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Initial paper produced by Karen Deacon, Director of Care at NCYPE  
on behalf of the Joint Epilepsy Council April 2004 [kdeacon@ncype.org.uk](mailto:kdeacon@ncype.org.uk)

Revised and updated by Simon Wigglesworth, Deputy Chief Executive, Epilepsy Action,  
on behalf of the Joint Epilepsy Council, March 2005 [swigglesworth@epilepsy.org.uk](mailto:swigglesworth@epilepsy.org.uk)

**The Joint Epilepsy Council  
of the U.K. & Ireland  
PO Box 186  
Leeds  
LS20 8NH**

**Tel: 01943 871852  
Email: [sharon.jec@btconnect.com](mailto:sharon.jec@btconnect.com)**

**[www.jointepilepsycouncil.org.uk](http://www.jointepilepsycouncil.org.uk)**

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The Joint Epilepsy Council

# Joint Epilepsy Council

Epilepsy prevalence,  
incidence and other statistics

**The JEC has produced the following recommended epilepsy prevalence and incidence data in response to requests from member organisations. The data is intended to provide a consistent approach to epilepsy statistics and members are invited to use the information if they so wish.**

**(Note this paper is for UK use only.)**

**It is acknowledged that no exact figures for the numbers of people with epilepsy can be produced due to the complicating factors such as mis-diagnosis rates, inconsistent reporting etc.**

A variety of sources were reviewed in the production of this data, namely the Royal College of Physicians, The Institute of Child Health, Great Ormond Street, GP Data sets, World Health Organisation statistics, Work for Census Analysis, various papers by leading physicians, individual organisations, particularly Epilepsy Scotland, Epilepsy Connections, Epilepsy Action, NCYPE and NSE and overseas organisations such as The Australian Epilepsy Association. A further 13 papers containing recommendations regarding epilepsy incidence and prevalence were also reviewed.

The final prevalence figures are based on the Office of National Statistics, Epilepsy prevalence and prescribing patterns in England in Wales, autumn 2002 (1), and recalculated for the mid 2003 population figures across the United Kingdom (2).

The ONS paper drew its primary evidence from the General Practice Research Database which draws on information from 2.7 million patients. The figures are based on patients with a diagnosis of epilepsy that are being prescribed anti-epileptic drugs (AEDs) for their epilepsy.

The numbers do not therefore include patients with epilepsy who are not receiving AED treatment, for whatever reason.

The figures used are in line with the majority of papers considered.

## The Epilepsies

Epilepsy is a tendency to have recurrent seizures. It can affect anyone, at any age and from any walk of life. It is the most common, serious, neurological condition.

Epilepsy is not a single condition; there are about 30 different epileptic syndromes\* and over 38 different seizure types (6).

*\*Epilepsy Syndrome: A complex of signs and symptoms that define a unique epilepsy condition. (6)*

## Prevalence

Prevalence is a measure that allows us to determine a person's likelihood of having a disease or condition. Therefore, the number of prevalent cases is the total number of cases of disease or condition existing in a population at any given time.

A prevalence rate is the total number of cases of a disease existing in a population divided by the total population.

**Approximately 456,000 people in the UK have epilepsy** (based on 2003 census and a total UK population of 59,554,000)

**This is equivalent to 1 in 131 people** The Age Standardised Prevalence Rate of Epilepsy in the UK: 7.5 per 1,000.

**Prevalence by different sections of the community**  
See Appendix 1 for detailed figures.

**Children under 16 years of age** with epilepsy, the total is approximately 42,000 or 1 in 279.

**Children and young people under 18 years of age** with epilepsy, the total is approximately 58,000 or 1 in 242.

**People 25 years of age and below** with epilepsy, the total is approximately 87,000 or 1 in 213.

**People aged 65 and over** with epilepsy, the total is approximately 105,000 or 1 in 91.

**Women of childbearing age** (12 - 50) with epilepsy, the total is approximately 131,000.

As a proportion of the total population of people with epilepsy this equals 29 per cent.

**People with learning or intellectual disability:** More than one in five people with epilepsy have learning or intellectual disabilities (3).

**Social deprivation:** Epilepsy prevalence is 25 per cent higher in the most socially deprived areas compared to the least socially deprived areas (1).

**Worldwide:** Epilepsy affects around 50 million people worldwide, 80 per cent of them are in developing countries. In these countries, although most cases can be treated, around 90 per cent of people with epilepsy are not receiving appropriate treatment (4).

