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National End of Life Care Programme
Improving end of life care

Deaths from Neurodegenerative Diseases in England, 2002 to 2008

NEoLCIN Bulletin

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Deaths from motor neurone disease and progressive supranuclear palsy

The information contained in this report relies on mortality data derived from death certificates (please see note on death certification in the 'Introduction'). Following recent concern regarding the low numbers of deaths from progressive supranuclear palsy (PSP), indicated in official statistics and shown in an earlier version of this bulletin (released June 2010), it has been found that deaths from PSP are significantly under-recorded in the mortality figures published by the Office for National Statistics (ONS). This is due to international coding and processing issues which affect the official statistics relating to deaths from motor neurone disease (MND) and PSP. Both the SWPHO and the ONS will recommend a change to the international coding rules.

Following a request from the South West Public Health Observatory (SWPHO), the ONS has provided numbers of deaths for the period 2002–2008 based on a revised interpretation of the international coding rules as applied to MND and PSP. Deaths from MND and PSP are both affected as, according to existing international rules, the majority of death certificates which include a reference to PSP have been attributed to motor neurone disease in the official statistics. The numbers of deaths currently recorded in official statistics as involving MND will therefore reduce, at a national level, by approximately 11%–16% in each of the years. These preliminary results have been shared with the Motor Neurone Disease Association and the Progressive Supranuclear Palsy Association. The percentage change may vary at a sub-national level.

As a consequence, the numbers for MND and PSP presented in this bulletin for England are the best available at the time of publication. They are necessarily a combination of data specially extracted by ONS and routine mortality statistics.

A full explanation of the issues concerning the revised coding of MND and PSP is provided in the 'Methods' section, and the various tables and figures in this bulletin have been annotated accordingly to reflect the source of the data.

The SWPHO and National End of Life Care Intelligence Network would like to thank the MND Association and the PSP Association for helpful discussions, and particularly the ONS for their prompt investigation of the published figures and advice on the technical issues.

Note: Recent information from ONS indicates that multiple system degeneration deaths between 2002 and 2005 were coded to ICD-10 R68.8 'Other specified general symptoms and signs' rather than ICD-10 G90.3 as was the case in the years 2006 onwards. Consequently ONS are extracting the death certificates that were previously coded to 'Other specified general symptoms and signs' and re-coding those that mention multiple system degeneration to ICD-10 G90.3 so that the tables in future versions of this bulletin show consistently coded numbers for the whole time period 2002 to 2008.The online version of this bulletin will be updated when this information becomes available.

1 Introduction

1.1 Definitions and caveats

The SWPHO is currently undertaking analyses of a variety of sources of information to help inform and support the implementation of the National End of Life Care Strategy. This first phase of analysis on end of life care for people with a neurodegenerative disease uses information compiled by the ONS based on death registrations. In this document the analyses are restricted to people who were usually resident in England and who died 'from' or 'with' various neurodegenerative diseases between 1st January 2002 and 31st December 2008. Full details are listed in the Methods section below.

An **'underlying'** cause of death is defined by the World Health Organisation in Mortality Statistics DH2 no.32: pages xvi & xviii:[1] as:

i) the disease or injury that initiated the train of events directly linked to death; or
ii) the circumstances of the accident or violence that produced the fatal injury.

'Mentions' in this document are citations on a person's death certificate of diseases or conditions where they are recorded as the **'underlying'** cause of death, or as part of the causal sequence of events leading to death, or they contribute to the death but are not part of the causal sequence.

Each of the tables and charts in this document shows the source of the information as the Office for National Statistics, which reflects the original data source. All analyses, tables and charts, however, have been produced by the SWPHO.

It is worth noting that, according to the 'rules' concerning the recording of deaths, people who appear to die from a completely unrelated disease or event, perhaps a road accident, will not necessarily have a neurodegenerative disease recorded as either an **'underlying'** or **'mentioned'** cause of death. Consequently, the numbers of deaths referred to in this document are not a true measure of the numbers of people 'who die and who have' a neurodegenerative disease, nor are the numbers shown a measure of either incidence (numbers of people newly diagnosed with a neurodegenerative disease) or prevalence (numbers of people living with a neurodegenerative disease). However, the inclusion of a **'mention'** of a neurodegenerative disease should give an indication of the numbers of people dying where these diseases are a direct or important factor in those deaths.

