

MSc Public Health and Social Care in Practice
Community Care and Management of Longer-term Conditions
LCBS7003 | Component 1



EPILEPSY

An Information Booklet on the Management of a Long-Term Neurological Condition
Prepared for health and care service users and professionals in the United Kingdom

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1. Introduction

Long-term conditions (LTCs) are health conditions that cannot be cured but can only be managed with medication, therapy, and constant self-management assistance (Rapaport et al., 2025). One of the most common and poorly understood LTCs is epilepsy, a chronic neurological condition that affects millions of individuals across the globe and has devastating physical, psychological, and social implications.

Epilepsy is defined as the constant tendency to cause epileptic seizures and is caused by irregular, excessive, or synchronized brain neuron functioning. The booklet is an in-depth, evidence-based book on epilepsy among health and care professionals and service users in the UK. It entails the definition and aetiology of epilepsy, its worldwide and national burden, the extensive physical, psychological, and social effects on individuals and families, the evidence-based management strategies offered by the NHS, the applicable models of care, the applicable UK policy and political climate, and specific recommendations on how to better person-centred care, both self-management support and end-of-life care planning.

2. What is Epilepsy? Definition, Types, and Aetiology

2.1 Defining Epilepsy

According to the International League against Epilepsy (ILAE), epilepsy is a brain disease with at least two unprovoked seizures separated by over 24 hours; with one unprovoked seizure and a risk of additional seizures of at least 60 percent within the next decade; or epilepsy syndrome (Beniczky et al., 2025). When a brain cell has a burst of heightened electricity, this results in an uncharacteristically high number of electrical discharges. This rapid rush will disrupt standard brain activity resulting in seizures (Wirrell *et al.*, 2022). These seizures may vary from person to person and may impact their ability to move around or carry out regular daily functions or the awareness/cognition of their surroundings.

2.2 Types of Seizures

Focal onset seizures: They originate in one brain hemisphere. May either be focal aware (previously referred to as simple partial) or focal impaired awareness (previously referred to as complex partial), and may secondarily generalise (Kumar and Sharma, 2019).

Generalised onset seizures: Are bilateral in onset. Tonic-clonic, absence, myoclonic, atonic, tonic, and clonic.

Unknown-onset seizures: When the onset is unknown, it usually occurs because it was not observed or happened at night.

Status epilepticus: A medical emergency that is characterized by a seizure that is longer than five minutes, or two or more seizures without any recovery of consciousness - it is characterized by high mortality and morbidity (Freedman and Roach, 2023).

Myoclonic seizures: Myoclonic epilepsy would typically show a person exhibiting quick muscle jerks and could impact their ability to write, cook or hold items.

Tonic-clonic epilepsy: A patient with tonic-clonic epilepsy exhibits stiffened muscles followed by a rhythmical jerking of their arms and legs, which may result in them losing consciousness (Zhou *et al.*, 2024). In addition to physical harm from the seizures described above, a person with tonic-clonic epilepsy will generally suffer from fatigue and will likely be confused for some time following a seizure.

Collectively, there are various types of the illness that will potentially impact every aspect of a person's social, emotional, and physical well-being.

2.3 Aetiology and Risk Factors

Epilepsy develops due to a wide variety of causes. The ILAE groups the aetiologies

into six categories: structural, genetic, infectious, metabolic, immune, and unknown.

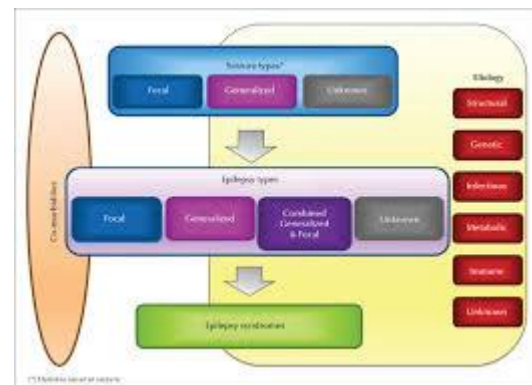


Figure 1: ILAE groups

(Source: Brodie *et al.*, 2018)

The etiology behind the disease is a clinical issue that can directly determine prognosis and treatment decisions. Structural causes are acquired brain injury due to stroke, traumatic brain injury, or brain tumours, and congenital malformations and hippocampal sclerosis, the most prevalent structural cause of focal epilepsy (Zhou *et al.*, 2024). Examples of genetic epileptics are Dravet syndrome and KCNQ2-related epilepsy, which are caused by mutations in certain genes that interfere with the functionality of ion channels (Oyrer *et al.*, 2018). Bacterial meningitis and viral encephalitis are also infectious factors of particular importance in low- and middle-income countries, and neurocysticercosis (pork tapeworm infection) is the most preventable cause of the disease worldwide (Yacubian *et al.*, 2022).