Based on the population census 2003 this equates to prevalence in each country as follows (to the nearest 1,000).

	Population 2003 Census estimate	People with epilepsy (pwe)
<b>England</b>	49,856,000	382,000
<b>Wales</b>	2,938,000	22,000
<b>Scotland</b>	5,057,000	39,000
<b>Northern Ireland</b>	1,703,000	13,000
<b>United Kingdom</b>	<b>59,554,000</b>	<b>456,000</b>

## Incidence

Incidence is a measure of disease or condition that allows us to determine a person's probability of being diagnosed with a disease during a given period of time.

Therefore, incidence is the number of newly diagnosed cases of a condition.

An incidence rate is the number of new cases of a disease divided by the number of persons at risk of the disease.

There is again much inconsistency in the incidence rates for epilepsy. The following have been calculate based on figures from MacDonald et al, Brain 2000.

In the UK the annual incidence is approximately 46 per 100,000 (5) or 0.46 cases per 1,000 of population.

Equivalent to 27,400 new cases diagnosed per year (based on 2003 census figures).

Equivalent to approximately 75 new cases each day of the year or 105 new cases each working day of the year.

### Incidence by age

The incidence of epilepsy varies significantly by age; no statistically reliable figures are currently available to give recommendations on incidence by age.

## Misdiagnosis

Misdiagnosis rates in the United Kingdom, where a diagnosis of epilepsy is incorrectly made, are between 20 - 31 per cent (7).

Using an assumed rate of 23 per cent this equates to 105,000 people with a diagnosis of epilepsy and receiving AEDs who do not have the condition.

This does not account for those with epilepsy who have been misdiagnosed as having a different condition for which figures are unavailable.

### Cost of misdiagnosis

These figures are based on those in the Clinical Guidelines and Evidence Review for the Epilepsies: the evidence base for the NICE Epilepsy Clinical Guideline.

	Population - 2003 (2)	People with epilepsy	Misdiagnosed 23% (7)	Medical Cost, £263 (7)	Non- medical, £1,262 (7)	Total
<b>England</b>	49,856,000	382,000	88,000	£23,144,000	£111,056,000	£134,200,000
<b>Wales</b>	2,938,000	22,000	5,000	£1,315,000	£6,310,000	£7,625,000
<b>Scotland</b>	5,057,000	39,000	9,000	£2,367,000	£11,358,000	£13,725,000
<b>Northern Ireland</b>	1,703,000	13,000	3,000	£789,000	£3,786,000	£4,575,000
<b>United Kingdom</b>	<b>59,554,000</b>	<b>456,000</b>	<b>105,000</b>	<b>£27,615,000</b>	<b>£132,510,000</b>	<b>£160,125,000</b>

## Treatment gap

- 70 per cent of the population with epilepsy in the UK could be seizure free with optimal treatment (3).
- Currently only 52 per cent of the population of people with epilepsy are seizure free (8).
- This 18 per cent treatment gap equates to 82,000 people with epilepsy having seizures when with optimal treatment they could be seizure free.
- 1,000 people every year in the UK die of epilepsy related causes. 370 of those deaths are young adults or children. 400 of the deaths per year are avoidable (9).
- 10 per cent of the population in the UK is affected by the social implications of epilepsy i.e. having epilepsy themselves, as a family member or carer, as an employer or as an educationalist involved in epilepsy treatments (10).

## Consequences of epilepsy

- It will cost 15 billion pounds to treat the total current UK population of children with epilepsy during their lifetimes. This figure does not include social services and educational costs. This is equivalent to 0.5 billion pounds per annum to treat children with epilepsy (10).
- It is recognised that children with epilepsy frequently underachieve at school; 50% achieve less than would be predicted from their IQ (11).
- 58,900 people with epilepsy in the UK are claiming disability living allowance. This costs £184 million per year (12).

## Funding of Epilepsy Research

- Only 1 per cent (£3.78 million) of the grant from the UK government's medical research council went to fund epilepsy research in 2002/2003 (13).
- Only 1.4 per cent of the total overall grants given by UK neurological funding bodies went to fund epilepsy research (10).

