

# Dementia in people aged 65 years and older: a growing problem?

Liz Kirby, Petra Lehmann and Azeem Majeed,  
*Demography and Health,*  
ONS

**This study examines trends in death rates from dementias and neurodegenerative disorders in people aged 65 and over in England and Wales between 1979 and 1996. In total, there were 171,590 deaths from dementias and neurodegenerative disorders, with the number of deaths per year increasing from 3,021 in 1979 to 10,415 in 1996. Age-standardised death rates for all diagnoses combined increased from 39 to 96 per 100,000 for men and from 45 to 101 for women between 1979 and 1996. The most dramatic increase was seen in death rates from Alzheimer's disease which increased from less than 1 per 100,000 in 1979 to 19 for men and 21 for women in 1996.**

## INTRODUCTION

Because of the increasing number of elderly people in most countries, the health of the elderly is becoming an important public health issue.<sup>1</sup> One of the more common disorders that affects elderly people is dementia (Box 1),<sup>2</sup> a condition in which there is disturbance of intellectual functions, including memory, thought processes, orientation, comprehension, learning capacity, language and judgement.<sup>3</sup> Dementia can also affect personality and behaviour, leading to problems such as neglect of personal care and hygiene, incontinence, emotional instability, and loss of social inhibitions.<sup>4</sup> Patients with dementia often have complex health needs, and can impose a considerable burden on carers as well as on health and social services.

The prevalence of dementia is strongly associated with age. Some degree of dementia is present in about 5% of people aged 65 years and over and more than 20% of those over 80 years of age.<sup>5</sup> Because of the increasing number of elderly people in the population, and the subsequent increase in the number of people suffering from dementia, some important public health issues can be identified. Primary care and community services will have to care for more patients with dementia in the community. Hospitals will find that more of the patients they admit with acute medical problems will also suffer from dementia or from lesser degrees of cognitive impairment.

To help meet these challenges, information is required on the number of people with dementia in the population, on their likely needs for health and social care, and how these may change in future years. In this paper, we examine one aspect of the burden of dementia on the health of the population, death rates from dementias and neurodegenerative disorders in people aged 65 years and over. Dementia in younger patients has very different causes to

## Box 1

### Definition of dementia

Dementia is the global impairment of higher cortical functions, including memory, the capacity to solve the problems of day-to-day living, the performance of learned perceptuo-motor skills, the correct use of social skills and the control of emotional reactions, in the absence of gross clouding of consciousness. The condition is often irreversible and progressive.

Source: Royal College of Physicians of London<sup>2</sup>

that in older patients, with different implications for health and society. Mortality from dementia and neurodegenerative disorders in younger people is examined separately.<sup>6</sup>

### METHODS

The number of deaths were obtained for selected dementias and neurodegenerative disorders from data held by the Office for National Statistics, in people aged 65-69, 70-74, 75-79, 80-84 and 85 years and over for residents of England and Wales in the 18 year period 1979 to 1996. The causes of death selected and their respective codes in the ninth revision of the International Classification of Diseases, (ICD9) are shown in Box 2. 1979 was chosen as the start date because this was the first year that ICD9, as opposed to ICD8, was used to code the causes of death given on death certificates.