3. Prevalence: Global and UK Burden of Epilepsy

3.1 Global Burden

Epilepsy is a serious neurological disorder that is prevalent in the world. According to the estimates by the World Health Organisation, it is estimated that around 50 million individuals in the world have epilepsy, and it is, therefore, a big global public health issue (WHO, 2024).

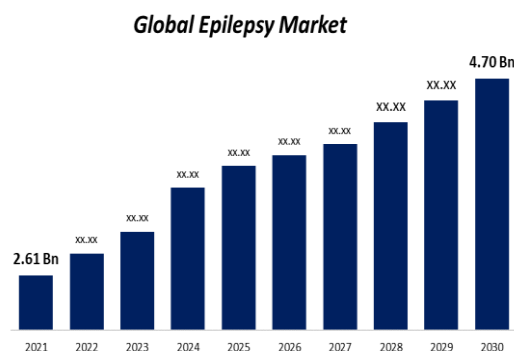


Figure 2: Global Epilepsy Market

(Source: Spherical Insights, 2023)

More importantly, the majority (80) of epileptic patients will reside in low- and middle-income countries (LMICs), where the availability of diagnosis and treatment is catastrophically poor. WHO estimates that with adequate diagnosis and treatment, up to 70 percent of epileptic patients would live without seizures, whereas in LMICs, the treatment gap (the percentage of epileptic patients who are untreated) is 75 percent or more.

3.2 UK Prevalence and Impact

Epilepsy is a condition that is present in the United Kingdom in approximately 630,000 individuals, that is, 1 in 103 individuals. In the UK, some 87 individuals per day are diagnosed with epilepsy, and some 21,000 new cases are being identified each year.

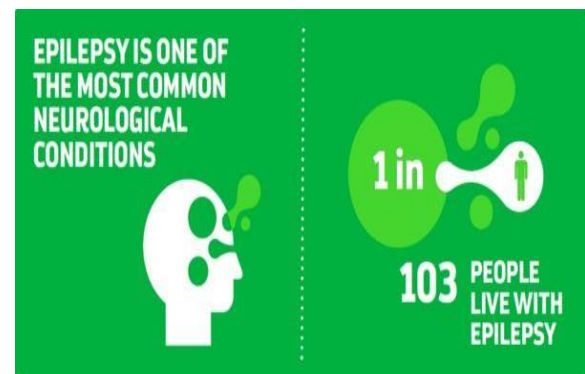


Figure 3: People live with epilepsy

(Source: Bsp.org.uk, 2023)

Access to epilepsy specialist nurses (ESNs) and specialist review also contains serious inequalities across dissimilar regions of the NHS (National Guideline Alliance, 2022). Health inequalities are pronounced: people from socio-economically deprived backgrounds receive lower quality epilepsy care, have higher rates of uncontrolled seizures, and are more likely to experience SUDEP. There are also significant disparities in access to epilepsy specialist nurses (ESNs) and specialist review across different NHS regions.

4. Impact of Epilepsy on Individuals and Families

4.1 Physical Impact

The physical effects of epilepsy are far beyond the seizures. Injuries related to seizures, such as head injuries, fractures, burns, and aspiration pneumonia, are frequent and may lead to death. The tonic-clonic seizures are associated with specific risks of harm because of the loss of consciousness and violent motor activity. Driving restrictions (six months without seizures in the UK by DVLA requirements), swimming, and working at heights are major limitations to independence and safety (GOV.UK, 2026).

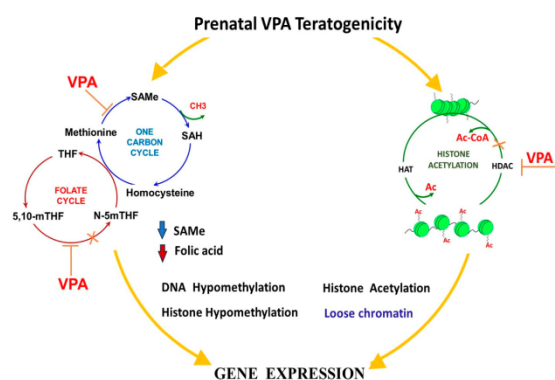


Figure 4: Valproic Acid in Pregnancy

(Source: Ornoy, Echefu, and Becker, 2023)

The grave birth defect/neurodevelopmental risks of valproate when exposed during pregnancy, which is about 10 percent of children born to a valproate-taking mother (Watkins et al., 2019).

