



Public Health
England

Protecting and improving the nation's health

Deaths Associated with Neurological Conditions in England

2001 to 2014

Data briefing

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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Key messages

- there is an increasing proportion of neurological deaths: a 39% increase in neurological deaths compared to a 6% decrease in all-cause deaths since 2001. Two major factors are likely to be contributing to this; the improving survival rates from other conditions and better diagnosis and recognition of neurological conditions.
- premature deaths: deaths associated with a neurological condition are 35% more likely to be premature. A focus on epilepsy and falls related deaths could reduce avoidable mortality
- impact of deprivation: epilepsy associated deaths in the most deprived areas are nearly three-times more likely than in the least deprived areas
- neurological conditions can be fatal: 50% of underlying causes of death in the cohort are recorded as a neurological condition
- 49% of deaths associated with neurological conditions occur in hospitals

Introduction

This briefing presents key findings from the analysis of deaths associated with neurological conditions in England and supplements the data analysis report. The collections of resources related to this project are produced by the Neurology Intelligence Network (NIN) and National End of Life Care Intelligence Network (NEoLCIN). These are available at: <https://www.gov.uk/guidance/neurology-data-and-analysis-a-guide-for-health-professionals>.

This study used the Public Health England (PHE) Office of National Statistics (ONS) Annual Births and Mortality Database for 2001-2014 to investigate four key areas of interest in relation to deaths of those aged 20 years and over:

- numbers of deaths associated with neurological conditions and recent trends
- demographic characteristics of people dying with neurological conditions
- underlying cause of death and association with the broad disease groups
- place of death

This document is targeted at individuals in a commissioning or policy role responsible for the provision of services for people with neurological conditions. This briefing provides insight into deaths at the England level. Local areas may wish to review their local data, where available, in light of this briefing and consider whether there are opportunities to improve the provision of services for people who live and die with neurological conditions.

More people in England are living and dying with a neurological condition

Deaths with a neurological condition

During the study period of 2001 and 2014 there were 366,728 deaths with a neurological condition recorded on the death certificate. The annual number of deaths for these conditions increased by 39% over the period 2001 to 2014, while the annual number of all-cause deaths over the same period decreased by 6%.ⁱ

In 2014, there were 31,925 recorded deaths of people aged 20 and over (Figure 1), representing 7% of all deaths in England. The largest numbers of deaths in the cohort were with Parkinsonism etc, accounting for around 10,000 deaths, which was twice the number of deaths associated with tumours etc, three-times the number of deaths associated with epilepsy and with traumatic brain and spine injury, and five times that associated with motor neurone disease.

Box 1: Definition of study group

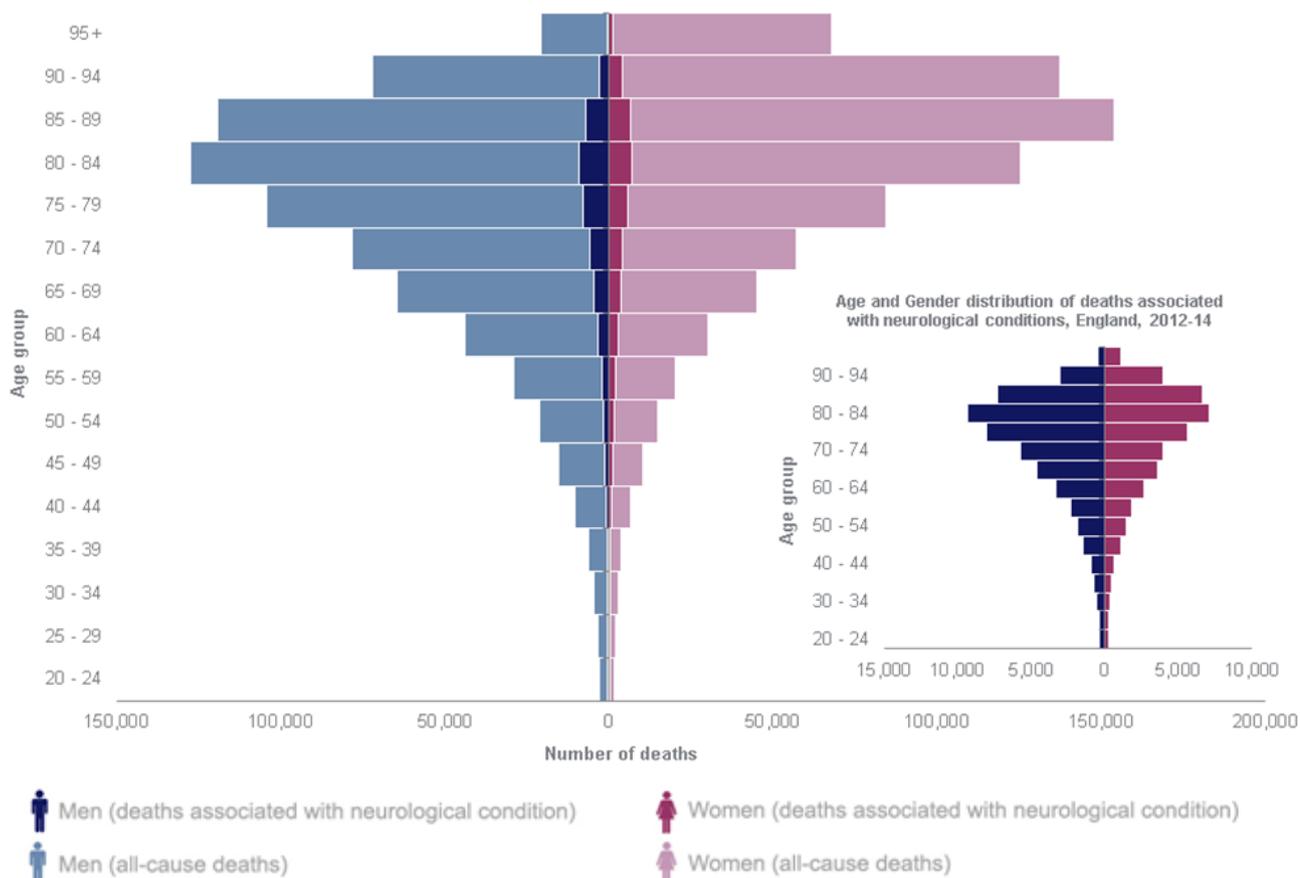
- all deaths with a resident code for England in the adult population aged 20 and over, where a reference to a neurological condition was included in any of the 16 code positions on the death certificate – referred to as an associated death
- adult neurological conditions are defined by 473 ICD10 codes and described in the National Neurology Intelligence Network technical briefing⁽¹⁾
- the specific conditions are: epilepsy, motor neurone disease and spinal muscular disorders (MND), multiple sclerosis and inflammatory disorders (MS), neuromuscular diseases, Parkinsonism and other extrapyramidal disorders/tic disorder, traumatic brain and spine injury and tumours of the nervous system

