

Working with Epilepsy and Homelessness

Guidance for Community Nurses

'People experiencing homelessness have a greater risk of living with epilepsy than the housed population.'

Introduction

Research evidence shows that people experiencing homelessness have a greater risk of living with epilepsy than the housed population. In landmark research from France, even discounting the presence of alcohol-related seizures, 8% of a homeless population had active epilepsy.¹ This is at least 8 times the prevalence within the general population. St Mungo's Broadway also cites epilepsy as one of the most common conditions affecting its hostel residents.²

People without a home may struggle to access the specialist services they need and so frontline nurses should be confident that they know how to identify epilepsy, give basic advice, and link people to specialist services.

Developed with Epilepsy Specialist Nurses across the UK and nurses with clinical and research experience working with homeless people, this guidance is intended as a resource for professionals and their patients during health appointments.

It is acknowledged that not all of the listed help strategies in this guide will be practicable when working with people experiencing homelessness; however it is important for nurses to have an awareness and understanding of what helps. As and when the circumstances of clients change (e.g. moving from rough sleeping to hostels), there may be opportunities to provide guidance commensurate with a client's new environment.

This briefing aims to improve knowledge, confidence and practice relating to epilepsy care for people in general and particularly for people experiencing homelessness. The guide gives an overview of what epilepsy is, how it is treated, and the support nurses can give to a person to minimise the risk of harm and to live well with their epilepsy.

'Epilepsy is a serious health problem among the homeless and it contributes to the social exclusion process.'

What is Epilepsy?

Epilepsy is defined as a tendency to recurrent seizures of primary cerebral origin. Epilepsy is the most common serious neurological condition in the United Kingdom. According to the mid-2010 population from the Office for National Statistics, this equates to 600,000 patients with epilepsy in the UK today, and 32,000 newly treated cases each year.⁴

The prevalence of active epilepsy within people who are homeless is estimated to be 8 times higher than the general population⁵ and 25% of this group had to give up employment due to their epilepsy.⁶

Causes

Epilepsy has its roots in many different causes. It can be the result of brain infections such as meningitis, encephalitis or a cerebral abscess. It can be inherited through having a low seizure threshold or through rare genetic disorders, of which epilepsy can be a symptom, such as tuberous sclerosis. Structural damage can cause epilepsy. This may happen as a result of stroke, tumours, injury and subsequent scarring, lesions, prolonged drug or alcohol abuse and trauma at birth.

Shortly after birth, some babies lose oxygen supply to the cerebrum at a critical stage of development, which can cause epilepsy. Pre-term babies are vulnerable to haemorrhage, which can cause developmental disabilities such as cerebral palsy and epilepsy.⁷ Congenital malformation may also lead to epilepsy.

Epilepsy can be diagnosed at any age, and affects people of all ages. Although epilepsy can start at any age, it is more commonly diagnosed in people under 20 and people over 65.⁸ Some causes are unknown. Neurological researchers continue to uncover more of the mysteries of epilepsy.

Diagnosis

Having a seizure does not necessarily mean someone has epilepsy. A diagnosis of epilepsy follows a series of investigations which could include seizure semiology, Magnetic Resonance Imaging, Electroencephalography (EEG), Video EEG telemetry, physical examinations, Electrocardiography (ECG) and blood tests. The amount of diagnostic tests and time required can present barriers for people who are homeless to get the diagnosis they need in order to receive treatment. This careful history is taken to check whether seizures or blackouts are caused by epilepsy. Health services can proactively support vulnerable people to attend diagnostic appointments. As technologies such as mobile EEG have advanced, there is now scope for direct outreach diagnostics, which can be targeted towards high-risk groups.

Seizures

Seizures are a disturbance of normal brain activity. They are characterised by excessive discharges of neurons. In the patient this leads to disturbance of their awareness, behaviours, emotions, motor functions or sensations. It is important to note that every seizure (even a minor one) has a damaging effect on the brain. Seizures are classified in various ways. There are over 40 seizure classifications⁹. People experience seizures in many different ways, although there are some common characteristics based on their focal point within the brain and the effect this has on the patient. Neurologists estimate that 70% of people with epilepsy can live seizure-free with the correct medication and care.

