible in their area.

Specialist Circumstances – Pregnancy

The Medicines and Healthcare Products Regulatory Agency (MHRA) has issued specific guidance on the prescribing of sodium valproate to women of child bearing age due to the risk of congenital malformations.

Women of child bearing age should be prescribed folic acid 5mg due to the risk of foetal abnormalities for all AEDs

Living with epilepsy

For someone with a diagnosis of epilepsy the stress of being homeless, together with the associated sleep deprivation, the potential alcohol and drug abuse, poor medication adherence, and potential infections, dehydration, constipation and diarrhoea can all increase the risk of having seizures.

It is also well documented that people with epilepsy have a one in five chance of having associated mental health issues. This can be due to underlying aetiology of the condition, or the effect of medication or the psychosocial aspects of having epilepsy. This is often exacerbated by homelessness.

Anxiety caused by a fear of seizures can be more disabling than the seizures themselves, and support with understanding can often improve the person's acceptance. People with epilepsy need to be supported and encouraged to self-manage, and to assess, understand and mitigate risks within their daily lives. This can often improve their knowledge, understanding and acceptance of their condition.

Seizures may affect cognitive function, memory, and concentration. The concern which people most often seek help for is poor memory. This may be due to the cause of the epilepsy itself, or the effects of the seizures, or the side effects of medications.





'I've got bad memory because of my epilepsy, y'know my short term memory is shot to hell, I canny remember the last time I blew my nose.' 40 years old, male (Paudyal et al 2017)

People with epilepsy are entitled to a free bus pass if they are not legally able to drive because of their seizures. <https://www.gov.uk/apply-for-disabled-bus-pass>

There are a few employment restrictions for people who continue to have seizures for further information <https://www.epilepsy.org.uk/info/employment>

Substance use

It is vital that people are encouraged and supported to minimise or stop substance use in order to manage their epilepsy. The effects of recreational drugs vary greatly. They may directly affect the brain and lead to seizures, or interact with seizure medications. Effects vary for different drugs and from person to person.

For more information and advice on the risks associated with recreational drugs see: <https://www.epilepsy.com/learn/triggers-seizures/drug-abuse>

For information specifically about novel psychoactive substances, see the Neptune Clinical Guidance <http://neptune-clinical-guidance.co.uk>

Alcohol

Alcohol is a common trigger for seizures, especially in the hangover period when the brain is dehydrated. Alcohol can also disrupt sleep patterns which increases the risk of seizures, or make medications less effective. Patient information leaflets associated with AEDs should detail whether a patient can drink alcohol safely. Binge drinking and alcohol withdrawal carry a high risk for seizures and status epilepticus.

For more information and advice on the risks associated with alcohol see: <https://www.epilepsy.org.uk/info/daily-life/alcohol>
<https://www.epilepsy.com/learn/triggers-seizures/alcohol>

Withdrawal seizures are most common amongst people who have abused alcohol for years, and can occur up to 72 hours after binge drinking has stopped. It is risky to substitute alcohol, or start a withdrawal schedule in the community. This should be managed carefully following NICE guidance.

There is some evidence to suggest that chronic abuse of alcohol can lead to the development of epilepsy in some people.

During palliative care, withdrawal may not be possible at all, and it may be that managed drinking is appropriate. See the NICE guidance at <http://pathways.nice.org.uk/pathways/alcohol-use-disorders/acute-alcohol-withdrawal>

Risks

The majority of people with epilepsy manage their own epilepsy. Good physical and mental health can have a beneficial effect on reducing seizure frequency. Poor general health can trigger seizures, as may infections, constipation, diarrhoea, dehydration which all need prompt treatment in their own right.

To reduce the risks associated with epilepsy it is important to:

- take the correct medication, at the correct doses, at the right time
- not suddenly stop medications as this can lead to more seizures or even death
- avoid substance and alcohol misuse
- make friends, carers and hostel staff aware of epilepsy diagnosis
- carry some form of ID with seizure descriptions and medications. Bracelets and wallet-sized booklets are available. Epilepsy Action has free products available <http://shop.epilepsy.org.uk/cat/id-cards-and-seizure-diaries/406/400/>
- take special care around open water and heights. Possibly to have showers not baths, unless supervised
- consider risks at night, especially for those who have regular seizures. Seizures during sleep carry a higher risk as the person is generally on their own.
- have a good working relationship with a local pharmacist if possible

'I'm on methadone, salbutamol, seretide, something for my chest, epilim for my epilepsy. Only got diagnosed with epilepsy last year and I've been asthmatic all my life. Probably got made a lot worse when I was homeless.' 40 years old, male (Paudyal 2017)

Sudden unexpected death in epilepsy (SUDEP)

Sudden unexpected death in epilepsy (SUDEP) accounts for over 50% of epilepsy deaths per year. It is associated with poorly controlled epilepsy, seizures during sleep and tonic clonic seizures. There is a growing body of evidence that having a seizure whilst on your own increases the risk.

For people who are homeless, adherence to medication, identifying triggers will be helpful and regular epilepsy monitoring can reduce their risk.

For further information <https://sudep.org/> this includes reporting epilepsy deaths <https://sudep.org/epilepsy-deaths-reports>



Summary

Epilepsy is a common and serious neurological condition. Every person's experience will be different depending upon the type, cause and severity of their epilepsy. It is important for health services to support people who are homeless to effectively manage their epilepsy.

Community nurses need to liaise with specialist epilepsy services regarding support, information and treatments. However, if services are not available they should be able to provide basic information to people with epilepsy to ensure a person's safety.

SUDEP is a high risk for people experiencing homelessness, but there are measures that can be taken to reduce those risks.

'A change in attitude is clearly needed among the public and health care professionals towards people living with the triple stigmata of homelessness, alcoholism, and epilepsy.' (Laporte 2006).

Supporting Resources

Further information about epilepsy is available via the following resources:

- NICE guidance. Epilepsies: diagnosis and management <https://www.nice.org.uk/Guidance/CG137>
- Epilepsy Society: <https://www.epilepsysociety.org.uk>
- Epilepsy Action www.epilepsy.org.uk
- SUDEP Action <https://sudep.org/>
- Epilepsy Research UK https://www.epilepsyresearch.org.uk/?fca_lpc_skip=24197

The second edition of this guidance has been thoroughly reviewed and edited in 2020 by:

- Caryn Jory, Epilepsy Specialist Nurse, Queen's Nurse, Cornwall Foundation Partnership Trust
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The Queen's Nursing Institute welcomes feedback and professional evidence of how this guidance supports practice.

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