



INFORMATION BOOKLET

Dementia as a Long-Term Condition in UK Health and Social Care

A critical examination of management, policy and person-centred care

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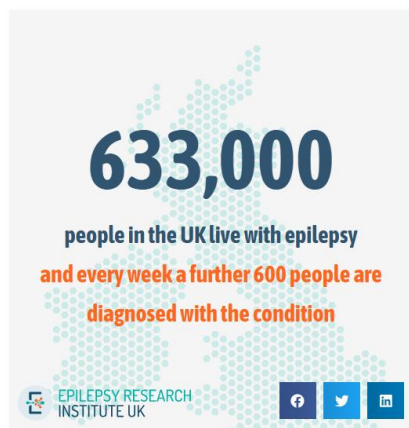
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Introduction

Definition of Epilepsy

Epilepsy is a long-term neurological condition that is typified by an ongoing tendency to produce recurrent unprovoked seizures caused by the aberrant stimulation of electrical activity in the brain (Katyal, 2025). The diagnosis of epilepsy is made by the National Institute for Health and Care Excellence (NICE) Guideline NG217, with two or more unprovoked seizures, or one unprovoked seizure when there is a high risk of recurrence (Jones et al., 2023). Depending on the part of the brain involved, seizures may be mild or severe, and may be short temporary state of unconsciousness or extended convulsions. Diagnostic and follow-up management are critically needed to reduce the number of seizures, decrease complications and enhance quality of life.



Source : (Dallas, 2019; Spanos et al., 2024)

Why Epilepsy is a Major Long-Term Condition

Epilepsy is also one of the most prevalent neurological conditions in the world, and a major issue of public health concern (Chen et al., 2023). According to estimates made by the World Health Organization (WHO), there are about 50 million epilepsy patients in the world today, which means it is one of the most common neurological disorders globally (Shan et al., 2024). Epilepsy affects an estimated 630,000 individuals in the United Kingdom or about 1 in 100 people and almost 80 people are diagnosed with epilepsy each day (Epilepsy Action, 2023).

Purpose of the Booklet

This information booklet is an evidence-based summary of epilepsy, including its causes, types of seizures, prevalence, diagnosis and effects on the individual, family and society. It critically examines the existing NHS management, health policies in the UK, international models and person-centred programs that can assist in efficient seizure management, self-management and long-term better outcomes of people with epilepsy.

Understanding Epilepsy

Definition and Classification

Epilepsy is a long-term neurological condition that is characterised by a predisposed state of recurrent and unprovoked seizures, which are as a result of abnormal electrical releases in the brain (Karaman, Gözde and Önder, 2023).

Types of Seizures

Focal seizures start in a single hemisphere of the brain and can be experienced at a preserved or partial awareness. Generalised seizures occur on both sides of the brain since its onset and encompass tonic-clonic, absence, myoclonic, tonic, clonic and atonic seizures. The unknown onset seizures are identified when it is impossible to clearly define the onset. Focal seizures are the most frequent type of seizure in clinical practice and occur in approximately 60% of epileptic patients.

Pathophysiology

Epilepsy is a disorder of the brain due to an unbalanced over-excitation of cortical neurons by excitatory neurotransmitters (mainly glutamate) and inhibitory neurotransmitters (gamma-aminobutyric

acid [GABA]) (Singh and Panda, 2024). The abnormality of the brain structure, genetic mutations, metabolic disorders, infections and traumatic brain injuries can modify the excitability of neurons making them more prone to frequent seizures. The sustained neuronal abnormal firing may disrupt cognitive, behavioral and neurological functions in the long run.

Signs and Symptoms

Epilepsy has different clinical manifestations depending on the type of seizure and the part of the brain that is involved (Asadi-Pooya et al., 2023). Typical manifestations are loss of consciousness, muscle rigidity, jerky movements, gazing, involuntary falls, confusion, sensory dysfunctions and automatic movements like lip-smacking or repetitive hand movements. There are also people who have an aura preceding the seizure, which are described as strange sensations, visual impairments or strange smells.

Burden of Disease

Global Prevalence (WHO Statistics)

Epilepsy is a neurological condition and one of the most prevalent disorders in the world and a significant burden of disease (Zhang et

al., 2023). WHO estimates that 70 percent of all people living with epilepsy might be seizure free, should they get timely diagnosis and proper use of anti-seizure drugs, and this is where the provision of health care services comes in (Housam Soboh, Theitler and Revital Gandelman-Marton, 2024).

UK Prevalence (NHS, NICE and Epilepsy Action)

The prevalence of epilepsy in the United Kingdom is estimated to be about 630,000 individuals (about 1 in 100 individuals), and 80 individuals are estimated to be diagnosed each day (Dallas, 2025). Epilepsy has no age restrictions but is most often diagnosed in childhood and in adults over 60 years old.