Figure 1: Summary mortality statistics for individual neurological conditions, persons aged 20 years and over, England

	Number of deaths (2001-14)	Number of deaths (2001)	Number of deaths (2014)	Percentage change (2001 - 2014)
Neurological conditions	366,728	23,051	31,925	39%
Parkinsonism and Other Extrapyrimal disorders/Tic disorder	111,949	6,963	10,067	45%
Tumours of the nervous system	74,725	4,995	5,605	13%
Epilepsy	34,121	1,936	3,291	70%
Traumatic brain and spine injury	30,561	1,773	2,902	64%
MND and Spinal muscular atrophy	25,921	1,574	1,846	18%
MS and inflammatory disorders	21,107	1,301	1,701	31%
Neuromuscular diseases	11,435	563	1,028	83%
All-cause deaths	6,590,453	492,205	464,556	-6%

The majority of deaths associated with neurological condition are male (56%), whereas for all-cause deaths 52% are female. Male deaths outnumber female deaths in all age groups for neurological conditions except those aged 90 years and older (illustrated in Figure 2).

Figure 2: Age and gender distribution of all-cause deaths and deaths associated with neurological conditions, persons aged 20 and over, England, 2012-2014



While deaths associated with neurological conditions account for around 7% of all deaths in England, this proportion varies considerably with age. Deaths in the 20 to 29 year age group are four-times more likely to be associated with a neurological condition than those in the 85 years plus age group (16% and 4% of all-cause deaths respectively).