## Box 2

<b>Dementias and neurodegenerative disorders: preferred terms and their corresponding codes in the ninth revision of the International Classification of Diseases (ICD9).</b>		323.8	Encephalitis, myelitis and encephalomyelitis, other
		323.9	Encephalitis, myelitis and encephalomyelitis, unspecified
<b>Group 1. Senile &amp; presenile organic psychotic conditions</b>		331	<i>Other cerebral degenerations</i>
290.0	Senile dementia, simple type	331.1	Pick's disease
290.1	Presenile dementia	331.3	Communicating hydrocephalus
290.2	Senile dementia, depressed or paranoid type	331.4	Obstructive hydrocephalus
290.3	Senile dementia with acute confusional state	331.8	Other cerebral degeneration
290.4	Arteriosclerotic dementia	331.9	Other cerebral degeneration, unspecified
290.8	Senile dementia, other	333	<i>Other extrapyramidal disease and abnormal movement disorders</i>
290.9	Senile dementia, unspecified	333.0	Other degenerative diseases of the basal ganglia
331.2	Senile degeneration of the brain	333.1	Essential and other specified forms of tremor
<b>Group 2. Alzheimer's disease</b>		333.2	Myoclonus
331.0	Alzheimer's disease	333.3	Tics of organic origin
<b>Group 3. Other dementias and neurodegenerative disorders</b>		333.4	Huntington's chorea
046	<i>Slow virus infection of central nervous system</i>	333.5	Other choreas
046.1	Creutzfeldt-Jakob disease	333.6	Idiopathic torsion dystonia
046.2	Subacute sclerosing panencephalitis	333.7	Symptomatic torsion dystonia
046.3	Progressive multifocal leucoencephalopathy	333.8	Fragments of torsion dystonia
046.8	Other	333.9	Other and unspecified
046.9	Unspecified	334	<i>Spinocerebellar disease</i>
298	<i>Other non-organic psychoses</i>	334.0	Friedreich's ataxia
298.9	Unspecified psychosis	334.1	Hereditary spastic paraplegia
323	<i>Encephalitis, myelitis and encephalomyelitis</i>	334.2	Primary cerebellar degeneration
323.5	Encephalitis following immunization procedures	334.3	Other cerebellar ataxia
		334.4	Cerebellar ataxia in diseases classified elsewhere
		334.8	Other
		334.9	Unspecified

**Table 1** Age- and sex-specific mortality rates per 100,000 from dementia and other neurodegenerative disorders in the elderly, England and Wales, 1979–1996

Year	Age Group											
	65-69		70-74		75-79		80-84		85 and over		65 and over*	
	M	F	M	F	M	F	M	F	M	F	M	F
1979	9	8	46	16	46	37	76	93	171	242	39	45
1980	10	8	40	16	40	43	84	91	188	233	41	45
1981	9	8	43	17	43	40	88	104	206	263	43	48
1982	8	6	43	20	43	45	98	112	208	285	44	52
1983	9	8	49	20	49	46	103	120	251	309	50	56
1984†	21	18	138	40	138	111	294	269	637	750	131	130
1985	25	18	153	45	153	120	347	296	724	818	150	142
1986	22	18	145	45	145	125	359	308	663	830	142	145
1987	20	17	151	46	151	119	342	311	657	810	140	142
1988	21	18	155	48	155	123	354	307	749	860	151	148
1989	21	20	153	48	153	131	345	324	793	895	154	155
1990	21	18	147	50	147	130	351	322	755	846	148	150
1991	23	19	142	47	142	132	351	307	773	882	150	152
1992	21	17	139	39	139	124	339	303	781	829	147	142
1993†	14	10	76	25	76	73	182	179	428	527	82	88
1994	14	11	83	27	83	77	183	187	434	524	85	90
1995	15	12	85	29	85	84	219	200	507	604	97	101
1996	15	12	89	30	89	83	212	222	503	587	96	101

\* Age-standardised to the European standard population.

† Highlights the changes in coding practice for underlying causes of death on death certificates (see methods section).

The annual numbers of deaths in each age group were used with population estimates for the respective year to calculate age-sex specific death rates for each cause of death between 1979 and 1996. Direct age-standardisation to the European standard population was used to adjust for any differences in overall mortality rates that may have arisen simply as a result of changes in the age structure of the population between 1979 and 1996. To simplify the presentation of the results, causes of death were grouped into three main categories: senile & presenile organic psychotic conditions (ICD9 290 & 331.2); Alzheimer's disease (331.0); all other dementias and neurodegenerative disorders. Population figures for England and Wales for 1996 were also used with estimates of the prevalence of dementia from the EURODEM study<sup>5</sup> to estimate the number of people with dementia currently living in England and Wales.