Economic Burden on the NHS

Epilepsy is a significant financial burden to the NHS in terms of emergency hospital admissions, outpatient neurology services, long term medication, diagnostic tests like EEG and MRI and surgery to treat refractory epilepsy.

Morbidity and Mortality

The morbidity and premature mortality of epilepsy are high. Individuals are at increased risk of injuries, fractures, burns, drowning, mental health disorders and

cognitive impairment (Hashmi, Rithvik Gundlapalli and Ifrah Zavar, 2024). One of the concerns is Sudden Unexpected Death in Epilepsy (SUDEP) which has been estimated to occur in an approximated 1 in every 1,000 adult with epilepsy annually with the risk being significantly greater in those with poorly controlled tonic-clonic seizures (CDC, 2024).

Risk Factors and Causes

Non-Modifiable Factors

There are a number of non-modifiable risk factors that predispose to epilepsy (Nindrea and Hasanuddin, 2023). The role of genetic predisposition is quite prominent, especially in idiopathic epilepsies, which involves inherited gene mutations, which influence the neuronal excitability. Another determinant is age where epilepsy is greatest among children (below age five years) and adults (above age 60 years).

Modifiable Factors and Seizure Triggers

Epilepsy is not always treatable but there are a number of factors that are modifiable to make such individuals more prone to seizures (Scheffer et al., 2024). Triggers are

most frequently sleep deprivation, psychological stress, missed doses of anti-seizure medication, alcoholism, recreational drug use, infections and metabolic imbalances such as hypoglycaemia. Photosensitive epilepsy can also occur in about 3-5 percent of individuals with epilepsy, in which flickering or flashing lights can be the triggers of photosensitive epilepsy, and so, avoiding triggers becomes a significant part of the seizure management process (Wirrell, 2024).

Neurological Causes

Epilepsy can be caused by structural, infectious, metabolic or immune-mediated complications of the brain (Costa and Vale, 2024). The most common neurological causes are stroke (applying to about 30-50 per cent of new cases of epilepsy in older adults), traumatic brain injury, brain tumours, infection of the central nervous system (including meningitis and encephalitis), congenital brain malformations and prior hypoxic brain injury (Zhao et al., 2018).

Comorbidities

Epilepsy is often combined with other chronic health issues, such as depression, anxiety disorders, intellectual disabilities,

autism spectrum disorder, migraine and cardiovascular disease. Mental illnesses occur in one out of every three epilepsy patients, and they lead to worse quality of life, decreased medication compliance and health care use.

Impact of Epilepsy

Physical Impact

Epilepsy is a serious physical condition especially in those with frequent or uncontrollable seizures. The frequency of falls, fractures, burns, head injuries, drowning and road traffic accidents leads to high morbidity due to recurrent seizures. Status epilepticus (prolonged seizures) is a medical emergency that is linked to additional neurological damage and death. Sudden Unexpected Death in Epilepsy (SUDEP) is also more common in people with epilepsy, occurring in around 1 in 1,000 adults with epilepsy each year, and is more common in individuals with uncontrolled tonic-clonic seizures. Continuous convulsions can further affect memory, focus and thinking capabilities and make one less independent and overall quality of life.

Psychological Impact

Epilepsy can greatly impact the psychological well-being of those living with it. Patients often feel anxious, depressed, have low self-esteem and fear of having a seizure in front of the crowd. Studies show that one out of every three epileptic sufferers develop a mental illness in their lifetime.

Social, Educational and Employment Impact

Epilepsy may have a negative impact on education, employment and social participation. Academic performance and career opportunities can be disrupted by seizures and cognitive difficulties. In the UK, persons with epilepsy are usually not allowed to drive until at least 12 months without seizures, which may decrease the level of independence and work opportunities (Woodward et al., 2023).

Impact on Family and Carers

Family members and informal carers can be very instrumental in detecting seizures, first aid, medication compliance, and emotional support. Nonetheless, the caregiving needs can lead to psychological stress, caregiver burden and financial difficulties especially to those who have a person with frequent seizures or complex epilepsy.

Diagnosis

Clinical Assessment and Medical History

The first stage in the diagnosis of epilepsy is a thorough clinical examination and a medical history. Diagnosis, according to NICE Guideline NG217, should be made using a clear description of the seizure event in the patient, and an eyewitness account where feasible (2023). The clinicians assess the nature of seizures, length, state of consciousness, recovery, neurological disorders history and family history of epilepsy.

Electroencephalogram (EEG)

The most important diagnostic test that is employed to identify abnormal electrical activity in the brain is an Electroencephalogram (EEG) (Dubey et al., 2022). Even though EEG results cannot either prove or rule out epilepsy, they help in determining the type of seizure and epilepsy syndrome, which is used in deciding the treatment.