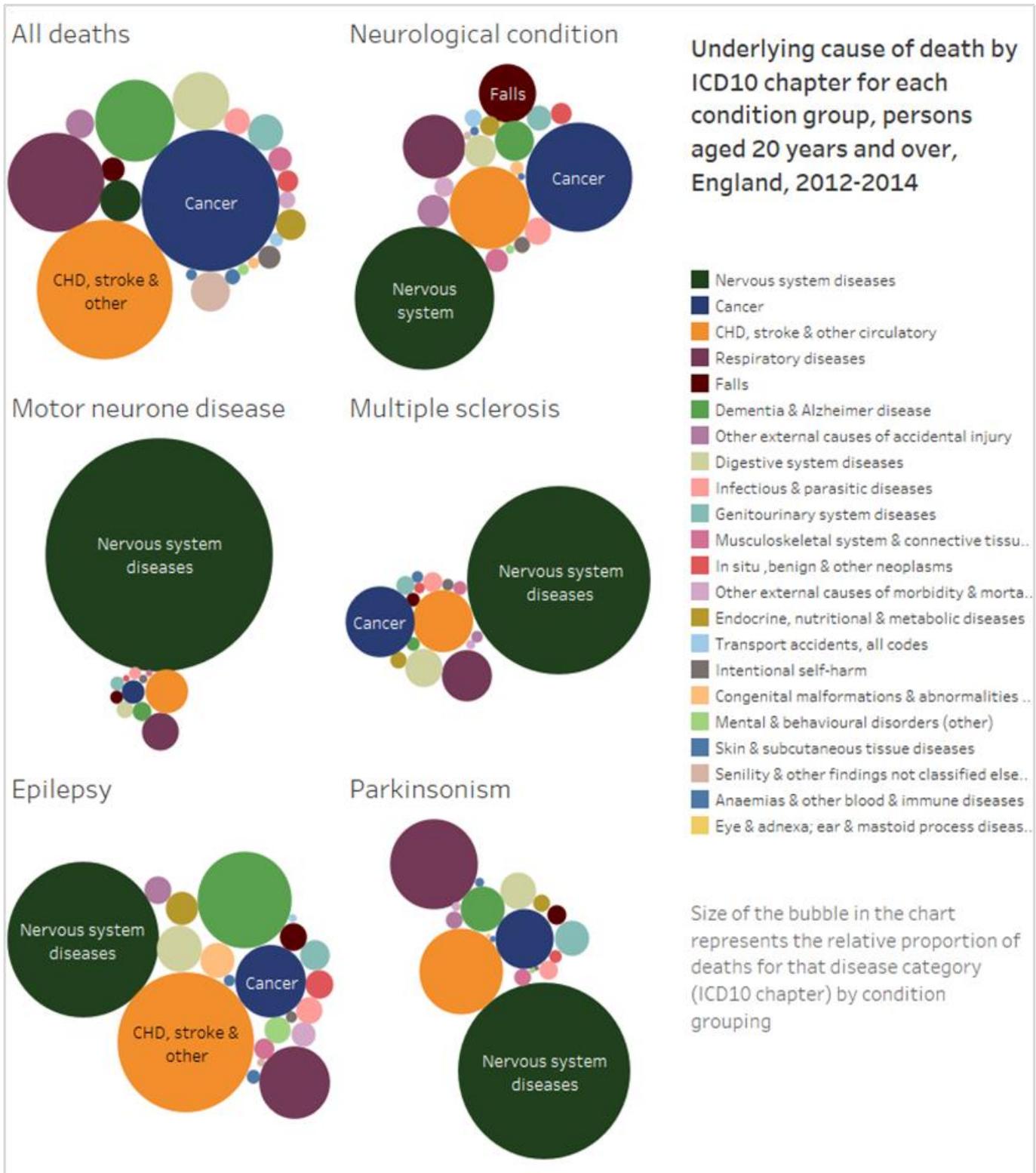
Younger deaths (20 to 29 years of age) are more often associated with neuromuscular disease, tumours of the nervous system, epilepsy and traumatic brain and spine injury, while older deaths (85 years plus) are more often associated with Parkinsonism and other extrapyramidal disorders/TIC disorder, as well as epilepsy and traumatic brain and spinal injury. However, as with the all-causes of deaths, a higher number of deaths occur in the older age groups.

Neurological conditions may not, in themselves, be perceived as fatal (for example, when compared to cancer) but this study shows that of the 91,685 deaths in the period 2012-2014, in half¹ the underlying cause² of death was recorded as a neurological condition.

¹ Including 11% related to tumours of the nervous system.

² Defined as the primary reason for the cause of death.

Figure 3: Underlying cause of death by ICD10 chapter for each condition group, persons aged 20 years and over, England 2012-2014



The condition groups with the largest proportion of deaths classed as a disease of the nervous system³ (excluding tumours of the nervous system) are MND and spinal muscular atrophy (91% of related deaths); multiple sclerosis and inflammatory disorders (70%); Parkinsonism and other extrapyramidal disorders/TIC disorders (55%) illustrated in Figure 3.

However, living with a neurological condition can be compounded by the presence of other common conditions such as cancers, diseases of the circulatory system (CHD, stroke etc) and respiratory conditions. This is most evident in epilepsy, where the underlying cause of death was recorded as diseases of the circulatory system (26%), dementia and Alzheimer's disease (13%) or cancers (7%), nearly half of the cohort deaths in the period.

Nearly 7% of deaths associated with a neurological condition had an underlying cause of death recorded as a fall. This accounted for 2,000 deaths in 2014.

The proportion of deaths in England associated with a neurological condition is increasing

More people than ever are dying with a neurological condition recorded in the death certificate. The annual number of deaths associated with neurological conditions increased by 39% over the period 2001 to 2014, while the annual number of all-cause deaths over the same period decreased by 6%.

When standardised for a growing and ageing population, the overall mortality rate of deaths associated with a neurological condition had increased by 13%⁴, while the all-cause mortality rate had decreased by 18% over the same period. This increasing trend in deaths associated with all neurological conditions is seen in all seven of the major condition groups in terms of crude rates and all but tumours of the nervous system when standardised by age and gender for the period (illustrated in Figure 4).