Note on death certification

Death certificates are the best source of national data on what people die from and where they die. They are collectively used to generate mortality statistics which are useful in informing commissioning, the need for provision and the quality of care.

However, as with many routine national sources, the data derived are influenced by the quality of recording and sometimes processing. For death certificates, it is known that this is a complex area and understandably there is imperfect recording by medical practitioners of the causes of death and the contributing conditions leading to death (DH2 no.32: pages xxvii).[1] Very rarely there is also a problem created by the coding or processing of the causes of death which may result in the incorrect allocation of causes of deaths, of which PSP and MND are examples.

[1] http://www.statistics.gov.uk/downloads/theme_health/Dh2_32/DH2_No32_2005.pdf (accessed 25th October 2010)

1.2 Overview

Analysis of the ONS annual mortality statistical extracts, routinely available to a number of organisations, showed that 73,502 deaths during the period 1 January 2002 to 31 December 2008 to people who were normally resident in England **'mentioned'** one of the following neurodegenerative diseases (please see list below), listed in Volume 1 of the *International Statistical Classification of Diseases and Related Health Problems* (ICD-10 codes)[2].

	ICD-10 code
Parkinson's disease	G20 (any 4th digit)
Motor neurone disease	G12.2
Multiple sclerosis	G35 (any 4th digit)
Huntington's disease	G10 (any 4th digit)
Multiple system degeneration	G90.3
Progressive supranuclear palsy (also known as progressive supranuclear opthalmoplegia)	G23.1

Note: The list of diseases and ICD-10 codes used in this document are subject to possible revision as more information about the coding of neurodegenerative diseases becomes available.

Of the 73,502 people who died with a **'mention'** of at least one of the neurodegenerative diseases listed above and recorded on the annual mortality extracts, 46,515 (63%) people had one of these diseases recorded as the **'underlying'** cause (please see Table 2). For the remainder of people, 26,987 (37%), the disease was recorded as being either: i) part of the causal sequence of events leading to death; or ii) a contributing factor to the death but not part of the causal sequence. 284 (0.4%) people had more than one neurodegenerative disease **'mentioned'**, and whilst this does happen, as the ratio of the total of 73,794 **'mentions'** to the number of deaths (73,502) illustrates, namely a ratio of 1.0, this is a rare or rarely recorded event.

It was subsequently discovered, however, that the current international guidelines, which ONS coders are obliged to follow, meant that in many instances the text on a death certificate indicating PSP had to be coded to ICD-10 G12.2, namely motor neurone disease. This of course meant that the number of deaths where progressive supranuclear palsy was implicated was in fact under-recorded in official statistics, and motor neurone disease was correspondingly over-recorded. Please see the 'Methods' section for a detailed explanation of this issue.

At the request of the SWPHO the death certificates of all people whose statistical records indicated motor neurone disease were extracted by ONS in order to ascertain whether or not the statistical records were a true reflection of what was written on the death certificate: in many instances it was not.

[2] *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision*: World Health Organisation, Geneva 1992.

2 Methods

In the initial analysis, records from the annual mortality extracts from the Office for National Statistics were included where:

- any of the ICD-10 diagnosis codes (in the list above) were **'mentioned'** in any of the causes of death fields, i.e. **'underlying'** cause of death, secondary cause of death, cause of death, and 14 non-neonatal causes of death; and
- the usual place of residence of the deceased was in England, identified using the Government Office region (place of residence) codes 'A','B','D','E','F','G','H','J','K' (4,762 records were excluded as the usual place of residence was not England); and
- the calendar year of death was between 1st January 2002 and 31st December 2008;
- postcodes were valid and located within England (27 records with a missing or an invalid postcode were excluded).

Note: neonatal deaths were excluded from the analyses as these deaths are not assigned an **'underlying'** cause.

