Epilepsy deaths: learning from health service delivery and trying to reduce risk

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Word count (Excluding references/tables): 4781

Highlights

* Epilepsy associated deaths in England are rising, despite falling all cause mortality
* Preventable premature deaths are occurring in men and women especially under 50
* Social deprivation is strongly associated with the likelihood of dying with epilepsy
* Variability in access to specialists and missed opportunities for intervention are contributing
* Investment in services and improved education about risks and SUDEP are essential

**Abstract**

Two recent UK reports have highlighted data of concern in relation to potentially preventable epilepsy deaths. Public Health England, an executive agency of the Government Department of Health, using National Health Service Data from 2001-2014 reported a rise in direct age-standardised mortality for epilepsy-associated deaths, in contrast to a reduction in all cause deaths over the same period. Premature death was seen in people aged below 50 years, especially in men, and where epilepsy was a contributory cause rather than an association. The Scottish Epilepsy Deaths Study, analysing deaths between 2009 and 2016, similarly found death in those with epilepsy was significantly higher than the matched population below the age of 54, especially between the ages of 16 and 24 (6 times higher). Sudden Unexpected Death in Epilepsy accounted for 38% of epilepsy related deaths under the age of 45. Both studies found a strong relationship between risk of death and deprivation; we discuss the implications of these and other data for planning service delivery and improving epilepsy care.

Keywords: SUDEP; Epilepsy; Service Provision; Epilepsy nurses; Deprivation

**Funding:** HC and PM did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors related to this work. SD is PI of the Scottish Epilepsy Deaths Study (Epilepsy Research UK Grant Number R44007)

**Declaration of interests:**

Prof. Cock reports personal fees from Sage Pharmaceuticals Ltd, personal fees from Eisai Europe Ltd, personal fees from UCB Pharma Ltd, personal fees from European Medicines Agency, personal fees from UK Epilepsy Nurse Specialist Association, non-financial support from Special Products Ltd, grants from U.S NIH Institute of Neurological Disorders and Stroke, non-financial support from International League Against Epilepsy, Status Epilepticus Classification Task Force, non-financial support from International League Against Epilepsy, Epilepsy Certification (education) Task Force, non-financial support from European Academy of Neurology, personal fees from Bial and Eisai, outside the submitted work. Dr Duncan declares speakers fees from UCB Pharma. Dr Morrish has no interests to declare.

# Introduction:

In the United Kingdom politics and health care are intentionally and inextricably linked through a National Health Service. We present and discuss nationally collected data that shed light on life and death with epilepsy, how services are delivered, and how that affects people with epilepsy (PWE). We consider how this information can inform the planning of a health system to reduce avoidable death, from all causes, in people with epilepsy. We conclude with suggestions for service improvement that will improve epilepsy care in the UK.

The medical system in the UK is divided between primary (General practitioners), secondary (General hospitals) and tertiary care (specialist services within hospitals). Whilst similar throughout the UK, the constituent nations vary in management and funding. Health care in the wider community in England is managed and funded through 211 regional Clinical Commissioning Groups (CCGs) including, since 2015, the provision of general neurology outpatient services. Neurology services within neuroscience centres, those specialist hospitals with neurosurgery on site, are funded differently, through the Specialised Services route funded directly by NHS England. Specialised services are, according to NHS England’s definition, those provided in relatively few hospitals, accessed by comparatively small numbers of patients. In Scotland, funding for all medical care comes through a single route, 14 geographically-based NHS boards, each responsible for community and hospital services within its territory. NHS services in Scotland are devolved, being administered separately from the rest of the UK by local Parliaments. The total NHS budget for England in 2015-6 was £101.3 billion of which £9.6 billion went to CCGs [1], and NHS Scotland had an operating budget of £12.2 billion in 2015-6 [2].