A **simple partial seizure** is characterised by no loss of awareness by the patient. Indeed sensations may change or heighten with strong feelings of déjà vu, smell, or taste. Strong autonomic signs such as increased heart rate and sudden sweating may occur. Muscles may twitch or move unexpectedly. The patient may perceive an aura or a warning feeling which may progress into a complex or generalised seizure.

A **complex partial seizure** is characterised by impaired awareness. The seizure may or may not start as a simple partial seizure and then progress. The person may become blank and unresponsive; they may fall, repeat speech or mumble and may lose continence. This may be followed by a period of confusion. People who are homeless may find that people on the streets and in health settings may consider them drunk and fail to spot this as epilepsy.

'The observed increase in the proportion of persons with seizures after two years of homelessness, independently of alcohol consumption, suggests either that homelessness increases the risk of epileptic seizures and/or that seizures reduce a homeless person's chances of leaving the streets.'

Generalised seizures include **absence seizures** characterised by brief periods where the person 'blanks out' and loses moments of awareness. This may also be characterised by stopping when walking, or tripping over speech. To the patient, they may miss periods of speech while you are talking to them. It is important that teachers are aware of absence seizures, as they have been mistaken for lack of concentration in school children. For patients who are homeless, and may be walking around big cities, stopping suddenly and staring may put them at higher risk, such as from vehicles when they are crossing the road. It may increase their vulnerability to becoming a victim of crime and can be mistaken for a mental health condition.

Tonic Clonic seizures are characterised by falling to the floor and muscles jerking and increasing in tone (particularly in the limbs), and fluctuations in heart rate. The person may cry out, bite the inside of their cheeks or tongue, salivate or lose continence. The jerking phase of the seizure lasts between 1 and 3 minutes. Immediate patient reaction can involve low blood pressure, drowsiness, confusion or aggression, headache, sleepiness and muscle ache.

Atonic seizures are characterised by a loss of muscle tone. This may include drooping eyelids, dropping items the person may be carrying and/or falling to the floor. As with a Tonic Clonic seizure there may follow a period of confusion and other effects.

Tonic seizures are characterised by a sudden increase in muscle tone. This has the effect of stiffening muscles suddenly and will usually make a person fall and will have similar effects to a Tonic Clonic Seizure. Head injury, confused behaviour, and incontinence can contribute to a general stigma from the public and health professionals, and also a false perception of alcoholism.

Myoclonic seizures are characterised by limbs or other muscles suddenly contracting and relaxing. It is common for all people to experience myoclonic effects in their body from time to time, for example, in their diaphragm muscles (hiccups). In seizures it may lead to unusual arm or leg movements, which can lead people to drop items, slip, or kick. For a person experiencing homelessness, a myoclonic seizure may be perceived by people nearby as violence or intimidation, which may heighten their vulnerability.

'Seizures reduce a homeless person's chances of leaving the streets.'

Status epilepticus is a long-lasting seizure which can be classified within any of the types above. There is a danger of serious brain damage, coma or death associated with status epilepticus. However, it is possible to stabilise and treat someone with status epilepticus given fast access to a medical professional.

Sudden unexpected death in epilepsy (SUDEP)

Sudden unexpected death in epilepsy, more commonly referred to as SUDEP, is the most important direct epilepsyrelated cause of death. Each year, more than 1 out of 1,000 people with epilepsy die unexpectedly from SUDEP.¹¹ Most SUDEP appears seizure-related. Two recent case-control studies suggest that seizure frequency is the strongest risk factor for SUDEP.¹² The person with epilepsy is found dead lying face down. No one is sure about the cause of death in SUDEP.¹³

Ensuring people who are homeless have and comply with the correct medications, and are able to reduce other trigger factors in their lives (stress, sleeping patterns, alcohol use) will reduce their likelihood of dying as a result of SUDEP.

SEIZURE FIRST AID

Emergency medical help is needed if it is a person's first seizure, if the seizure lasts for more than 5 minutes, or if the person has a seizure, briefly recovers and then lapses into another seizure.

This brief knowledge is essential to know and important to share with your patients, even if they do not have epilepsy, as they may be living with or near people who are at heightened risk.