Low numbers of deaths from PSP did not initially arouse concern as it was assumed that the ONS official statistics were correct and reflected the fact that the condition was believed to be comparatively rare and difficult to accurately diagnose except post mortem. According to the PSP Association, who contacted the SWPHO, the low numbers were due to the condition being poorly recorded on death certificates: it is worth noting at this point that the SWPHO does not have access to the death certificates, only the official statistics.

Research by Nath et al entitled 'Population based mortality and quality of death certification in progressive supranuclear palsy (Steele-Richardson-Olszewski syndrome)' published in 2005 (J Neurol Neurosurgery and Psychiatry 2005;76:498–502) was subsequently brought to our attention. This research analysed death certificates coded to ICD-9 but also highlighted potential problems with ICD-10: please see the following extract from page 498 of the Nath article.

> "In ICD-10, progressive supranuclear ophthalmoplegia and Steele-Richardson-Olszewski syndrome' are indexed to code G23.1, the tabular list entry for which is 'progressive supranuclear ophthalmoplegia'. 'Progressive supranuclear palsy' is not so indexed, so the ICD-10 index would still code 'palsy/paralysis, supranuclear', for which the tabular list term is 'motor neurone disease', with an inclusion term for progressive bulbar palsy. There is still no entry for 'Palsy, supranuclear progressive' in ICD-10."

In short, the international coding rules, which ONS were obliged to follow, meant that even when progressive supranuclear palsy was mentioned on the death certificate, it was coded to motor neurone disease. Consequently, the ONS official statistics, whilst being coded in accordance with the rules, were not in fact a true representation of what was recorded on the death certificate. This in turn meant that: PSP deaths were under-estimated in the official statistics; MND deaths were over-estimated; and death certificates, with respect to PSP deaths, were found to be better recorded than had previously been thought.

ONS were contacted and they immediately instigated an investigation into this issue, re-extracting all death certificates that had previously been coded to MND ICD-10 G12.2 and which met the inclusion criteria of this report (please see above), in order to check what was written on the death certificate.

These certificates were then manually searched and flagged as possible 'palsy' deaths if the following terms (using an enhanced list of terms based on those used by Nath et al) were mentioned in the text: 'palsy', 'plasy', 'plasey', 'palsey'.

The same certificates were also manually searched and flagged as possible PSP deaths if the following terms were mentioned in the text: 'supra', 'super', 'supru', 'supa', 'supra' 'nucl', 'nucul', 'neural', 'ncear', 'neucl', 'nuel', 'nuchl', 'ncl', 'muchl'.

These records were then reclassified as 'PSP mentions' if they had previously been coded as having a mention of MND ICD-10 G12.2 and the textual information on the death certificates indicated both 'palsy' and 'possible PSP'.

These records were then reclassified as 'PSP underlying cause' if the underlying cause was previously coded as MND ICD-10 G12.2.

The new numbers in this bulletin for PSP include those already recorded as PSP and previously shown in the June 2010 version.

Tables 1 and 2 in the **'Results'** section show the new numbers for these two conditions. The equivalent numbers from the ONS annual mortality extracts only are shown below in Table A and Table B below:

Table A: 'Mentions' of motor neurone disease and progressive supranuclear palsy at death using ONS annual mortality extracts, England, 2002 to 2008

Any 'mentioned' cause	2002	2003	2004	2005	2006	2007	2008	Total
Motor neurone disease	1,559	1,560	1,642	1,705	1,779	1,775	1,806	11,826
Progressive supranuclear palsy	22	15	13	9	3	4	4	70

Source: Office for National Statistics, annual mortality extracts

Table B: 'Underlying causes' of motor neurone disease and progressive supranuclear palsy at death using ONS annual mortality extracts, England, 2002 to 2008

Underlying' cause	2002	2003	2004	2005	2006	2007	2008	Total
Motor neurone disease	1,378	1,399	1,422	1,491	1,554	1,574	1,610	10,428
Progressive supranuclear palsy	19	14	10	5	3	3	3	57

Source: Office for National Statistics, annual mortality extracts

As previously stated, the numbers shown in this bulletin are therefore a combination of information extracted from the routinely published annual mortality extracts (for Parkinson's disease, multiple sclerosis, Huntington's disease, and multiple system degeneration) and information provided separately by ONS to the SWPHO (for motor neurone disease and progressive supranuclear palsy).