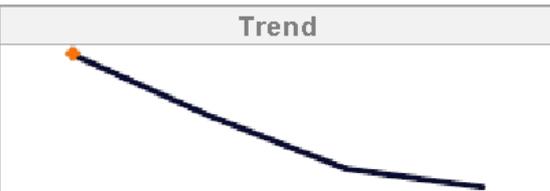
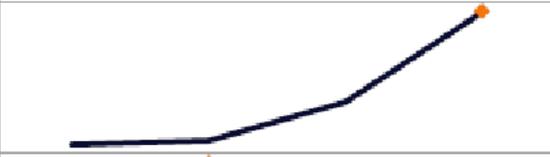
In absolute numbers, the largest increase is with Parkinsonism etc. where there were 3,000 additional deaths in 2014 compared to 2001, with numbers associated with epilepsy and traumatic brain and spine injuries increasing by 1,300 and 1,000 deaths

³ ICD10 Chapter 6 – Diseases of the nervous system (G00 – G99) broadly represents the neurological conditions defined in this briefing excluding tumours of the nervous system (C70, C71, C72, C79.3, D32, D33)

⁴ Three-year 2003-2005 to 2012-2014

respectively. In terms of percentage increases, the largest changes are associated with neuromuscular diseases (83%), epilepsy (70%) and traumatic brain and spine injuries (64%).

Figure 4: Neurological conditions – age directly standardised mortality rates per 100,000 population, people aged 20 years and over, England 2003-2005 to 2012-2014

Conditions	2012-2014	Trend
All deaths	1213.4	
Neurological conditions	79.8	
Epilepsy	8.1	
Motor neurone disease & spinal muscular disorders	5.7	
Multiple sclerosis & inflammatory disorders	4.3	
Neuromuscular diseases	2.6	
Parkinsonism & other extrapyramidal disorders/tic disorder	24.3	
Traumatic brain & spine injury	6.9	
Tumours of the nervous system	14.6	

Notes: Each chart in this figure is based on its own vertical axis and therefore charts are not directly comparable but are indicative of the direction of change. The highest value in each series is marked with an orange diamond.

More people are living with a neurological condition

Two major factors are likely to be contributing to the increasing trends in deaths associated with neurological conditions. The largest is the improving survival rates in other conditions.

Between 2004 and 2014 the mortality rates² of the other conditions had reduced by considerable margins, such as all cancers with a 10% reduction in deaths, respiratory diseases with a 22% reduction and cardiovascular conditions with a 41% reduction. As larger proportions of the population grow older, there are more cases of neurological conditions (such as Parkinson's disease, Alzheimer's disease and epilepsy) in which prevalence⁵ and incidence⁶ rise with age.

Using the diagnosis of epilepsy as an example illustrative condition for all neurological conditions, the prevalence of epilepsy⁷ has increased by over 25% between 2004/05 and 2014/15 from 0.60% to 0.79% of registered populations aged 18 years and over.

Further research may be required to address appropriate clinical management in this older population with neurological illness, and how to deal with the likely increasing demand on the health service.

Another contributing factor to the increasing deaths associated with neurological conditions may be an improvement in detection and diagnosis practices, ie that more people are being diagnosed and thus being registered as living with the neurological condition.

A greater awareness of neurological conditions among healthcare professionals may also be contributing to the increase in recorded deaths, through better/more complete recording of conditions on the death certificate.

⁵ The total number of diagnosed cases at a point in time.

⁶ The total number of new diagnosed cases in a time period.

⁷ Cases recorded on primary epilepsy registers collected by the Quality Outcomes Framework process

Having a neurological condition reduces life expectancy

The data analysis study shows that deaths associated with neurological conditions occur at a mean age of 74 years, which is four years younger than all-cause deaths (Figure 5). The mean age at time of death for all the major neurological condition groups are less than the all-cause mean age except for Parkinsonism etc.

The lowest mean age at death is for deaths associated with MS and inflammatory disorders, which occurs on average 12 years younger than all-cause deaths.

Figure 5: Mean age at time of death (years) for individual neurological conditions, England 2012-2014

	Mean Age - People	% Deaths under 75 years of age - people
Neurological conditions	74	42%
MS and inflammatory disorders	66	73%
Tumours of the nervous system	68	66%
Epilepsy	70	49%
MND and Spinal muscular atrophy	72	55%
Neuromuscular diseases	72	43%
Traumatic brain and spine injury	75	33%
Parkinsonism and Other Extrapyrmidal disorders/Tic disorder	82	15%
All-cause deaths	78	31%

Premature mortality

The probability of a death being classed as premature⁸ is higher among those associated with a neurological condition than for all-cause deaths. 42% of deaths with a neurological condition occur under the age of 75 years compared to 31% of all-cause deaths, ie deaths associated with a neurological condition are one-third more likely to be premature.

This is the case for all seven main neurological condition groups, except Parkinsonism etc (15%). The conditions with the largest proportion of premature deaths are MS and

⁸ Occurring under the age of 75 years

inflammatory disorders (73%) and tumours etc (66%) where deaths for both groups are more than twice as likely to be premature.