In 1984, the Office of Population Censuses and Surveys (now the Office for National Statistics) introduced a change in the rules used by coders to select the underlying cause of death for mortality statistics from the various causes of death recorded on a death certificate. In 1993, an automated coding system was introduced which incorporated a reversal of this rule change. These changes in coding practice alone led to changes in death rates for a number of conditions.<sup>7</sup> For example, the change introduced in 1984 led to an apparent increase in deaths from neurological conditions, while the change introduced in 1993 led to an apparent decrease. For this reason, any changes in death rates between 1983 and 1984, and between 1992 and 1993, have to be interpreted cautiously.

## RESULTS

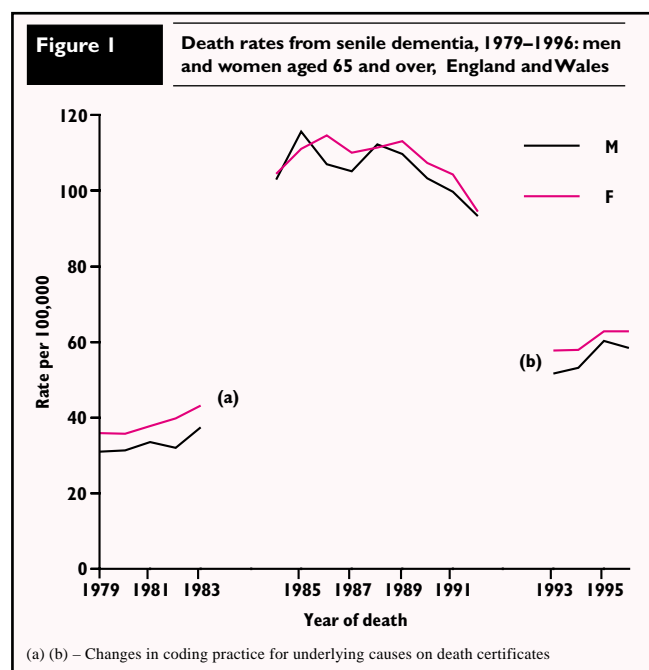
### Senile and pre-senile dementias

There were 123,419 deaths from senile dementia between 1979 and 1996, with the number of deaths per year increasing more than two-fold from 2,416 in 1979 to 6,547 in 1996. Age-standardised death rates increased by a smaller amount during the same period, from 31 to 58 per 100,000 for men at ages 65 and over and from 36 to 63 for women (Figure 1). Death rates for both men and women

decreased between 1984 and 1992, before beginning to increase again in 1993. Women had slightly higher death rates than men for most of the study period but sex differences in death rates were generally not very large.

### Alzheimer's disease

There were 15,459 deaths from Alzheimer's disease between 1979 and 1996, with the number of deaths per year increasing more than 100-fold from just 17 in 1979 to 2,082 in 1996. Age-standardised death rates from Alzheimer's disease at aged 65 and over were less than 1 per 100,000 until 1983, after which death rates began to increase rapidly (Figure 2). From 1984 to 1992, death rates increased from 3 to 21 per 100,000 for men and from 3 to 20 for women. Changes in coding practice led to a decrease in death rates