# Methods:

In 2018 Public Health England (PHE), an executive agency of the Government Department of Health, reported on death associated with neurological conditions in England [3]. In England and Wales, cause of death must be certified, by a registered medical practitioner that has attended the deceased’s final illness. Their responsibility is to complete a certificate that asks the disease thought to be the underlying cause of the death (UCOD, the disease or injury that initiated the train of events leading directly to death) as well as other conditions considered to have contributed to the death. Since 2015 certificates are also scrutinized by local medical examiners. Where this is not achievable, and in a range of other circumstances, cases may be referred to a coroner for certification. This information is coded using ICD-10 and forwarded to the UK Government Office of National Statistics. PHE used this information to report on the 366,728 recorded deaths in neurological illness (excluding stroke and dementia) in England in those over 20 years old between 2001 and 2014. Of these, 34,121 were associated (either UCOD or contributor) with epilepsy. The report interprets these deaths in comparison with death from all causes and death from other neurological conditions. Data about death can be correlated with other nationally collected information, such as deprivation. Deprivation is quantified by a single statistic, the index of multiple deprivation (IMD), that quantifies deprivation in all small neighbourhoods of England; it is a composite derived from 37 indicators concerning seven domains of deprivation; income, employment, education, health, crime, barriers to housing and services, and the living environment. For this report the 32,482 neighbourhoods in England were given an index of deprivation and separated into deciles of deprivation.

The General Medical Services contract through which General Practitioners are paid has, since 2004,included rewards for completion of indicators of quality of care. Between 2011 and 2014 these Quality and Outcome Framework (QOF) indicators included three indicators specific to epilepsy [4]; keeping a register of people with epilepsy and receiving treatment, recording the percentage of these people that had been seizure free for the preceding 12 months, and recording the percentage of women with epilepsy aged between 18 and 54 where there was a record of contraception and preconception counselling. Results from this and other nationally held statistics are included in an online database of tools [5 ] to assist with planning service provision [6].

In Scotland an ongoing nationwide population-based study [7] in Sudden Unexpected Death in Epilepsy (SUDEP) and other Epilepsy-related deaths in adults has been collecting data since 2009, and information on the first 2,149 epilepsy-related deaths are available. In 2011 Scotland enacted legislation to change death certification coming into effect in 2015. Like England and Wales certificates are scrutinised by a medical examiner who can ask the physician who completed the certificate for more information or who can examine the deceased’s case records. In addition all sudden and unexpected deaths in Scotland must be discussed with the Procurator Fiscal (Investigating Magistrate) who determines whether further information including ordering post mortem examination is required before the deceased can by buried or cremated [8] .

The Royal College of Physicians carries out an annual census [9][9] in which it records the number of Full-Time Equivalent Physicians working in the National Health in each specialty in each part of the UK and calculates a figure to estimate the size of population served by each consultant.

The Association of British Neurologists (ABN) has carried out two surveys of its members , the majority of the medical neurological workforce, concerning neurological services in the UK [10, 11].

The National Audit of Seizure Management in Hospitals (NASH) [12] has collected data, in 2011 and 2013, concerning seizure management in 154 hospital emergency departments across the United Kingdom.

# Principal Findings:

## Mortality

Annual deaths associated with epilepsy in England rose from 1936 people in 2001 to 3291 in 2014, during which time annual all-cause deaths in England reduced from 492,205 to 464,556 [3]. In consequence, epilepsy-associated death has risen from 0.39% to 0.71% of all-cause deaths. The direct age-standardised mortality (a statistical method of comparison that compensates for differences between population age distributions, DASM) rate for epilepsy per 100,000 rose from 6.1 per 100,000 in 2003-5 to 8.1 in 2012-14. In comparison, DASM in all-cause death decreased, from 1471 per 100,000 in 2003-5 to 1213 in 2012-4. In 2012-14 average age at death where death certification included epilepsy was 73 in women, 67 in men. Average at death of all-causes in 2014 was 81 in women, 76 in men. Hence, on average, women with epilepsy die 8 years early, men with epilepsy 9 years early. Whilst the total number of men and women overall is similar, 21% of men with epilepsy died at 50 years old or younger, compared to 12% of women (Figure 1). In contrast, in the general population in 2017 (England and Wales) 9.2% of male deaths were under 50, 5.7% of women. In the 1586 epilepsy deaths under 50 years old, 1004 were male, 582 female; epilepsy was recorded as the UCOD in 55% of both males and females.