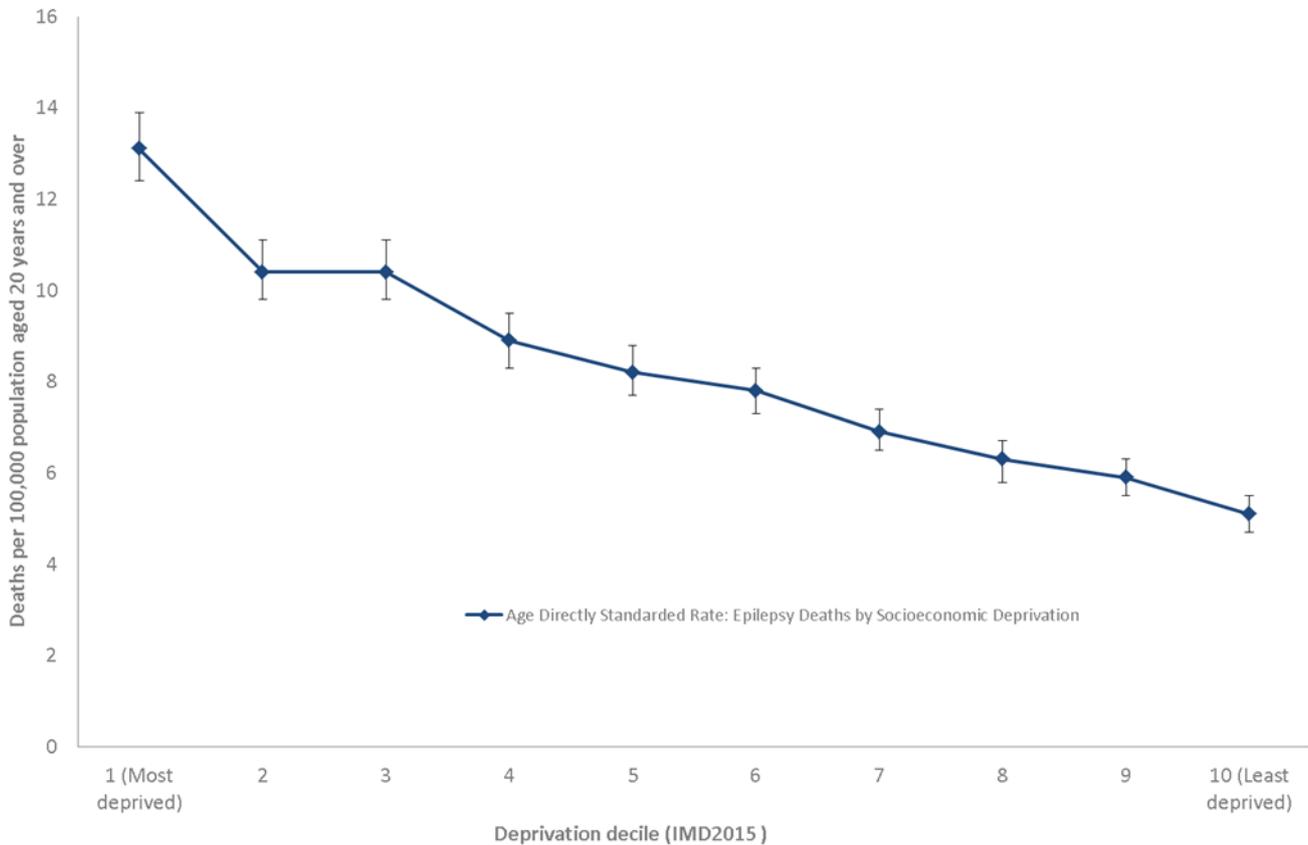
Preventable premature mortality – focus on epilepsy

Around 3,100 deaths each year were associated with epilepsy, of which 49% were premature, with the mean age at death being 70 years. In this group approximately half the deaths also have a combination of comorbidity relating to circulatory disease and respiratory disease. Over one-third had an underlying cause of death recorded as CHD, stroke and other diseases of the circulatory system, or related to a fall.

The study also shows that a greater proportion of epilepsy related deaths occur in areas of higher levels of deprivation. In fact when standardised by age, the rate of deaths associated with epilepsy in areas ranked as the most deprived in England is nearly three-times larger than in the least deprived areas, 13 deaths per 100,000 population verses 5 deaths per 100,000 population as illustrated in Figure 6.

Furthermore the rates of deaths in the second and third most deprived declines are also statistical higher than those in the rest of the cohort. It is well documented, but not as yet well explained, that epilepsy prevalence varies with social deprivation; it is not clear whether this inequality in mortality is the consequence of prevalence, of poor care or both. Socioeconomic poverty is a well-known determinant of poor general health³, which underlines the health inequalities link in relation to epilepsy related deaths.

Figure 6: Age standardised death rates for epilepsy by deciles of deprivation, persons aged 20 and over, England 2012-2014



In 2002 the National Audit of Epilepsy-Related Deaths⁴ concluded that 39% of epilepsy deaths were avoidable and in 54% of deaths there was a deficiency in the care received by individuals. The NASH⁵ study in 2015 provides a more contemporary view on the care provided to those with epilepsy, where it found that 61% of attendances at emergency departments relating to seizures were of people with a prior diagnosis of epilepsy, a significant proportion of those with active epilepsy were not being seen within specialist services. With better community care many of the acute episodes might have been prevented.

The findings of the data analysis study suggest that there are opportunities to improve the morbidity and quality of life of people with epilepsy, in particular in areas of socioeconomic deprivation. There is need for a better understanding of the links between deprivation, prevalence of epilepsy and the premature death of those with epilepsy.