Neuroimaging and Laboratory Investigations

Magnetic Resonance Imaging (MRI) is an imaging modality of choice to detect

structural abnormalities in the brain like tumours, cortical malformations, stroke or hippocampal sclerosis, which can cause epilepsy. Computed Tomography (CT) can be applied in emergency, where acute intracranial pathology is suspected. Blood tests such as glucose, electrolytes, calcium, liver and renal tests are used to determine metabolic abnormalities or other reversible causes of seizures.

Diagnostic Classification

After assessment, epilepsy is categorised based on the International League Against Epilepsy (ILAE) system into focal, generalised or unknown onset epilepsy, and as much as possible further differentiation of underlying aetiology (Egesa, Newton and Kariuki, 2021).

Evidence-Based Treatment in the UK (NHS)

Lifestyle Management and Trigger Avoidance

The NHS and NICE Guideline NG217 suggest that the management of epilepsy should include a combination of pharmacological and lifestyle interventions to maximise seizure control and quality of life (UK,

2022). Patients are advised to take regular sleep schedules, take medicine as required, handle stress, limit alcohol use and determine their own seizure triggers through a seizure diary. It is especially necessary that trigger avoidance be considered in the case of people with photosensitive epilepsy, as such exposures to flashing lights can trigger seizures. Education on the first aid of seizures and safety measures is also needed to minimize the chances of injury.

Anti-Seizure Medications (ASMs)

The initial treatment of the majority of epilepsy patients is Anti-Seizure Medications (ASMs). NICE suggests the choice of medication based on the type of seizure and epilepsy syndrome (Tandon et al., 2024). ASMs that are commonly used are lamotrigine, levetiracetam, sodium valproate, carbamazepine and oxcarbazepine.

Advanced Therapies

In the case of people with drug-resistant epilepsy, one should be referred to a specialist epilepsy centre. The ketogenic diet, especially in children with refractory epilepsy, Vagus Nerve Stimulation (VNS) and epilepsy surgery are all evidence-based treatment options, used in selective cases of

focal epilepsy (Rotondo et al., 2022). Surgery has proven to provide long-term seizure control in a large proportion of eligible patients, greatly enhancing quality of life and decreasing the likelihood of seizure-related complications.

Regular Monitoring

The epilepsy treatment is a long-term management, which involves frequent follow-ups with a neurologist or epilepsy expert to assess the frequency of seizures, adherence to medication and adverse effects of treatment. Mental health and cognitive function, driving eligibility, pregnancy planning, safeguarding and the risk of Sudden Unexpected Death in Epilepsy (SUDEP) should also be assessed during ongoing reviews.

Models and Frameworks

UK Model

NHS Long Term Plan and Integrated Neurology Care

The NHS Long Term Plan (2019) focuses on the diagnosis, treatment and ongoing management of neurological diseases, such as epilepsy, by means of integrated and

patient-centred care (Giorgi et al., 2025). The plan encourages earlier referral to specialist epilepsy services, better access to diagnostic tests like Electroencephalography (EEG) and Magnetic Resonance Imaging (MRI), and increased utilization of digital health technologies to aid in the management of diseases in the long term (Aklamanu, 2025). Another aspect that the NHS intends to achieve is to decrease preventable emergency hospitalizations through enhanced community-based care and multidisciplinary teamwork.

Multidisciplinary Epilepsy Care Model

In the NHS, epilepsy is treated using a multidisciplinary team (MDT) that consists of neurologists and epilepsy specialist nurses, General Practitioners, pharmacists, psychologists, dietitians and social care professionals (Shillito and Wood, n.d.). The MDT engages in thorough evaluation, medication optimisation, education about seizures, mental health support and frequent follow-up. Care plans, seizure action plans and regular reviews are personalised care plans that allow to increase medication adherence, minimise the number of seizures and emergency hospital admissions. Collaborative care also

helps people with epilepsy to be educated, employed and live on their own.

International Model

WHO Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Disorders (2022–2031)

WHO Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Disorders (2022–2031) The World Health Organization (WHO) Intersectoral Global Action Plan (IGAP) gives a worldwide framework on how to enhance prevention, diagnosis, treatment and rehabilitation of epilepsy and other neurological conditions (Health, 2024). The plan will minimize disparities in epilepsy care by enhancing primary healthcare to raise the accessibility of affordable anti-seizure drugs, boosting the number of health workers trained on epilepsy, and decreasing stigma by raising awareness among the population. WHO estimates that proper diagnosis and treatment of epileptic people might enable them to live without having seizures up to 70 percent of their lifetime (WHO, 2024). IGAP framework also facilitates multidisciplinary care, patient empowerment, community involvement and access to universal neurological care, which in turn leads to better health status

and less disability and premature mortality due to epilepsy in the global village.