This information could save a life.

For other seizures, the best first aid is to 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.

Free seizure first aid guides are available from Epilepsy Society, www.epilepsysociety.org.uk.

Treatment

Good services should plan the needs of people with epilepsy who experience homelessness, to make sure they can access healthcare and advice at the necessary times.

Anti-epileptic drugs (AEDs) are the main form of treatment for people with epilepsy, though other treatments include specific diets, nerve stimulation, and surgery. Treatment in epilepsy has three aims; to prevent seizures which damage the brain, to have minimal adverse effects and to enhance quality of life. There are around 26 AEDs used to treat seizures, and different AEDs work for different seizures.¹⁴

Benzodiazepines like Clonazepam can be used to treat epilepsy, yet these are known to have addictive properties. It is important to be aware that even if your patient does not misuse substances, they may be more likely to be exposed to an environment where people do highly value these kinds of substances. This means that they may risk having their medication stolen. Following all the prescribing guidelines and having somewhere safe that patients can store and take medication is really helpful to help eliminate some of these risks and concerns.

AEDs are strong drugs designed to impact on brain function and nervous system processes in the body. They can some with a wide range of side effects. A woman considering becoming pregnant should always discuss this with her health professional, as some AEDs can cause problems for the developing foetus.

Managing medication is an important part of good epilepsy management. People must be able to decide what the best balance is for them in terms of seizure management and side effects, and health professionals play an important role – to educate patients about the choices available to them, and to offer guidance, advice and support to make those choices, relevant to their individual circumstances.

Living with epilepsy

The research suggests that the prevalence of epilepsy is far higher among people who are homeless. The indication is that the risk is even higher for those with alcohol problems and those who have been homeless for over 2 years.¹⁵ Further research is needed to unpick the complicated relationship between epilepsy and homelessness, but indicators suggest unstable epilepsy can lead to the poor mental and economic conditions which may end up with someone on the streets. It also indicates that living on the streets with associating risks of trauma and increased alcohol use, increase the risk of developing epilepsy. Due to stress, sleep deprivation and alcohol use, people may be at most risk of seizures at the onset of homelessness.

Adjustment

People diagnosed with epilepsy may need a period of months or even years to adjust to their diagnosis. They will need to learn first aid, driving regulations, harm minimisation, where to get support, how to take treatment and how it will affect them. Initial treatment efforts may be unsuccessful and people may have to undergo a series of treatments and repeated diagnostics which may feel like they do more harm than good, and can affect the person's wellbeing. For someone who is homeless, these extra challenges and adjustments may make life even harder. Charities like Epilepsy Society and Epilepsy Action have made great strides in reducing the stigma associated with epilepsy in the UK. However there is far more work to be done to reduce the stigmatizing effects of having epilepsy and being homeless.

Having regular seizures can affect the ability to concentrate, learn and build relationships. Anxiety caused by fear of seizures can be more disabling than the seizures themselves. Their unpredictability may lead people to become risk- averse, reducing their social interaction, leading to lower levels of self-esteem and poorer mental health. Conversely, people may take more risks (in which good self-care and management of epilepsy is not important to them), which can lead to more seizures, more brain damage, a higher rate of accidents and trauma and more hospitalisation. Medical professionals should consider epilepsy as a possible cause of falls, accidents, and confused behaviour.

Employment

It is also important to be aware that people with epilepsy can and should be encouraged to apply for a full range of employment opportunities. Some employers are guilty of imposing stigma or specifying jobs that require a driving licence, when public transport is perfectly acceptable to take on that role. It is important that people have the tenacity to challenge these employers, which is not always easy if one has been out of work. Making people aware that they cannot drive if they are experiencing seizures, and informing them that they may be entitled to a free bus pass, free prescriptions and reduced rate on rail travel is very helpful.

Managing care

During and immediately following seizures, people can be very vulnerable. Risk of harm through abuse and theft is much higher at these times. Being homeless magnifies these risks. As such it is important to ensure that care plans are personal to the patient and account for management of these risks. For people with very severe unmanaged epilepsy, and where epilepsy is co-existent with other conditions such as cerebral palsy, there are specialist centres

'Anxiety caused by fear of seizures can be more disabling than the seizures themselves.'

and supported living schemes available. It may be very helpful to contact these to help ensure your patient can get help to stabilise their condition. Other important issues affecting care management include language barriers, illiteracy and learning needs which may affect adherence. It is key for nurses and other medical staff to understand the capacity of the person to manage their care. Practical issues such as where to store medications may be a challenge.