3 Results

3.1 'Mentions' of the selected neurodegenerative diseases at death

Table 1 shows the number of times a neurodegenerative disease was **'mentioned'** for the 73,502 people who died with one of these diseases during the period 1st January 2002 and 31st December 2008. As previously stated, in certain instances, a person might have more than one disease recorded as being implicated in their death, and while this does happen, as the ratio of the total of 73,794 **'mentions'** to the number of deaths (73,502) – namely a ratio of 1.0 – illustrates, this is a comparatively rare or rarely recorded event.

Table 1: 'Mentions' of the selected neurodegenerative diseases at death, England, 2002 to 2008

Any 'mentioned' cause	2002	2003	2004	2005	2006	2007	2008	Total
Parkinson's disease	6,746	7,160	6,770	6,913	7,042	7,498	7,683	49,812
Motor neurone disease	1,365	1,364	1,437	1,461	1,526	1,485	1,528	10,166
Multiple sclerosis	1,361	1,439	1,289	1,436	1,409	1,504	1,528	9,966
Huntington's disease	201	213	204	215	226	211	236	1,506
Multiple system degeneration	16	20	11	31	149	171	209	607
Progressive supranuclear palsy	207	208	214	251	257	291	309	1,737
Total	**9,896**	**10.404**	**9,925**	**10,307**	**10,609**	**11,160**	**11,493**	**73,794**

Source: Office for National Statistics, annual mortality extracts, and unpublished MND and PSP reclassified deaths

- Of the diseases examined, the neurodegenerative disease most frequently implicated in a person's death is Parkinson's disease and, in common with the other diseases, the numbers appear to have increased over time. The reasons for this are not explored in this document.
- The numbers of people dying with a **'mention'** of multiple system degeneration recorded on their death certificate increased substantially in 2006 to 149. The number of people dying with this disease **'mentioned'** on their death certificate in 2005 was 31. Information from ONS suggests that this is the consequence of a coding change at ONS, and that prior to 2006 these deaths were being coded to ICD-10 R68.8 (Other specified general symptoms and signs). ONS have advised us that they will re-extract all death certificates with a mention of R68.8 between 2002 and 2005 and re-code mentions of 'multiple system degeneration' to ICD-10 G90.3 in order to provide consistent figures for the entire time period for this bulletin. The National End of Life Care Intelligence Network website will be updated with any information as it becomes available.

3.2 Selected neurodegenerative diseases as the 'underlying' cause of death

Table 2 shows how many times a neurodegenerative disease was recorded as the **'underlying'** cause of death for the 73,502 people who died with one of these diseases **'mentioned'** on the death certificate during the period 1st January 2002 and 31st December 2008. It shows that 46,515 people died with a neurodegenerative disease as the **'underlying'** cause of death.

Table 2: 'Underlying' causes of death from neurodegenerative diseases, England, 2002 to 2008

'Underlying' cause	2002	2003	2004	2005	2006	2007	2008	Total
Parkinson's disease	3,818	4,093	3,762	3,903	3,883	4,118	4,397	27,974
Motor neurone disease	1,224	1,233	1,253	1,292	1,359	1,332	1,373	9,066
Multiple sclerosis	868	929	838	908	876	970	970	6,359
Huntington's disease	161	166	170	173	169	166	186	1,191
Multiple system degeneration	13	14	9	27	117	133	177	490
Progressive supranuclear palsy	171	178	179	203	199	244	261	1,435
Total	**6,255**	**6,613**	**6,211**	**6,506**	**6,603**	**6,963**	**7,364**	**46,515**

Source: Office for National Statistics, annual mortality extracts, and unpublished MND and PSP reclassified deaths

- A further 26,987 (73,502 less 46,515) people died during the same period who had a neurodegenerative disease **'mentioned'** as being connected to the death, but it was **not** the **'underlying'** cause.
- A comparison of Tables 1 and 2 (please see Table 3), by disease shows that the proportion of neurodegenerative diseases in which the condition appears as the **'underlying'** cause varies considerably between 56% for Parkinson's disease and 89% for motor neurone disease.
- People with motor neurone disease are most likely, of the diseases selected, to die as a direct consequence of this disease, i.e. it was the **'underlying'** cause of death.