This may require improvement in the clinical management of people with epilepsy in the community and in hospitals, but also investigating and reducing mortality in this group by considering the general health of the cohort, and factors that might contribute to cardiovascular and circulatory risk such as smoking, excessive alcohol consumption and poor diet.

Preventable premature mortality – focus on falls

Between 2012 and 2014, 6,222 people aged 20 and over died with a reference to a neurological condition and a fall on the death certificate, accounting for 7% of those who died with a neurological condition. Furthermore 43% of all-cause deaths of people aged 20 and over where a fall was documented in the death certificate, also had a recording of a neurological condition.

Provision of care

People with neurological conditions should be supported by the health and social care system to manage their own care through the provision of good and relevant services that are appropriate to their needs. Such support would impact on the quality of life for the individual and potentially prevent premature death.

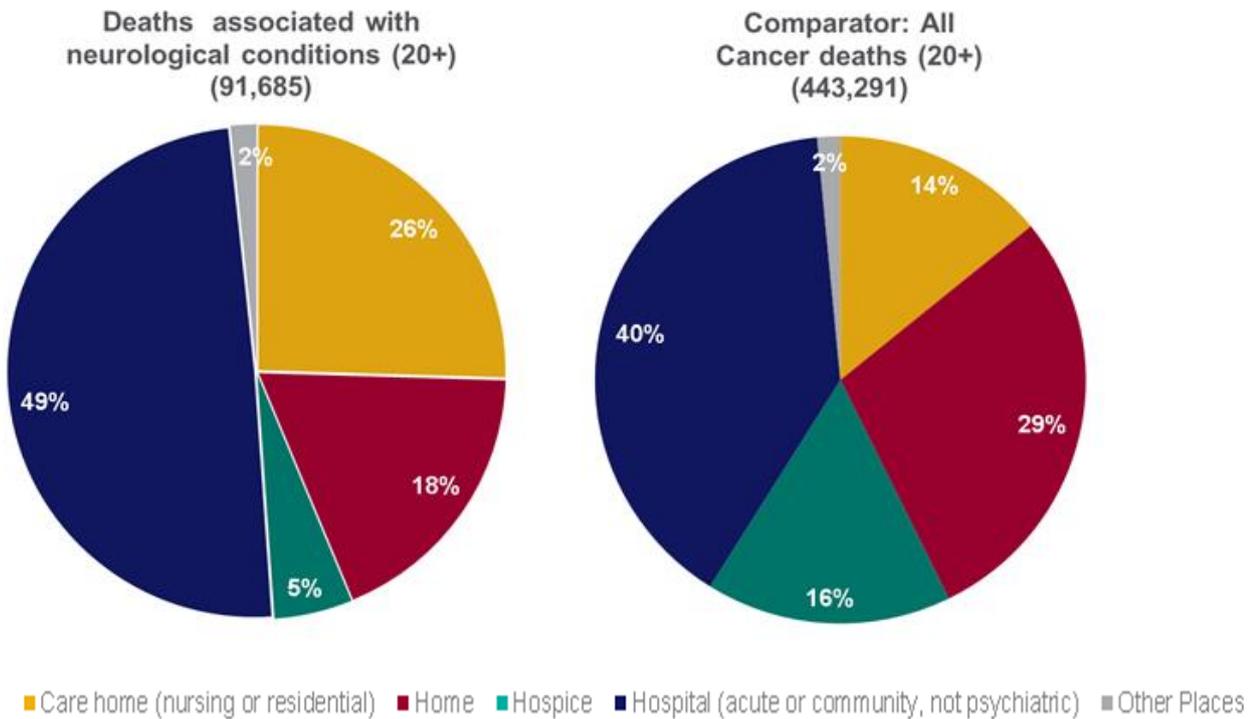
However, in the 2015 review into services for people with neurological conditions undertaken by the National Audit Office⁶, it was noted that improvements to the provision of such care were still required. It documented that only 65% of respondents to the GP Patient Survey, who had a long-term neurological problem were satisfied with the provision of services and around 21% reported they had not had sufficient support.

Findings of the Invisible Patient⁷ study by the Neurological Alliance also found gaps in the provision of support with 72% of respondents reporting that they had not been offered a care plan to help manage their condition. The 2016 follow-up study⁸ showed deterioration in several aspects of care, including 82% of respondents without the provision of a care plan. The well documented rapidly increasing prevalence of neurological conditions is placing increasing demand on specialist services.

Place of death

The findings of the data analysis study illustrated that the largest proportion of deaths associated with neurological conditions occurred in the hospital environment (49%), less than a quarter (23%) occurred at home or in hospice and a further quarter occurred in a care home (26%). By contrast, deaths associated with cancer are 50% more likely to occur at home and over three-times more likely to occur in a hospice. A smaller proportion of deaths associated with cancer occur in the hospital environment compared to deaths with neurological conditions, illustrated in Figure 7.