With advancing age, female deaths catch up. Between 2012-2014 the age at which most women with epilepsy died was 85-89, for men 81-84. The underlying cause of death in the entire group of people with epilepsy is shown in table 1. For 32% of the entire epilepsy population, epilepsy or another disease of the nervous system was considered the underlying cause. That will include sudden unexpected death in epilepsy (SUDEP), but the PHE data collection does not allow discrimination between neurological causes. As in the general population, vascular diseases including stroke make up the second commonest underlying cause of disease in people with epilepsy.

Deprivation is associated strongly with the likelihood of dying with epilepsy; there is an almost threefold difference (13.1 vs 5.1) between DASM in the most and least deprived deciles in England. (Figure 2). Prevalence of epilepsy varies with location and deprivation, and seizure freedom also varies with deprivation [5]. Whilst one CCG recorded that, on average, 87% of its patients were seizure-free in the preceding 12 months, another reported 46%. The most deprived decile of CCGs had an average of 55% seizure freedom, the least deprived 70% (Figure 3).

The Scotland death in epilepsy study [7] undertook a comprehensive retrospective analysis in Scotland between 2009-16, of 2149 epilepsy-related deaths. As everyone in Scotland is assigned a unique community heath index (CHI) number, investigators can trace case records of the deceased, verify the diagnosis of epilepsy and build a narrative of the events leading up to the patient’s death. Whilst as in England, the majority of deaths were in older patients, below the age of 54, death in those with epilepsy was significantly higher than the matched population. Between the ages of 16 and 24 death was six times that of an age matched entire population. SUDEP accounted for 38% of epilepsy-related deaths under the age of 45 (Table 2). Fifty-nine percent of epilepsy related deaths in the 16-44 year old cohort were in the two most deprived quintiles of the Scottish Index of Multiple Deprivation (SIMD)

## Service Provision

The 2016-7 Royal College of Physicians manpower survey [13] reports that the general population per Full-Time Equivalent (FTE) neurologist in England varies between 28000 and 147000 adults per neurologist according to sub-region. If all neurologists were to have responsibility for epilepsy care the number of PWE per FTE neurologist would vary between 161 and 1200 (Table 3). The UK Epilepsy Specialist Nurse Association reports [PM & HC personal communication] that there are 159 adult epilepsy nurses in UK, or 2900 PWE per Epilepsy Specialist Nurses (ESN). The Association of British Neurology [11] reports that the UK has 28 neuroscience centres, 21 District general hospitals (DGH) with neurology beds and at least one “resident” neurologist, 134 DGHs with a visiting neurologist, and 6 DGHs with no resident or visiting neurologist. Others such as associate specialists, or GPs with a special interest also play key roles in some regions, but clearly access to specialist care is not equitable on numbers alone.

The National Audits of Seizures in Hospital (NASH2) [12] reported on 4544 presentations with seizure at 154 emergency departments across the UK in 2013. 18% of patients were on no anti-epileptic therapy, and 48% were on monotherapy. Assessments were often incomplete, with 42% not seeing a senior doctor. For those suffering a first seizure, 27% received advice on further seizure management and 55% were referred onwards to a neurologist or epilepsy specialist. Of those over 80, only 25% were referred on. The proportion of patients with epilepsy that were admitted as an emergency to hospital in England and were managed by a neurologist during their admission varies between 3 and 44% according to CCG [5].

# Discussion

The National Health Service permits the collection of an enormous amount of data that can be processed and interrogated, then used to understand and improve the way that healthcare is delivered. Such interrogation is only possible where there is freedom of access and presentation, and it is to the credit of the UK Government that the analysis can be presented here.