People may also be harmed physically due to an unexpected occurrence of a seizure, potentially resulting in slips/falls, burns, or trauma to the person's head. Following repeated seizures, it is common for some

people to exhibit symptoms of: fatigue, muscle pain, headache, or transient disorientation (Strzelczyk *et al.*, 2023). In certain instances, the effects from epilepsy can also include deficits in coordination, short-term memory, and/or decreases in ability to focus on tasks which may directly affect their functioning in school or at work (Strzelczyk *et al.*, 2023). Available statistics from the World Health Organisation state that due to the erratic nature of seizures, this will have a major negative impact on gaining independence and/or on an individual's ability to operate a vehicle or machinery (World Health Organization, 2023).

4.2 Psychological Impact

Epilepsy has a high psychological cost, which is often underestimated during clinical practice. The most common psychiatric comorbidities are depression and anxiety, which have a prevalence of about 30 percent and 20 percent of individuals with epilepsy, respectively, which are significantly larger than the levels within the general population (Ioannou et al., 2022).

This unpredictability of the seizures creates anxiety, hypervigilance, and avoidance behaviours that are chronic. The fear of seizure in the hallway, the loss of independence, or of SUDEP results in a strong sense of psychological burden that

greatly reduces the quality of life. Epilepsy may also result in emotional or mental health-related difficulties for various individuals (Rozensztrauch and Kołtuniuk, 2022). Of these difficulties, many individuals display emotional stress or anxiety and/or experience depression from having seizures and/or from the fear of being socially labelled or discriminated against. Individuals may also feel embarrassed or have difficulty socializing as a result of having a seizure in a public venue. Epilepsy has a far-reaching effect on a person's overall well-being through medical care, changes in lifestyle and coping strategies that may impact their sense of self-worth and their quality of life (Rozensztrauch and Kołtuniuk, 2022). Therefore, epilepsy affects a person's physical condition and also their mental health and social functioning.

4.3 Social Impact

Stigma, both performed (not accepted by others) and experienced (the expected shame), has always been one of the most significant barriers to a good life among people with epilepsy. Social stigma causes the diagnosis to be hidden, avoidance of social life, and a lack of seeking help.

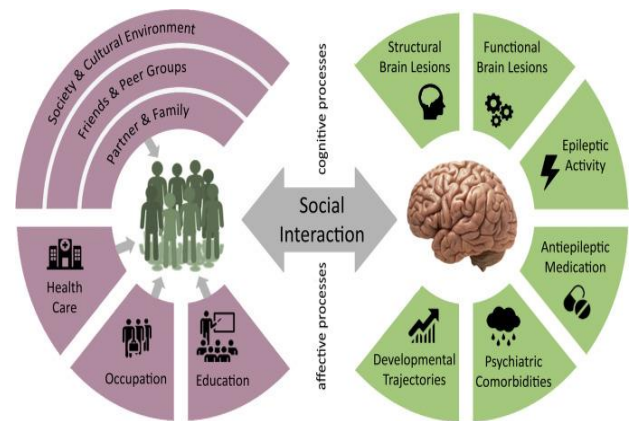


Figure 5: Social Challenges

(Source: Steiger and Jokeit, 2017)

The presence of legal limitations on driving, a major requirement for most jobs, exacerbates occupational disadvantage.

Having numerous seizures or fearing a seizure in public can lead people with epilepsy to avoid places like social functions, sports, and community events resulting in social isolation (Zhou *et al.*, 2024). Children with epilepsy may have difficulty maintaining regular school attendance and may have teachers and peers who do not understand how to treat him/her, which may impact the child's education and confidence level. Adults may encounter work-related barriers (e.g., lack of available employment due to fear of employer safety and productivity), which may impact their relationships with loved ones, self-esteem, and overall quality of life (Rozensztrauch and Kołtuniuk, 2022). Epilepsy not only affects a person's health, but it also has an impact on an individual's

social integration and acceptance throughout the greater community.