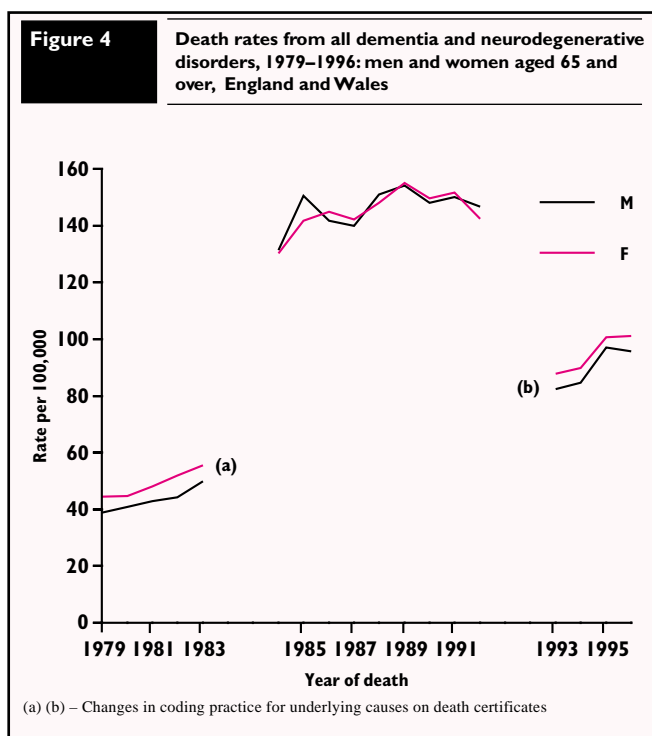
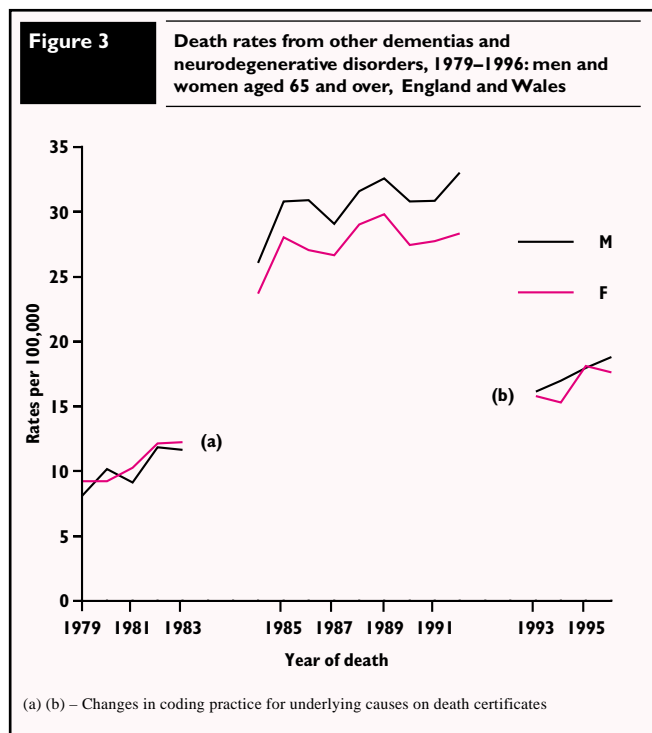
between 1992 and 1993, but rates then continued to increase between 1993 and 1996, from 15 to 19 for men and from 15 to 21 for women. For the most of the study period, there were only very minor differences in death rates from Alzheimer's disease between men and women but from 1994 onwards, death rates were higher for women than for men.

**Other dementias and neurodegenerative disorders**

There were 33,316 deaths from the other selected dementias and neurodegenerative disorders between 1979 and 1996, with the annual number of deaths increasing three-fold from 635 in 1979 to 1,826 in 1996. Between 1979 and 1996 age-standardised death rates increased from 8 to 19 per 100,000 for men and from 9 to 18 for women (Figure 3). Except between 1984 and 1992, when death rates were higher for men than for women, death rates from these remaining conditions were very similar for men and women.

**All dementias and neurodegenerative disorders combined**

There were 171,590 deaths from all the dementias and neurodegenerative disorders between 1979 and 1996, with the number of deaths per year increasing from 3,021 in 1979 to 10,415 in 1996. Between 1979 and 1996, age-standardised death rates increased from 39 to 96 per 100,000 for men and from 45 to 101 for women (Figure 4). The very large increase in 1984 and the corresponding large fall in 1993 were both due to changes in coding practice. Age and sex specific death rates for all diagnoses combined between 1979 and 1996 are shown in Table 1. Death rates from dementias and neurodegenerative disorders rise substantially with age. In 1996, mortality at aged 85 and over was 33 times higher than at age 65-69 years for men, and 48 times higher for women. All age groups experienced an increase in death rates between 1979 and 1996 with the largest absolute and relative increases seen in people aged 75 years and over.