Figure 7: The proportion of deaths associated with neurological conditions and cancer deaths by place of death, deaths of people aged 20+, England 2012-14



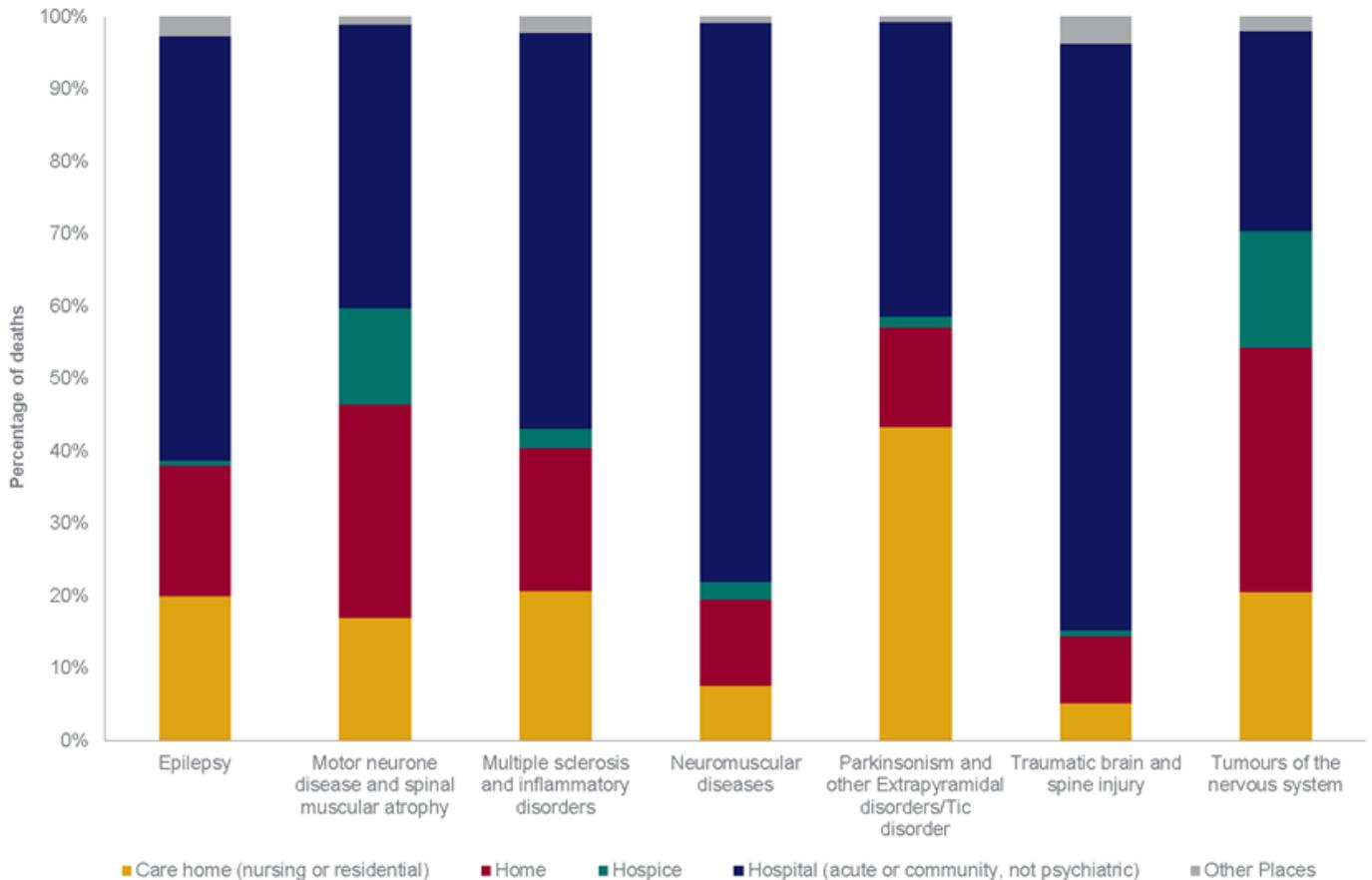
Significant variation also exists in the location of death relative to the associated neurological condition (Figure 8). The condition groups with the largest proportions dying at home or in a hospice are tumours of the nervous system (50%) and motor neurone disease and spinal muscular atrophy (43%), while the smallest proportion were those deaths related to traumatic brain and spine injuries.

Around 84% of deaths associated with Parkinsonism etc occur either in hospital (41%) or a care home (43%), with only 14% occurring at home. Around 59% of epilepsy related deaths occur in the hospital environment.

Having a good death

The 2008 National End of Life Care Strategy⁹ sought to ensure that all people, including those with neurological conditions, could access the palliative care services they need and expect a good death. The A time and place study¹⁰ in 2013 by the charity Sue Ryder found that the preferences for a good death were: being free from pain and discomfort (78% of respondents); being surrounded by loved ones (71%); having privacy and dignity (53%); being in familiar surroundings (45%).

Figure 8: Place of death – proportions with associated with specific neurological conditions; deaths of people aged 20+ England, 2012-14



The current study did not measure the quality of a good death. The only element from the dataset that was available was location of death; the study found that around 44% of neurological deaths occurred either at home or in a care home, which in most cases may have been usual place of residence. This is similar to the proportion of cancer related deaths (43%) in these locations.