Table 3: The proportion of deaths which 'mention' a selected neurodegenerative disease and have recorded it as the 'underlying' cause, England, 2002 to 2008

'Underlying' cause	%
Parkinson's disease	56
Motor neurone disease	89
Multiple sclerosis	64
Huntington's disease	79
Multiple system degeneration	81
Progressive supranuclear palsy	83

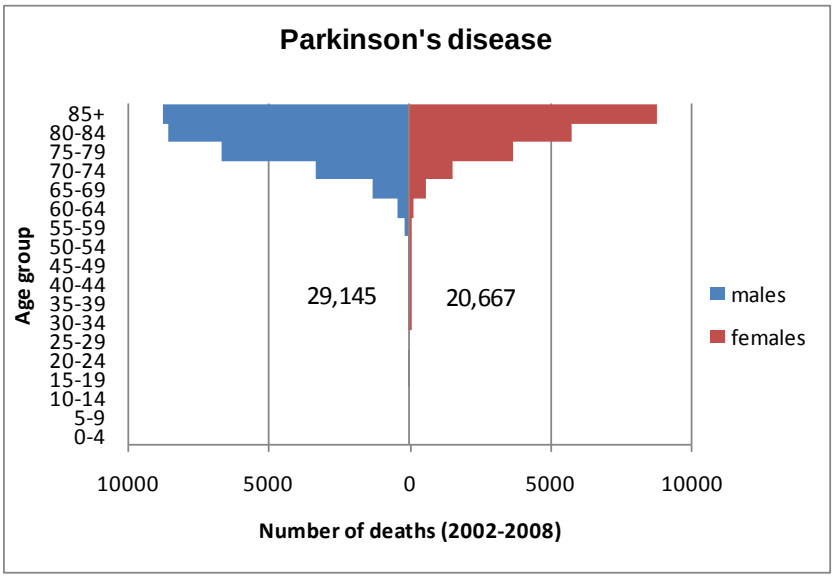
Source: Office for National Statistics, annual mortality extracts, and unpublished MND and PSP reclassified deaths

3.3 Numbers and percentage distribution of the neurodegenerative diseases by age and sex

The following population pyramid charts (Figures 1 to 6) show the distribution of **'mentions'** of neurodegenerative disease by age-group and sex for the time period 2002 to 2008. The degree of shading shown in each chart is specific to the disease in question and illustrates the percentage of people in each group. It is not an indication of the absolute numbers of people affected by that particular disease and therefore care needs to be taken when visually comparing the various charts. However, numbers for males and females are given below each of the shaded areas (blue for males on the left side and red for females on the right). The numbers when added equate to the numbers in the 'Total' column in Table1.

3.3.1 Parkinson's disease 'mentions' by age and sex

Figure 1: Age and sex distribution of people who died with a 'mention' of Parkinson's disease, England 2002 to 2008 (total for all years shown)



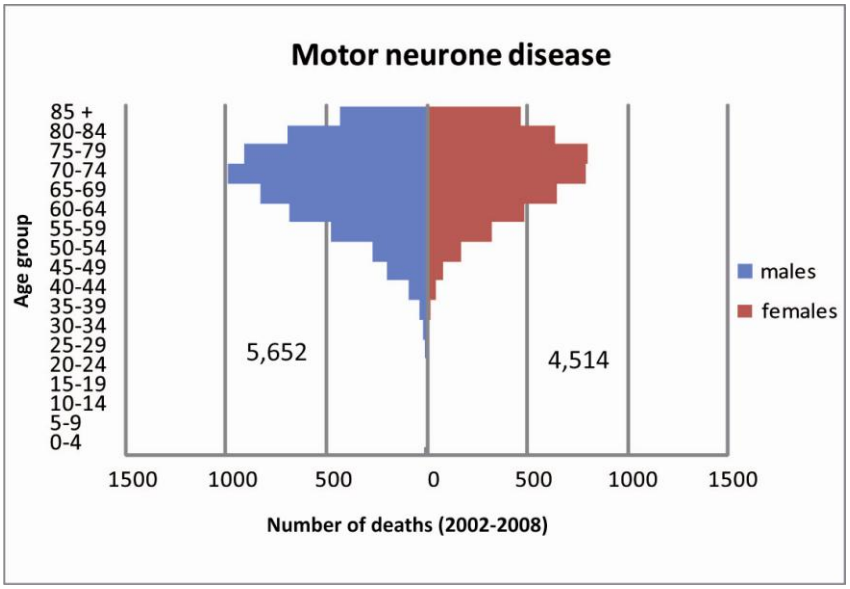
Source: Office for National Statistics, annual mortality extracts