## Appendix 1 - Age Specific Prevalence of Epilepsy

### Sources

Office of National Statistics, Epilepsy prevalence and prescribing patterns in England in Wales, Autumn 2002

Office of National Statistics, United Kingdom; estimated resident population by single year of age and sex;  
Mid-2003 Population Estimates

### Men

Age	0-4	5-15	16-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Prevalence per 1,000	1.9	4.4	6.6	7.9	8	8.4	9.5	10.9	13.9	15.1	
Population (2003) (000's)	1,733.1	4,269.3	3,444.8	4,018.1	4,513.5	3,769.8	3,321.8	2,354	1,370.7	313.1	<b>29,108</b>
Total number of pwe	<b>3,293</b>	<b>18,785</b>	<b>22,736</b>	<b>31,743</b>	<b>36,108</b>	<b>31,666</b>	<b>31,557</b>	<b>25,659</b>	<b>19,053</b>	<b>4,728</b>	<b>225,328</b>

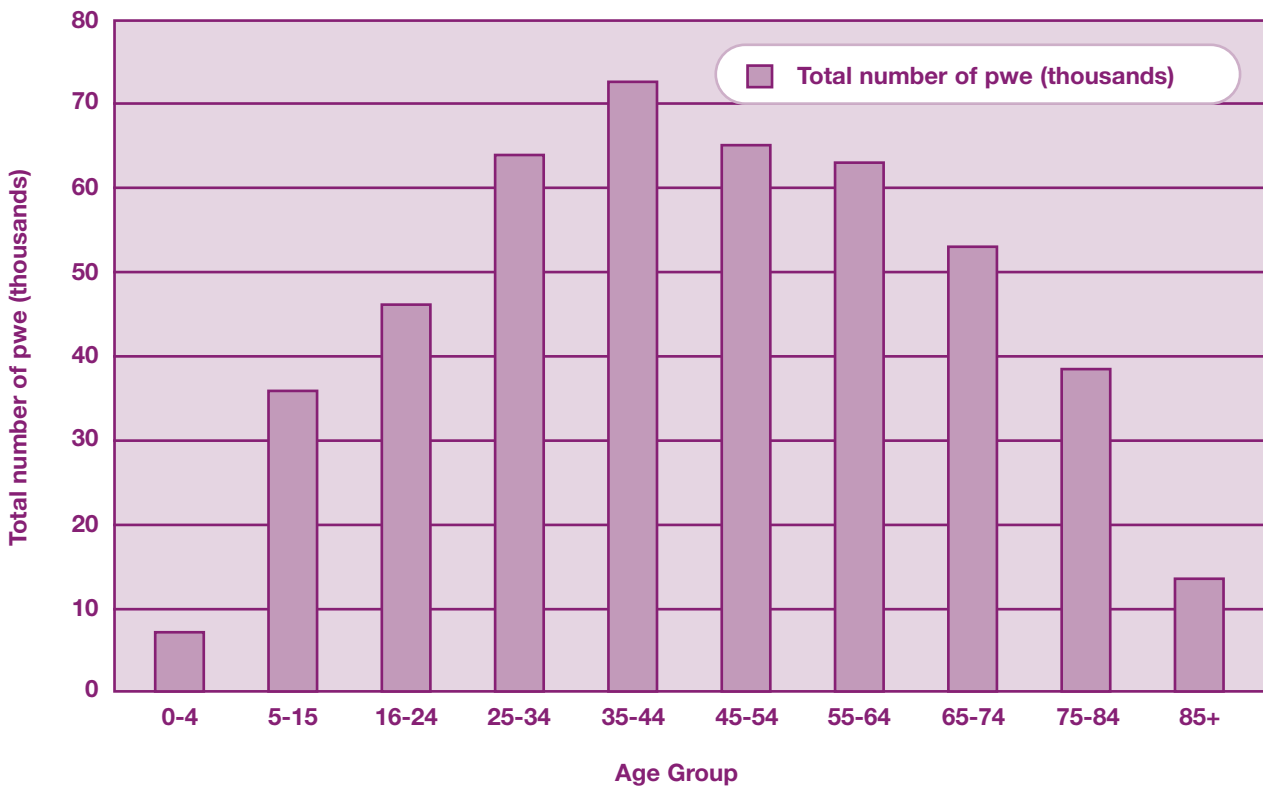
### Women

Age	0-4	5-15	16-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Prevalence per 1,000	1.8	4.1	6.9	7.9	7.8	8.7	9	10.2	9.9	11	
Population (2003) (000's)	1,649.6	4,060.4	3,341.7	4,052.2	4,594.4	3,844.2	3,431.1	2,650.9	2,030.1	791.2	<b>30,446</b>
Total number of pwe	<b>2,969</b>	<b>16,648</b>	<b>23,058</b>	<b>32,012</b>	<b>35,836</b>	<b>33,445</b>	<b>30,880</b>	<b>27,039</b>	<b>20,098</b>	<b>8,703</b>	<b>230,688</b>