## Increasing epilepsy deaths

## The PHE mortality report [3] tells that the proportion of the adult population living and dying with epilepsy is rising rapidly. Many of those PWEs are elderly and have multiple comorbidities. The report also tells us that dying with epilepsy is allied to deprivation, and that young men with epilepsy are dying, from all causes, twice as often as young women. The national picture of epilepsy then is one skewed towards the elderly and those living in deprivation, but that young people with epilepsy, particularly young men, are dying disproportionately.

The PHE mortality report is not a surprise. The incidence of epilepsy rises after the age of 50 and the population in England, as in other advanced countries, is ageing; as we develop prevention, treatment and cure for the common killers (e.g. heart disease) then a greater proportion of the population will have epilepsy. The commonest cause of new-onset epilepsy varies with age. One study of new-onset epilepsy [14] in the over 65s, in Japan, identified a cause in almost 50%, with cerebrovascular disease the commonest cause, followed by dementia, inflammatory disease, malignancy and trauma. One UK study, from the GP register [15] found that in all ascertained cases of epilepsy, at all ages, the aetiology was vascular in 19%, tumour in 7%, alcohol in 6% and trauma in 3%.

## Epilepsy, deprivation and death

## There are many studies that show how epilepsy prevalence varies with deprivation [16, 17]. Two explanations are commonly offered; that social deprivation causes epilepsy or that epilepsy causes social deprivation (by social drift). One study [16] looked at deprivation status, at diagnosis and ten years later, in those with newly-diagnosed epilepsy. No change in deprivation was noted. There are some studies of the relationship between epilepsy and deprivation in children. One study in Scotland showed no relationship between deprivation and childhood epilepsy admission [18] and a Swedish study of over 1 million children showed the odds ratio (OR) for childhood and adolescent epilepsy, for those in high-deprivation neighbourhoods versus those in low-deprivation neighbourhoods, was 1.15 [19]; if there is a relationship at birth between epilepsy and deprivation then it is a relatively small effect. Hence it appears to be neither the social circumstances at birth, nor social drift following diagnosis that explains best the effect of deprivation. Instead it is social circumstance, and its health consequence during childhood and adulthood that provides the most likely explanation. This doesn’t however preclude the possibility that people born into different social circumstances are born with a different innate propensity to acquire epilepsy. The high deprivation in some parts of London and the relatively low prevalence of epilepsy in the capital warrants comment. Prevalence is also related to age of a population, and London’s young population means that, despite deprivation, the prevalence of epilepsy is relatively low. Other factors, for example ethnicity, may be relevant but we believe that it is the age structure of a population and deprivation that are the most important.

How does deprivation cause epilepsy? Deprivation is linked to many health conditions; in England, the most deprived areas have a life expectancy that is, on average, 9 years less in men and 7 years less in women compared with the least deprived areas [20]. The difference in overall health begins at birth; in the most deprived communities twice as many children are born with low birth weight, and infant mortality is doubled compared to the least deprived communities. Figure 4 shows the effect of deprivation on the commonest causes of death. The aetiology of seizure in the older population offers one explanation of how deprivation causes epilepsy. The likelihood of death from stroke or cardiovascular disease under the age of 75 trebles with deprivation, and survivors are at an increased risk of seizure. Death under the age of 75 from liver disease (most commonly caused by alcohol abuse) trebles with deprivation and epilepsy is also a common ill-effect of alcohol abuse. Patients residing in more deprived areas have a higher incidence of head injury than those from less deprived areas (16.3% (858) v 10.6% (2074) [21]. In 2016-7 there were 450000 attendances with Head injury at A&E departments in England [22]. 154,000 people (68% male) with head injury were admitted, with the number increasing rapidly over the age of 65. Epilepsy can be a consequence of head injury.