4.4 Impact on Families and Caregivers

Epilepsy is a severe condition that affects families. Siblings and relatives - especially parents of patients with epilepsy and spouses of adults have often been reported to experience high levels of anxiety, depression, and carer burden (Musekwa and Makhado, 2023). The emergence of the unpredictability of the seizures generates a chronic hypervigilance state that may interfere with sleeping, working, and family functioning (Wirrell *et al.*, 2022).

5. Evidence-Based Management of Epilepsy in the UK

5.1 Anti-Seizure Medication (ASM)

The most important in the management of Epilepsy is the Anti-seizure medication (ASM), which is known to work in making about 70 percent of those who have epilepsy seizure-free. The epilepsy management NICE guideline CG137 (2022 revision) is the official clinical standard of managing epilepsy in the UK and advises the use of choice of ASM depending on the type of seizure, epilepsy syndrome, patient factors, and comorbidities (Chen *et al.*, 2024). Sodium valproate is still the best ASM in the case of generalised tonic-clonic seizures, but since it is teratogenic, it should

not be used in women of childbearing age unless a Pregnancy Prevention Programme is applicable and all other options have been fully utilised.

5.2 Surgical and Non-Pharmacological Interventions

In individuals who have drug-resistant focal epilepsy, the possibility of being seizure-free post-epilepsy surgery and the cost-effectiveness of the intervention when suggested by epilepsy specialist centres are viable solutions (Wirrell *et al.*, 2022). The most common epilepsy surgery is the temporal lobe resection, which brings seizure freedom to 60-80 percent of carefully chosen patients. Medication doesn't always fully control epilepsy.

5.3 Epilepsy Specialist Nurses and Self-management.

The role of the Epilepsy Specialist Nurses (ESNs) is key to quality epilepsy care in the UK, as they deliver patient education, medication counselling, seizure first-aid training, SUDEP risk counselling, and signpost to community support (Campbell *et al.*, 2019).

6. Models of Care for Long-Term Condition Management

6.1 UK Model: NHS Comprehensive Personalised Care Model

The NHS Comprehensive Personalised Care Model offers the UK umbrella model of dealing with long-term conditions, such as epilepsy (NHS, 2024). This model is based on the concept that people should be able to exercise authentic choice and control over their care depending on what matters to them the most, and therefore, it is directly applicable to the care of epilepsy, whereby the choice of treatment, the preferences of choice in the management of seizures, and the life goals of individuals differ enormously (Campbell et al., 2019).

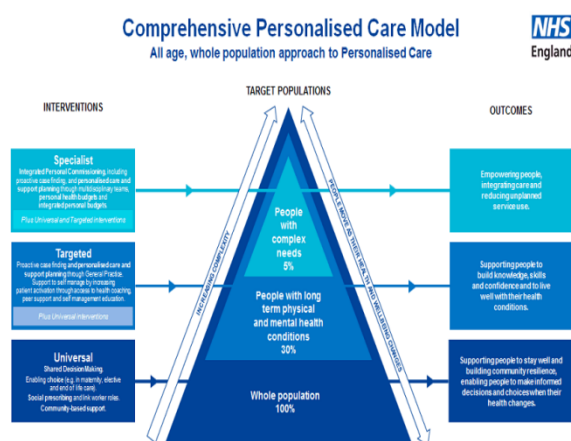


Figure 6: NHS Comprehensive Personalised Care Model

(Source: NHS, 2024)

There are three levels of operation of the model. On the universal level, the whole-population methods involve epilepsy awareness and first aid training. At the targeted level, individuals with epilepsy are provided with organised self-management education, social prescribing referral, and personalised care and support planning,

which covers seizure management, driving, employment, relationships, and mental health. At the intensive level, individuals with complex or drug-resistant epilepsy are provided with multidisciplinary specialist services, comprising neurology, neuropsychology, neuropsychiatry, and neurorehabilitation.

The NHS Personalised Care Model heavily relies on shared decision-making, which is especially needed in epilepsy, where treatment decisions are complex trade-offs, and determining whether to control seizures, manage medication side effects, drive qualifications, and reproductive consequences (Spanos et al., 2024). Another aspect of the model, personal health budgets, can empower individuals with complex needs (such as epilepsy) to purchase direct support services such as personal assistants, specialist equipment, or therapies based in the community.