'Epilepsy is a condition with high psychosocial and economic costs. To improve the overall management of epilepsy, concerns of both health professionals and people with epilepsy need to be taken into account.'¹⁶

Epilepsy can affect people's prospective memory. Useful medication reminders are available through medication diaries, pill boxes with daily compartments and smartphone apps. The proportion of people with access to smartphones is increasing and so newer technologies for remembering when to take medication are available. Good communication systems and joined up working between General Practices and pharmacies such as automatic repeat prescription ordering and prescription collection by pharmacy are also very useful. Home, hostel or refuge delivery of medication is very important for people who are vulnerable with a long term condition who are on repeat prescriptions and are less likely to come into the pharmacy on a regular basis. Talking to a person with epilepsy about what would be a useful memory aid to them is very important.

Substance use

Misusing substances heightens the risk of having seizures. It is important that patients are encouraged and supported to minimise and reduce substance use in order to manage their epilepsy. Local epilepsy support groups should be open and available for people who are facing the situation of being homeless.

It is important that people who want to manage their epilepsy seriously consider their lifestyle, if they are regular users of harmful substances.

Alcohol

- Some AEDs can change a person's alcohol tolerance levels. It is important to carefully follow medication recommendations.¹⁷
- Small amounts of alcohol (1-2 drinks in a day) may be tolerable for some people with well managed epilepsy.¹⁸
- Binge drinking and alcohol withdrawal can lead to seizures and status epilepticus.¹⁹
- Withdrawal seizures may occur 6-72 hours after binge drinking has stopped.²⁰
- Withdrawal seizures are most common amongst people who have abused alcohol for years.²¹
- Some studies have shown that chronic abuse of alcohol can lead to the development of epilepsy in some people.

The bodies of people who are alcohol dependent have adapted to needing alcohol. It can be very dangerous to replace alcohol, or start a withdrawal and this should be managed carefully, following NICE guidance. During palliative care, withdrawal may not be possible at all. See the NICE guidance at http://pathways.nice.org.uk/pathways/alcohol-use-disorders/acute-alcohol-withdrawal

For more information and advice on the risks associated with alcohol, visit Alcohol Concern's website at: www. alcoholconcern.org.uk

Harmful and addictive drugs (Information from Epilepsy Foundation)

- All people with epilepsy should avoid cocaine use, it is uniquely dangerous, with the potential to interrupt cardiac rhythm and cause death.
- Amphetamines and other stimulants like Ecstasy are likely to interrupt a person's need for restful sleep, and may lead to forgetting to take AEDs at the right time. The interaction can also trigger seizures, particularly at higher levels of use.
- THC and cannibidiol, the active ingredients in Marijuana, may trigger or improve seizures but not enough is known about the risks. As with alcohol, heavy long term users who stop suddenly expose themselves to greater risks of seizures.
- Heroin use may reduce oxygen supply to the brain and increase the risk of seizures. As with amphetamines, users are more likely to forget AEDs.
- Cigarette smoking may be risky, aside from the all the health harms, in that a seizure while smoking can cause burns, fires etc.
- Caffeine use may interrupt sleep and stress patterns and is best limited.

• Novel Psychoactive Substances (so called 'legal highs'), may present a range of unique risks dependent on their properties to people who have epilepsy and are homeless.

For more information and advice on the risks associated with drugs, see www.actiononaddiction. org.uk/home.aspx

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

Pregnancy

Some AEDs can cause defects to the developing foetus, and so specialist nurses and neurologists will be able to help and advise. Pregnancy may also increase seizure risks, and seizures and falls may risk harming mother and baby. Difficulties sleeping may increase likelihood of seizures, and vomiting may lead to inadequate levels of medication in the body. Pregnant women who experience homelessness are already at extremely high risk and immediate steps should be taken to try and secure safe housing and a care plan.