As prevalence of epilepsy varies with deprivation, it seems inevitable that death with epilepsy is also linked with deprivation, although the extent of the relationship is surprising. One major recent authoritative work on the links between deprivation and health has no mention of epilepsy [23]. However, epilepsy must now be considered another major, avoidable and potentially fatal illness of deprivation. Reducing deprivation must be a political imperative to reduce epilepsy associated mortality.

## What is causing death in people with epilepsy?

## The PHE mortality data are only as good as the certification of death. A 2004 study [24] demonstrated that epilepsy was on the death certificate of only a minority of patients, even where there was a history of relatively recent seizures, though awareness and processes have likely since improved. Not all of those that are certifying may be aware of sudden death in epilepsy and might instead give other causes. Misdiagnosis is common [25] in those with epilepsy attending neurology outpatients and in GP records; death certification may rely on that recording. Even where certification does list the UCOD as epilepsy, it doesn’t tell how an individual died, whether from SUDEP, Status epilepticus or something else.

A comprehensive review of death in epilepsy [26] published in 2004 estimated that 30% were dying through accidents, 23% through SUDEP, 16% through status epilepticus, and 14% through suicide. Figure 2 shows that people with epilepsy, as the population ages, are dying instead from a much wider variety of causes. One large UK case control population-based study [15] reported that death in epilepsy was increased by alcohol problems (Odds ratio,OR 2.96), having collected a prescription more than 90 days earlier (OR 1.83), injury in the previous year (OR 1.41) and being treated for depression (OR1.39), whilst seizure freedom for the previous year gave a reduction in mortality (OR 0.78).

The Scottish Epilepsy Deaths Study, one of the largest and most rigorous studies to date found 10% of deaths associated with epilepsy were thought due to SUDEP. The mean age of death in the SUDEP group was 41, 64% were male, 60% were from Scotland’s two most deprived Quintiles, and 94% were recorded as taking an AED (Table 3). In Cornwall a prospective study, from 2004 -2012 [27] found that 33% of deaths caused by epilepsy were due to SUDEP. In the SUDEP group the mean age was 42, 69% were male, 46% had alcohol problems, and 27% depression. Only 19% had contact with a specialist in the preceding 12 months, and an adherence problem was recorded in 55%.

## The importance of seizure freedom

The most commonly cited risk factor for SUDEP is seizure control [28]. Being male, with alcohol and/or mood problems adds to that risk. Seizure freedom in the preceding year is an independent predictor of death in epilepsy [14]. Monitoring of seizure freedom through QoF showed, for epilepsy, if the national ambition aim of good and equitable care in the UK was being achieved.**.** Those living in the most deprived groups had an approximately 24% lower chance of seizure freedom than those in the highest group (figure 3). Why does seizure freedom vary with deprivation? Patients in deprived areas might have more treatment-resistant epilepsy but that seems unlikely. Another possibility is that the most deprived group are not receiving the same quality of medical care as the least. It may also be that the most deprived group are less engaged in treating their epilepsy, less likely to take medication and less likely to behave in way that maximises seizure freedom. It has been estimated that the risk of epilepsy in the homeless (and therefore unlikely to be under medical care) is six times that in the general population [29].

it is important to understand the factors behind adherence and other behaviours, and develop approaches that work well for, and engage, all patients of whatever age and social group. The Kings Fund, looking at Patient Activation Measurement [30] concluded that “We cannot assume that, just because someone has a higher socio-economic status, they are also more activated and more likely to engage with their own health. Similarly, just because a patient comes from a lower socio-economic background, we cannot assume that they are less activated”. Epilepsy-specific research is needed, looking at motivation and demotivation in self-care in at-risk groups. Some communities and hospitals run groups for the newly-diagnosed. One promising initiative has been developed by a UK charity [31], offering on-line education and support. A mobile phone app (EpSMon) can help patients monitor their seizures and SUDEP risk. Education about SUDEP, and its risk factors seems vital yet we know that only a minority of patients are informed of this possibility and the risk factors both in the UK [32] and elsewhere [33]. Where there are local examples of proven good practice [33][34], then the whole country needs to learn from and follow those leads. Future research should be collaborative, between the NHS and the third sector.