**Estimated number of people with dementia**

The estimated numbers of people with dementia living in England and Wales in 1996, derived from the EURODEM study, are shown in Table 2. In total, about 665,000 people were expected to be suffering from significant dementia, a figure substantially greater than the 10,415 deaths certified as due to dementia and neurodegenerative disorders in the same year. Because there are more women than men in the population at this age, about twice as many women as men suffer from dementia even though the prevalence of the condition is similar in the two groups. As the number of very elderly people in the population continues to increase, we are likely to see a further increase in the total number of people with dementia.

**Table 2** Estimated number of people with dementia, England and Wales, 1996

Age group (years)	Prevalence (%) * Population of England and Wales 1996		Estimated no. of people suffering from dementia in England and Wales 1996				
	Men	Women	Men	Women	Men	Women	Persons
65-69	2.2	1.1	1,104,800	1,238,100	24,306	13,619	37,925
70-74	4.6	3.9	954,500	1,192,400	43,907	46,504	90,411
75-79	5.0	6.7	657,600	973,100	32,880	65,198	98,078
80-84	12.1	13.5	408,700	760,100	49,453	102,614	152,067
85 and over	27.4	30.3	248,900	720,700	68,199	218,372	286,571
All ages 65 and over	-	-	3,374,500	4,884,400	218,745	446,307	665,052

\* Source: Hofman A, Rocca A, Brayne C et al.<sup>5</sup>

## DISCUSSION

Age-standardised death rates from dementias and neurodegenerative disorders in people aged 65 and over in England and Wales more than doubled between 1979 and 1996. The most dramatic increase was seen in deaths from Alzheimer's disease, which by 1996 was recorded as the underlying cause of death in over 2,000 people, compared with just 17 deaths in 1979. This increase in the number of deaths from Alzheimer's disease will have occurred as a result of the increasing number of elderly people in the population and to changes in the clinical diagnoses made by doctors at the time of patients' deaths. Although Alzheimer's disease was first reported in 1905, it was initially thought to be a very rare condition, and for several decades was not given very much space in medical or neurology textbooks. The neuropathological features of Alzheimer's disease had been long established but it was only in the 1960s that these features were also shown to be present in many patients previously classified as having senile dementia.<sup>8</sup>

Over the next decade, Alzheimer's disease became acknowledged as one of the major causes of dementia and was allocated its own four-digit code when the ninth revision of the International Classification of Diseases was introduced in 1979 (under the eighth revision, it was included with pre-senile dementia). However, although Alzheimer's disease became an increasingly used clinical diagnosis, it was not until the mid 1980s, eighty years after it was first described, that it began to be recorded as a common underlying cause of death in England and Wales. Mortality attributed specifically to Alzheimer's disease began to increase earlier in the USA than in England and Wales, from 1,728 deaths in 1979 to 26,325 deaths in 1987.<sup>9</sup> The more rapid increase in the USA may reflect differences in the two health care systems, as a definitive diagnosis of Alzheimer's disease can only be made after neuropathological examination of brain samples. The American health care system, with its greater use of invasive and high technology investigations, may result in more people with dementia receiving a diagnosis of Alzheimer's disease.