### Men and Women

Age	0-4	5-15	16-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Total number of pwe	<b>6,262</b>	<b>35,433</b>	<b>45,794</b>	<b>63,755</b>	<b>71,944</b>	<b>65,111</b>	<b>62,437</b>	<b>52,698</b>	<b>39,151</b>	<b>13,431</b>	<b>456,016</b>

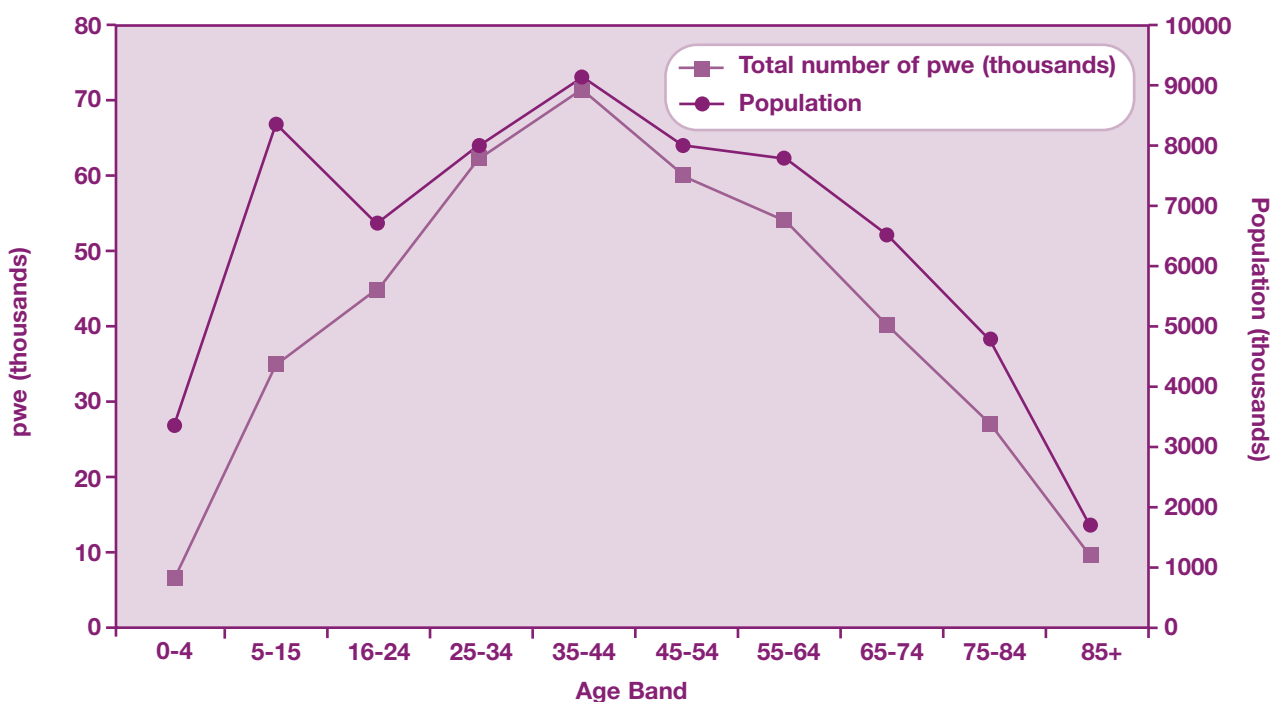
## Appendix 2 - Total number of people with epilepsy in the UK by age group (000's)



This demonstrates the number of people with epilepsy at any specific age. It does not indicate the likelihood of being diagnosed with epilepsy at any specific age.

The number of people in the population with epilepsy continues to increase for all those who are newly diagnosed. It only reduces for those people who may have had curative surgery, their epilepsy has gone away or they have died.

## Appendix 3 - People with epilepsy in the UK against total UK population (000's)



The chart compares the number of people with epilepsy in any given age group with the total population of the UK for that age group.