## Service provision & utilization

Epilepsy care is shared between General Practitioners, hospital generalists and specialists, and epilepsy specialist nurses. The average FTE GP will have between 1100 and 2200 patients on their list, the prevalence of epilepsy varies between 0.44 and 1.17 patients per 100 and so the number of PWE per FTE GP lays between 5 and 26.

QoF data showed that even those in the highest deprivation group are attending their General Practitioner at least once per year, and so primary care offers an opportunity for intervention [35]. In 2004 87% of practices achieved total points for epilepsy monitoring and in 2014 it was 100%. When incentivised, primary care evidently will identify patients with epilepsy and poor control. In 2015 QoF payment for epilepsy care was withdrawn. A recent study [36] showed that GP Trainees recorded poorer knowledge, less confidence and more perceived difficulty with neurology than with any other medical specialty. Hospital and community-based neurology teaching was graded as "poor" or "very poor" by over 60% of GP trainees. If General practitioners are to take a part in the challenge of reducing epilepsy death there needs to be acknowledgement of responsibility, education, support and the reinstitution of incentives like QoF. Risk assessment tools already exist in this area [37], which could be utilized to evaluate symptoms and alert GPs to “red flags” [38] .

The UK has 189 hospitals that see patients in outpatients, in Accident and Emergency departments and can admit patients acutely [11]. There are 60,000 visits to A&E and 40,000 admissions by PWE per year in England. The cost of epilepsy admissions to hospital was estimated in 2012 as at least £1billion [39]. It is also well-known that A&E and admission to hospital is deprivation-related. In 2017/8, there were twice as many A&E attendances (3 million attendances) for the 10% of the population living in the most deprived areas compared with the least deprived 10% (1.4 million attendances) [40]. If the at-risk population with epilepsy are attending hospital A&E departments, then what actually happens to them when they present to A&E or are admitted to hospital? The two major audits by NASH [12] have shown this very clearly. In 63% there was no documentation of alcohol consumption, in 72% there was no documented discussion of future seizure management, and 78% were not seen during the admission by a specialist in their illness. Whilst 56% were not referred on to a specialist outpatient appointment, in those over 80 only 25% were referred on. 63% of PWE presenting with seizure had not seen a specialist in the preceding year. The NASH audits found the hospital assessment service to be hugely variable, frequently inadequate and age discriminatory. An opportunity to reduce unnecessary death in people with epilepsy in the groups most at risk is being missed.

The prevalence of neurologists and the prevalence of epilepsy in the UK combine to give a seven-fold variation in the number of PWE per FTE neurologist in England (Table 3). The gradual increase in PWE, and demands related to new treatments and regulatory requirements will further increase strain on those services. In parts of the UK where neurologists have traditionally been scarce, then epilepsy care may be through GPs and specialists in other conditions. It would seem intuitive that access to a neurology specialist, someone with specialist knowledge, enthusiasm and a willingness to teach those around them, makes a difference to epilepsy care but more evidence might be demanded before reorganisation of services. The drive to minimise admission and shorten the duration of admission means that many patients will be admitted and discharged before the visiting neurologist arrives. A national network of epilepsy specialist nurses might help in identifying those at risk and advising on the reduction of risk factors (though it should be acknowledged that their work is different to that of a neurologist) but it is inconceivable that this could be achieved when, on average, almost 3000 people with epilepsy share access to each nurse.

## What can be and should be done?

As we review the current state of epilepsy care in the UK, we see simple and immediate changes, and larger organisational changes that would improve epilepsy care and reduce avoidable mortality.

Simple measures:

The widespread provision of rapid access appointments (including telephone/virtual which will often be sufficient) for people with an established diagnosis of epilepsy.