UK Health and Social Care Policies

Neurological disorders, such as epilepsy, are identified in the NHS Long Term Plan (2019) as a key area of focus to enhance long-term care by making sure that these disorders are diagnosed earlier, integrating services and offering personalised treatment paths. The plan fosters access to specialist neurology services in a timely fashion, improved community care and digital technologies to decrease unnecessary emergency hospitalizations and improve patient outcomes. NICE Guideline NG217 Epilepsies in Children, Young people and Adults gives clear, evidence-based guidance on the diagnosis, pharmacological treatment, specialist referral and continued review of individuals with epilepsy, which will result in uniform, quality care throughout the NHS (Amin et al., 2024).

The Quality and Outcomes Framework (QOF) encourages General Practices to keep epilepsy registers, carry out annual reviews and optimize medication management, enhancing continuity of care and medication adherence (Minshall and Neligan, 2025).

Person-Centered Care

The use of person-centered care is key to the successful management of epilepsy whereby treatment is based on the clinical needs of an individual, lifestyle, preferences and personal goals. Shared decision-making helps patients, families and health practitioners to choose the best anti-seizure drug together, discuss the advantages and disadvantages of therapy, and make knowledgeable choices on pregnancy choice, driving, education and work(Malmgren, 2024). This strategy enhances drug compliance, quality of life and sustained management of seizures. Patient education about medication adherence, seizure trigger identification, personalised Seizure Action Plans and use of first aid in seizure management promotes self-management. The use of a seizure diary helps individuals to track the frequency of seizures, identify patterns and assist in making treatment changes when they undergo clinical reviews.

Multidisciplinary team (MDT) that includes neurologists, epilepsy specialist nurses, General Practitioners, pharmacists, psychologists, occupational therapists and social care professionals is also needed to

effectively manage the epilepsy(Spanos et al., 2024). Collaborative care covers the areas of seizure management, mental health, cognitive functioning, psychosocial support and safeguarding needs, enabling individuals to live safely and independently as well as enhancing quality of life and minimizing unnecessary hospital admissions.

Recommendations

Improve Early Diagnosis and Community Screening

Early diagnosis is always necessary because epilepsy is often misdiagnosed or diagnosed late thus preventing adequate treatment. The NHS must enhance community education and facilitate speedy referral routes between primary care and specialty neurology care. The earlier diagnosis and the reduction of inappropriate treatment and better long-term control of seizures can be improved by improving access to Electroencephalography (EEG), Magnetic Resonance Imaging (MRI) and clinics specialized in epilepsy.

Expand Digital Monitoring and Specialist Services

Digital health technologies, such as the NHS App, electronic seizure diaries, wearable

seizure detection devices and remote consultations, should be increased in their use and application in order to improve the monitoring of seizures and adherence to treatment. Increased access to epilepsy specialist nurses and multidisciplinary epilepsy centres would enable prompt medication reviews, individualised care planning and greater support of the individuals with complex or drug-resistant epilepsy.

AI-Assisted Seizure Prediction

AI has a great potential to change the way epilepsy is treated by analyzing EEG records, wearable devices information and electronic health records. AI-based systems are able to detect seizure patterns, anticipate the risk of seizures and assist in personalised treatment choices. The application of AI in daily NHS neurology services can enhance the detection of diseases at an early stage, refine medication control and decrease the emergency department cases.

Improve Public Awareness, Reduce Stigma and Enhance Patient Education

The misconceptions and social stigmatization that commonly have an impact on education, employment and social inclusion should be addressed by national

awareness campaigns that enhance the understanding of epilepsy, first aid during seizures and the need to diagnose the disease early. Patients and carers should be empowered through structured education programmes on the importance of medication adherence, avoiding triggers, maintaining safety when taking medications, managing mental wellbeing and in case of an emergency. Special consideration is to be given to the youths who leave paediatric epilepsy services to adult services to maintain continuity of care and self-management.

Conclusion

Epilepsy is a long-term neurological condition, prevalent in the world with an estimated 50 million and the United Kingdom with approximately 630,000. Despite the ability of evidence-based treatment to achieve effective seizure control, about 30 percent of individuals still have drug-resistant epilepsy and are at a higher risk of injury, psychosocial issues and Sudden Unexpected Death in Epilepsy (SUDEP). The existing NHS initiatives, NICE Guide NG217, multidisciplinary care and person-centred management offer a powerful framework of enhancing clinical outcomes and quality of life. Further

investment in specialist epilepsy services, digital health technologies, AI-assisted seizure prediction, the creation of awareness and education of people with epilepsy and other factors will enable the

provision of earlier diagnosis, decrease health disparities and enhance long-term outcomes among people with epilepsy and create a more responsive and sustainable NHS.

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