However, the role of hospices in death in the two comparator groups is striking. More than three-times the proportion of cancer deaths occur in hospices (16%) than neurological related deaths (5%), with the corresponding proportion of individuals (40% and 49% respectively) dying in the hospital environment.

The reasons for the difference in the proportions of deaths in hospital between people dying with a neurological condition and people dying with a cancer were not investigated in this study, but are worth considering.

It can be suggested that the following factors may contribute to this variation: a lack of specialist hospice provision for people with neurological conditions; a lack of medical support (such as pain management) available in a non-hospital environment; a lack of

knowledge of the availability of hospice provision by those responsible for the care of the individual. Further investigation of end of life care planning is required to understand this picture fully and identify if there are actions required to address the above factors.

A further challenge in ensuring an individual with a neurological condition accesses the appropriate end of life care services is in identifying the trigger point for palliative care. Individuals can live for many years after their diagnosis, meaning that the health care professionals that manage their on-going care can find it difficult to judge when to introduce a palliative care approach.

This decision can be confounded by the complex physical and psychological needs of those with neurological conditions, and the relative rarity of the conditions, making care planning in the latter stages of life challenging for both experienced and inexperienced providers¹¹.

Research is being commissioned to inform the understanding of the palliative needs of those with a neurological condition and the effective service provision for this population. For example, Kings College London is currently undertaking a randomised fast-track trial of the clinical and cost-effectiveness of Short-term Integrated Palliative Care (SIPC) for people with advanced long term neurological conditions⁹. This and other studies can lead to service change that can have a significant impact on the quality of death for those with a neurological condition.

⁹ HS&DR Project: 12/130/47 <https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1213047/#/>

References

1. Public Health England. Defining adult neurological conditions 2015 [Available from: <http://webarchive.nationalarchives.gov.uk/20170302112650/http://www.yhpho.org.uk/resource/view.aspx?RID=207314>].
2. Office for National Statistics. Deaths Registered in England and Wales (Series DR), 2014 2015 [Available from: http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/dcp171778_422395.pdf].
3. Marmot M. Fair Society, Healthy Lives: The Marmot Review 2010 [Available from: <http://www.parliament.uk/documents/fair-society-healthy-lives-full-report.pdf>].
4. Hanna N J BM, Sander JW, Smithson WH, Appleton R, Brown S, Fish DR. The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy – death in the shadows. : The Stationery Office; 2002 [Available from: <https://sudep.org/sites/default/files/national-sentinel-clinical-audit-of-epilepsy-related-death-2002-summary.pdf>].
5. Dixon PA, Kirkham JJ, Marson AG, Pearson MG. National Audit of Seizure management in Hospitals (NASH): results of the national audit of adult epilepsy in the UK. *BMJ Open*. 2015;5(3).
6. O'Reilly A. VD. Services for people with neurological conditions: progress review: National Audit Office; 2015 [Available from: <https://www.nao.org.uk/wp-content/uploads/2015/07/Services-for-people-with-neurological-conditions-progress-review.pdf>].
7. The Neurological Alliance. The Invisible Patients: Revealing the state of neurology services 2015 [Available from: http://www.neural.org.uk/store/assets/files/495/original/Invisible_patients_-_revealing_the_state_of_neurology_services_final_14_January_2015_.pdf].
8. The Neurological Alliance. Falling short: How has neurology patient experience changed since 2014? 2017 [Available from: http://www.neural.org.uk/store/assets/files/668/original/Neurological_Alliance_-_Falling_Short_-_How_has_neurology_patient_experience_changed_since_2014.pdf].
9. Department of Health. End of Life Care Strategy: Promoting high quality care for all adults at the end of life 2008 [Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf].
10. Wood. C. SJ. A time and a place: What people want at the end of life: Sue Ryder; 2013 [Available from: <https://www.sueryder.org/~media/files/about-us/a-time-and-a-place-sue-ryder.ashx>].
11. Wilson E, Seymour J. Exploring the palliative and end-of-life care needs of those affected by progressive long-term neurological conditions. *Journal of Care Services Management*. 2007;2(1):92-102.

Find out more

The neurology intelligence network (NIN) was launched in June 2014. Its ambition is to:

- develop relevant, timely and authoritative intelligence tools and resources
- take a strategic lead across the system on the innovative development of information for improvement, embedding our intelligence tools and products in local systems
- develop strong partnerships with key stakeholders and the academic, commercial and voluntary sectors – with the aim of continually driving up standards in intelligence products aimed at improving population health and reducing health inequalities

The NIN website contains more information and resources. See:

www.gov.uk/guidance/neurology-data-and-analysis-a-guide-for-health-professionals

The NIN is part of National Mental Health Dementia and Neurology Intelligence Network (NMHDNIN) and a member of the Health Intelligence Network family sponsored by Public Health England and NHS England.

For more information about the National End of Life Care Intelligence Network (NEoLCIN) and its partners see www.endoflifecare-intelligence.org.uk.

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-