Death rates from senile and pre-senile dementias and from other neurodegenerative disorders also increased between 1979 and 1996, although less dramatically than for Alzheimer's disease. There was a decrease in death rates from senile and pre-senile dementias between 1984 and 1992, but this decrease occurred at a time when death rates from Alzheimer's disease were increasing rapidly, and is probably a result of diagnostic transfer rather than a true decrease in death rates. Senile and pre-senile dementias still remain more common than Alzheimer's disease as an underlying cause of death, in contrast to the results of most prevalence

surveys, which have generally concluded that Alzheimer's disease is the cause of between 50-70% of all cases of dementia.<sup>10 11</sup> This suggests that many cases of Alzheimer's disease are being misclassified at death as cases of senile dementia. Technically, dementia is a syndrome (a grouping of symptoms) and not a disease in its own right, as many different diseases and disorders can lead to dementia.<sup>12</sup> Perhaps the use on death certificates of non-specific terms such as senile or pre-senile dementia should be discouraged and instead, doctors should be encouraged to use more precise diagnoses such as Alzheimer's disease? However, the clinical diagnosis made during life in patients with dementia is often found to be inaccurate once the results of post-mortem become available.<sup>13</sup> As most older patients dying of a dementing illness do not undergo post-mortem examination,<sup>14</sup> death certification in the elderly is likely to remain imprecise.

It is difficult to draw conclusions about trends over time in the incidence of dementia from mortality data. Age and sex-specific death rates increased between 1979 and 1996, but it is not clear whether this was due to a true increase in incidence, or to greater recording of dementias and neurodegenerative disorders on death certificates by doctors, or to a combination of both. Awareness of dementia amongst health professionals would have increased between 1979 and 1996, as would the diagnostic technology available.<sup>15</sup> Doctors may be making the diagnosis of dementia more frequently now than in the past, even if the incidence of dementia remains unchanged. An important limitation of this study in interpreting trends in dementia has been the two major changes in the rules used to select the underlying cause of death from the various causes given on the death certificate. These changes occurred in 1984 and 1993, and because of them, it is difficult to interpret changes in death rates between 1983-1984 and 1992-1993. Since 1993, all causes of death listed on the death certificate have been recorded on the mortality file held by the Office for National Statistics. This should allow analysis of deaths by other conditions mentioned on the death certificate as well as by the underlying cause of death.

Death rates will greatly under-estimate the burden of disease caused by chronic diseases such as dementia. Previous cohort studies suggest that only about one-quarter of patients diagnosed with dementia during life have dementia recorded as the underlying cause of death on their death certificate.<sup>16 17 18</sup> Hence, it is likely that patients for whom dementia is later given as the underlying cause of death are the most severely affected group, representing only the 'tip of the iceberg' of dementia sufferers. Prevalence data could potentially provide a better estimate of the burden of disease from dementia, but prevalence surveys are expensive and difficult to carry out. Another major limitation of prevalence surveys is that different diagnostic criteria can give very different estimates of prevalence. For example, in one recent American study, the prevalence of dementia in people aged 65 years and over varied from 3% to 29% depending on the diagnostic criteria used.<sup>19</sup> When we used one of the widely accepted estimates of the prevalence of dementia,<sup>5</sup> we calculated that there were about 665,000 people aged 65 years and over with significant dementia in England and Wales in 1996.

The number of elderly people in England and Wales will continue to increase in the future, leading to a further increase in the number of people suffering from dementia. This in turn will have important implications for carers, and for health and social services. Hence, the impact of dementia on the morbidity and mortality of the population should continue to be monitored. Monitoring trends in death rates from dementias and neurodegenerative disorders will be an important part of this process.

## Key Findings

- Age-standardised death rates from dementias and neurodegenerative disorders for people aged 65 and over in England and Wales more than doubled between 1979 and 1996.
- The most dramatic increase was seen in deaths from Alzheimer's disease which by 1996 was recorded as the underlying cause of death in over 2,000 people, compared with just 17 deaths in 1979.
- It is estimated that in 1996, about 665,000 people aged 65 years and over in England and Wales were suffering from significant dementia.
- The number of elderly people in England and Wales will continue to increase in the future, leading to a further increase in the number of people suffering from dementia. This in turn will have important implications for the number of carers needed, and for health and social services.

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