- Most deaths occur in the older age-groups and more males than females have this disease **'mentioned'** at death.
- Approximately 36% of the deaths with a **'mention'** of Parkinson's disease occurred amongst those who were 85 years and older when they died, approximately 18% of whom were males and 18% were females, whereas in the next oldest age-group, those aged 80 to 84 years, the figure for males was 17% and for females 12%.

Note: Parkinson's disease is the **'underlying'** cause of death in just 56% of deaths where it is **'mentioned'** (Table 3). Therefore, many of the people represented in Figure 1 would have had something other than Parkinson's disease recorded as the **'underlying'** cause of death.

3.3.2 Motor neurone disease 'mentions' by age and sex

Figure 2: Age and sex distribution of people who died with a 'mention' of motor neurone disease, England 2002 to 2008 (total for all years shown)

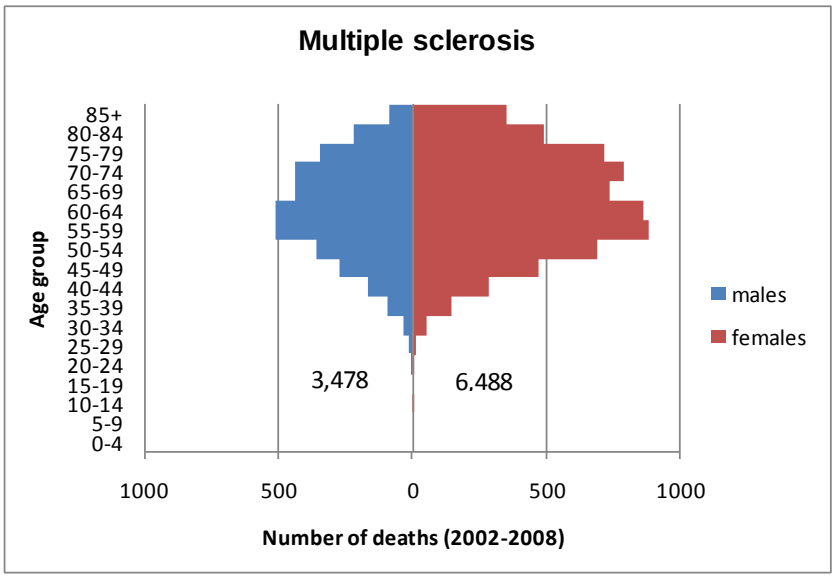


Source: Office for National Statistics unpublished MND and PSP reclassified deaths

- More males than females have motor neurone disease recorded as being implicated in their death.
- Except in the oldest age-group (85 years and over), there are more male than female deaths.
- Compared to Figure 1 showing numbers for Parkinson's disease, deaths with a **'mention'** of motor neurone disease start to occur in greater numbers at younger ages.