6.2 International Model: WHO Intersectoral Global Action Plan (IGAP) and ICCF Framework

On the international level, the most comprehensive global policy framework of epilepsy is the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) 2022-2031 by the WHO (World Health Organization, 2023). The IGAP was endorsed in 2022 by the World Health Assembly and provides the world

with ambitious goals to cut the gap in epilepsy treatment in LMICs by 50 by 2031, reinforce stigma reduction, and integrate global systems of primary health care with epilepsy care systems (Leonardi et al., 2024). The WHO framework, Innovative Care for Chronic Conditions (ICCC) Framework, is a complement to the IGAP, offering a framework of systems-level chronic disease management.

7. Political, Policy, and Health Agenda Context

7.1 NICE Guidelines and National Standards

The national and definitive guideline in the care of epilepsy in England relates to the Epilepsy: Diagnosis and Management NICE Clinical Guideline CG137 (first published in 2012 and updated in 2022). It requires all individuals with a first suspected seizure to be referred to an epilepsy specialist within two weeks; ASM should be prescribed only by a specialist; and that all those with epilepsy have access to an ESN. The current Quality Standard NICE Quality Standard QS26 (as of 2023) contains quality indicators that can be measured and against which NHS organisations are measured, such as access to ESNs, the provision of SUDEP counselling, or the organization of annual

assessments (Epilepsysociety.org.uk, 2020).

The Valproate Safety Programme of the Medicines and Healthcare products Regulatory Agency of the MHRA (2018, reinforced 2023) is an important UK policy to address the fact that valproate continues to cause harm to pregnancy. Mandatory risk acknowledgement annual forms and obligatory specialist assessment of all women with childbearing potential on valproate constitute a significant change in the prescribing practice in the United Kingdom (Dale et al., 2024). In-SAFE programme and Sodium Valproate Action Group still press the need to improve the implementation of these measures.

7.2 NHS Long Term Plan and Neurological Conditions.

The NHS Long Term Plan (2019) undertakes to deliver better outcomes to patients with neurological conditions, including epilepsy, by providing better access to specialist neurology services and better community neurology pathways, and reducing health inequities (NHS England, 2020). The Plan assists the creation of the integrated care systems (ICSs), which help organize the care across primary, secondary, and community environments, and in the case of epilepsy, in which the fragmentation of care adds to the

unsatisfactory outcomes and unnecessary damage.

The report published by the National Clinical Audit on Seizures and Epilepsy demonstrated a considerable difference in the quality of epilepsy care among NHS organisations, with unacceptable delays to specialist review, low SUDEP counselling rates, and lack of access to ESNs (Seong Hoon Lee et al., 2023).

8. Recommendations for Person-Centred Care

8.1. Strengthening Self-Management and Education

The active management of epilepsy by people with the condition is essential in enhancing their outcomes and quality of life. Every individual with recently diagnosed epilepsy ought to obtain structured self-management education provided by an ESN within four weeks post-diagnosis, comprising seizure recognition and first aid, adherence, trigger identification and prevention, safety planning, redundancy of epilepsy on driving, employment, and lifestyle, and the implications of epilepsy.

8.3; Health Inequality Reduction.

The integrated care boards should order fair services in epilepsy that are proactive in addressing the socioeconomic and

geographic differences. It involves the assurance of ESN provision to the standards of the NICE in all localities; attention to the access of people in deprived areas to tertiary epilepsy assessment to drug-resistant epilepsy; commissioning culturally sensitive epilepsy education; and the integration of epilepsy quality indicators in ICS population health management models. The gap between clinical and community-based help can be bridged through community health workers and social prescribing link workers who can intervene on social determinants of epilepsy outcomes.

9. Conclusion

Epilepsy is a heterogeneous long-term neurological disorder that is difficult to diagnose and has about 630,000 cases in the United Kingdom and 50 million cases around the world. Quite on the contrary, epilepsy is not simply a state of seizures, but a heavy burden of physical complications, psychological suffering, social exclusion, and family effects that requires a person-based care perspective. Although effective anti-seizure drugs and surgical interventions exist, a substantial number of individuals with epilepsy in the UK are not well treated or supported, especially as regards the mental health and

SUDEP counselling as well as equal access to epilepsy specialist nurses.

The NHS Comprehensive Personalised Care Model and the WHO Intersectoral Global Action Plan offer complementary models on the provision of integrated, patient-centred and equitable epilepsy care available in both macro environments, including the national policy, and micro environment, including shared decision-

making on an individual level. It has a solid starting point to make any advancements, as the NHS Long Term Plan focuses on the enhancement of neurological care, and the clinical guidelines offered by NICE are solid and effective, and the efforts of organisations like Epilepsy Action and Epilepsy Society are advocacy-based and, therefore, worthy of consideration.

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