Pregnant women with epilepsy may need additional monitoring from community midwives before labour, and from midwives and health visitors after birth. The impact of sleep deprivation during labour and in the months after birth presents a heightened seizure risk. There are risks with some AEDs of transferring them through to baby via breastmilk and advice on realistic options should be given.

You can find facts and advice about pregnancy and epilepsy on the NHS website: www.nhs. uk/conditions/pregnancy-and-baby/pages/epilepsy-pregnant.aspx

Care

All people experiencing homelessness should be able to access excellent epilepsy care in accordance with their needs. Each person with a diagnosis of epilepsy should be supported to find a healthy lifestyle balance that encourages them to live a normal life, and pursue goals just as others would, with respect for the way their condition affects them. Community nurses can also help by supporting people with their routines, and helping them know where to go for help. It is essential to check all signs and symptoms, and support the person regardless of the circumstances they are facing at that time. Nurses can support people to make efforts to be healthier, and help them to manage the effects of stress, illness, drugs, alcohol or poor sleep on epilepsy, and have regular blood tests to ensure treatments are set at the right doses.

The Specialist Nurse or GP can help people consider treatments, discuss lifestyle, access medication, and keep in touch with appointments. Nurses can remind and help people to see a GP or Neurologist if seizures change in severity or frequency. A neurologist should diagnose, and work with the patient to develop an appropriate treatment regime. Given the higher risks, and difficulties they have accessing secondary and tertiary care, epilepsy specialist nurses and neurologists should consider ways they can work with people who are homeless, by linking with local homelessness organisations.

There are major challenges in ensuring people who are homeless receive the care they need for their epilepsy. It is important that barriers are lifted to provide access to specialist advice and care, regular treatment, and adjust for unhealthy environments. It is important that epilepsy is considered when people who are homeless present with seizures and that access to benefits, concessions and information needs are met.

'It is essential not to be judgemental and to check all signs and symptoms.'

Self-Care

It is very important that people who have epilepsy have a good relationship with their specialist nurse, neurologist, or other clinician making decisions regarding their care. For the majority of people with epilepsy, their care is managed - for the majority of the time - by themselves and so it is important to:

- Remember to take medication
- Take the correct medication and dosages
- Not stop taking medication suddenly. This can be very dangerous for someone who has epilepsy. Medication must be slowly withdrawn, possibly involving other medications such as Clonazepam over a short period to remove the risk of brain-damaging seizures.

In a situation where someone is homeless, the importance of having people around with knowledge about epilepsy is important, and also uniquely how that person's epilepsy affects them. Carers are very important even in well-managed epilepsy. Nurses should understand that hostel staff and people working with homeless people usually cannot necessarily assist them with their medication directly.

Nurses and GPs can support people with epilepsy and encourage them to carry information about their medical contact, condition and medicines, in case they have a seizure in public. 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/

'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.'²²

Summary

Epilepsy is a common and serious neurological condition. It will be experienced by every patient very differently depending on the type, cause and severity of their epilepsy, and how well it is diagnosed and managed. Neurologists estimate that 70% of people living with epilepsy should be able to live seizure-free with the correct care plan.

It is important for health services to reach people who may be having uncontrolled seizures, to ensure they get access to appropriate epilepsy diagnostic and treatment services, and the relevant care they need. Homelessness has many causes, including ill health and unemployment. Epilepsy is not always easy to detect and nurses should be vigilant to ask people experiencing homelessness if they have ever had seizures, to consider epilepsy as a cause.

Studies have shown that a homeless population had 8 times the prevalence of epilepsy as the general population.²³It is therefore vital that epilepsy services reach people who are at risk of homelessness, and people who are already homeless. Poor living environments, low levels of support and negative coping strategies can put people at greater risk of seizures and of having poorly managed health which, without care, can keep people living on the streets or in insecure housing for longer.

Supporting Resources

Further information about epilepsy is available via the following resources:

- NICE pathways: https://pathways.nice.org.uk
- Epilepsy Society: www.epilepsysociety.org.uk
- Epilepsy Action: www.epilepsy.org.uk

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The Queen's Nursing Institute welcomes feedback and professional evidence of how this guidance supports practice.

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