Assessing all patients with active epilepsy, at each and every opportunity, for risk of SUDEP, depression, anxiety, suicidality, alcohol and drug addiction. Education about SUDEP, and its risk factors seems vital yet we know that only a minority of patients are informed of this possibility and the risk factors both in the UK [32] and elsewhere [33]

All people with epilepsy having an identified single first point of contact for advice if there is an increase in seizures.

Advice with all anti-epileptic packaging/prescription reinforcing the need to seek advice from their local multi-disciplinary epilepsy team, GP or other nominated contact should there be an increase in seizures.

Annual completion of a risk index for premature death with an alert appended to the patient’s electronic patient record

All medical/nursing letters to be transmitted by email to the GP and any clinicians known to be supporting the patient outside hospital setting (e.g. practice nurse, midwife, pharmacists, mental health team), carers and the patient within 48 hours of the consultation.

* All patients to be directed to the website of their national or regional epilepsy charity, which should include information about SUDEP and risks, and links to specialist charities in these areas.

Clear pathways and rapid referral from Accident and Emergency Units to the multi-disciplinary epilepsy team for any patient presenting with seizures.

The restoration of reporting seizure freedom to QoF (if QoF is to continue in the General Medical Services contract).

Longer term and organisational change:

* Each local health system must identify a single responsible individual that understands the causes of epilepsy, monitors deaths with and from epilepsy and works to develop approaches to reduce them. Many more Epilepsy Nurse Specialists need to be trained and recruited, particularly in those areas of high prevalence, high deprivation and poor seizure freedom.
* For healthcare professionals to whom people with epilepsy present, across secondary care and community settings there needs to be education about death in epilepsy, particularly SUDEP, uniformly comprehensive high level care, and a local service that is rapidly responsive to the multidisciplinary needs of the patients that present to them.
* Neurologists must have greater involvement in the care of patients in the community and in those arriving at A&E departments. Acute neurology services that are cost effective, reducing admissions and length of stay can be effective in both district general [41] and specialist centres [42]. Neurologists need to be advocates for better local services on behalf of their patients..
* National professional medical leadership must recognise that the service, as it currently stands, is failing too many people with epilepsy. As an exemplar in the UK, adequate provision and appropriate distribution of neurology consultant and training posts is needed if neurology is to provide a national epilepsy service, with support from other healthcare professionals. Alternatively it should be acknowledged that neurology is unable to do that, and other specialties that are available outside of neuroscience centres (eg acute, general and elderly care specialists) encouraged to prioritise epilepsy care in their hospitals and communities, working with their local epilepsy teams. Otherwise patients will continue to fall into a precarious gap between GP and specialist.

# Conclusions

The major causes of premature death in epilepsy have been known for over two decades. Sander and Bell wrote in 2004 [43] that “the time has come to make the reduction of mortality paramount in the management of epilepsy” and of improvements in care that might reduce avoidable death in epilepsy. The UK NHS has an obligation to treat individuals regardless of geography, wealth and social status yet, for epilepsy, it fails spectacularly, and with devastating consequence. Loss of life in epilepsy can surely be reduced if at-risk patients are identified, and appropriate intervention instituted.

One can’t read of difficulties in epilepsy care in a National Health Service without reflecting on the importance of active political intervention. Poverty leads to epilepsy, and the ageing population is increasing the number living with active epilepsy. Political commitment is needed to reduce inequality and social deprivation [44], and the associated illnesses contributing to the rise in the number of those living and dying with epilepsy alongside service improvements for those affected.

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|  |  |  |
| --- | --- | --- |
| Condition groups | All cause  | Epilepsy  |
| Diseases of the nervous system | 2.51% | 32.47% |
| CHD, stroke and other diseases of the circulatory system | 27.83% | 26.30% |
| Dementia and Alzheimer disease | 9.60% | 12.52% |
| Cancer | 28.61% | 7.07% |
| Respiratory diseases | 14.10% | 7.05% |
| Diseases of the digestive system | 4.89% | 2.89% |
| Congenital malformations incl. Down syndrome; Pregnancy and childbirth | 0.18% | 1.66% |
| Endocrine, nutritional and metabolic diseases | 1.36% | 1.49% |
| Diseases of the genitourinary system | 1.88% | 1.25% |
| In situ ,benign and other neoplasms | 0.67% | 1.11% |
| Other external causes of accidental injury | 1.22% | 1.03% |
| Falls | 0.84% | 1.01% |
| Other mental and behavioural disorders | 0.18% | 0.98% |
| Intentional self-harm  | 0.76% | 0.18% |

Table 1: Underlying cause of death for all deaths and for those associated with epilepsy, England 2012-2014. Data from [3]. Epilepsy associated deaths were defined as any deaths where epilepsy was listed anywhere on the death certificate whether or not it was considered the underlying cause of death.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Age in years** | **Average, 2009-2016** | **National Average mortality rate per 100,000** | **Expected** | **Observed** | **SMR** | **Lower** | **Upper** |
| **yearly deaths in general population** | **size of population**  | **yearly size of epilepsy population**  | **Number of deaths in epilepsy population** | **95% CI** |
| 16-24 | 283 | 622,729 | 3,740 | 45 | 2 | 10 | **6** | 2.3 | 9.7 |
| 25-34 | 593 | 680,591 | 4,908 | 87 | 4 | 16 | **4** | 1.9 | 5.6 |
| 35-44 | 1,233 | 710,935 | 5,408 | 173 | 9 | 21 | **2** | 1.3 | 3.2 |
| 45-54 | 2,682 | 789,569 | 6,324 | 340 | 21 | 34 | **2** | 1.1 | 2.1 |
| 55-64 | 5,355 | 664.607 | 5,126 | 806 | 41 | 49 | 1 | 0.9 | 1.5 |
| 65-74 | 10,213 | 506,658 | 3,297 | 2,016 | 79 | 62 | 1 | 0.6 | 1.0 |
| 75+ | 34,031 | 418,089 | 2,889 | 8,142 | 235 | 115 | 0 | 0.4 | 0.6 |

Table 2: Data from the Scotland Epilepsy Deaths study [7]. SMR = Standardized Mortality Ratio. CI = Confidence Intervals. Significant differences shown in bold

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| NHS region | Sub-region | Population per FTE Neurologist | People with Epilepsy per FTE Neurologist | Training posts |
| London | North East/Central London | 28,111 | 161 | 74 |
| North West London | 77,946 | 423 |
| South London | 48,684 | 281 |
| Midlands and East | East Midlands | 146,651 | 1200 | 16 |
| East of England | 86,554 | 669 | 26 |
| West Midlands | 90,830 | 790 | 22 |
| North of England | North West | 96,673 | 881 | 23 |
| Northern | 98,625 | 923 | 18 |
| Yorkshire and the Humber | 86,363 | 758 | 27 |
| South of England | Kent, Surrey and Sussex | 99,837 | 763 | 19 |
| South West | 73,394 | 611 | 20 |
| Thames Valley | 62,939 | 423 | 9 |
| Wessex | 108,477 | 839 | 10 |

Table 3: Neurology manpower, training posts and population. Manpower Data from [9] and population data from [3] and [5]. Figures are estimates, due to differences in data years.



Figure 1: Age distribution in men and women of deaths associated with epilepsy in England, 2012-14. Figure and Data from [3]



Figure 2: Death with epilepsy per 100,000 population, according to deprivation decile. Figure and data from [3]

Figure 3. Deprivation and seizure freedom for individual Clinical Commissioning Groups in England. Data from [5] CCG = Clinical Commissioning Group. IMD = Index of Multiple Deprivation.

Figure 4: The effect of deprivation on the leading causes of death in England and Wales. Figure and data from [20]. Numbers/shaded bars refer to Deprivation deciles ranging from most deprived (10) to least deprived (1). Horizontal axis is number of deaths in 2016.