3.3.3 Multiple sclerosis 'mentions' by age and sex

Figure 3: Age and sex distribution of people who died with a 'mention' of multiple sclerosis, England 2002 to 2008 (total for all years shown)

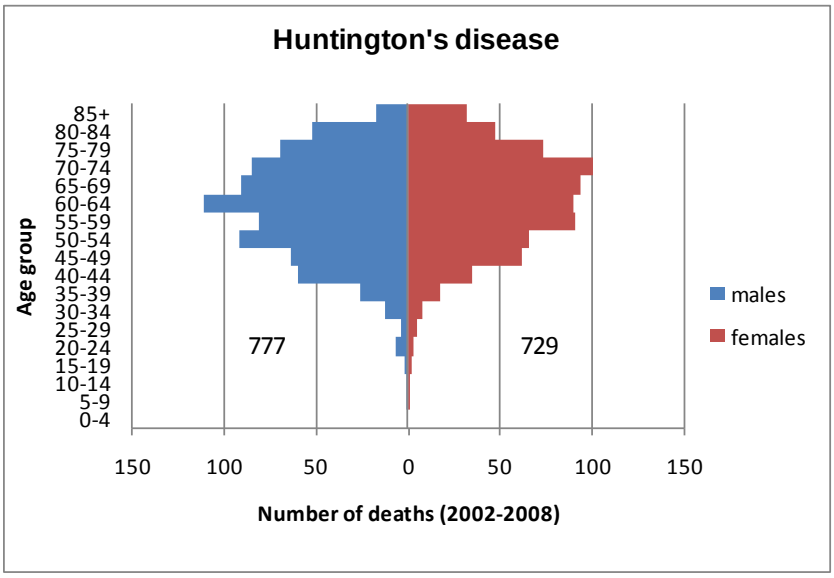


Source: Office for National Statistics, annual mortality extracts

- Deaths involving multiple sclerosis affect females to a much greater extent: approximately twice as many females as males were recorded as having died with multiple sclerosis **'mentioned'** on the death certificate.
- The majority of deaths occurred in early 'older age' rather than in the oldest age-groups.

3.3.4 Huntington's disease 'mentions' by age and sex

Figure 4: Age and sex distribution of people who died with a 'mention' of Huntington's disease, England 2002 to 2008 (total for all years shown)

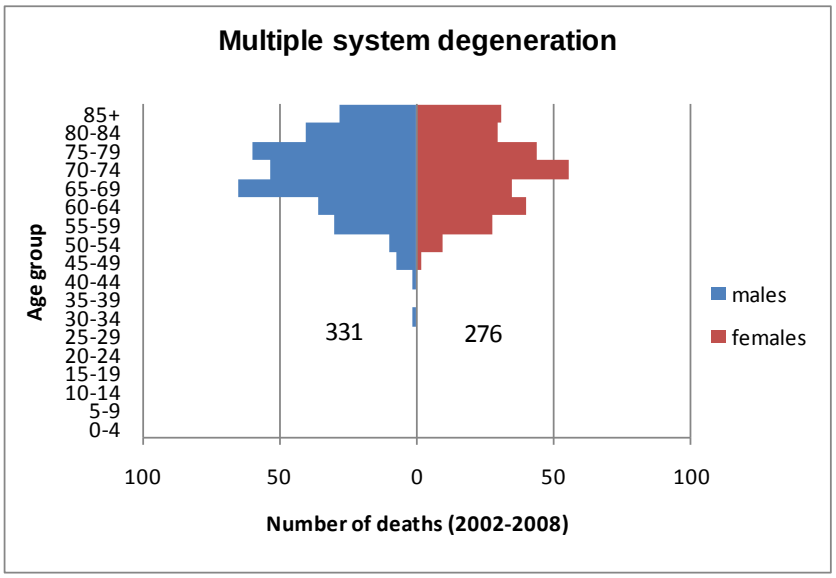


Source: Office for National Statistics, annual mortality extracts

- Although the numbers of deaths relating to Huntington's disease occur almost equally amongst males and females, with the majority of deaths occurring in late 'middle age' / early 'older age' rather than in the oldest age-groups, recorded deaths amongst males appear to start at an earlier age. For example, 18% of the deaths in which Huntington's disease is **'mentioned'** occur in males under the age of 55 years, compared to 13% for females.

3.3.5 Multiple system degeneration 'mentions' by age and sex

Figure 5: Age and sex distribution of people who died with a 'mention' of multiple system degeneration, England 2002 to 2008 (total for all years shown)



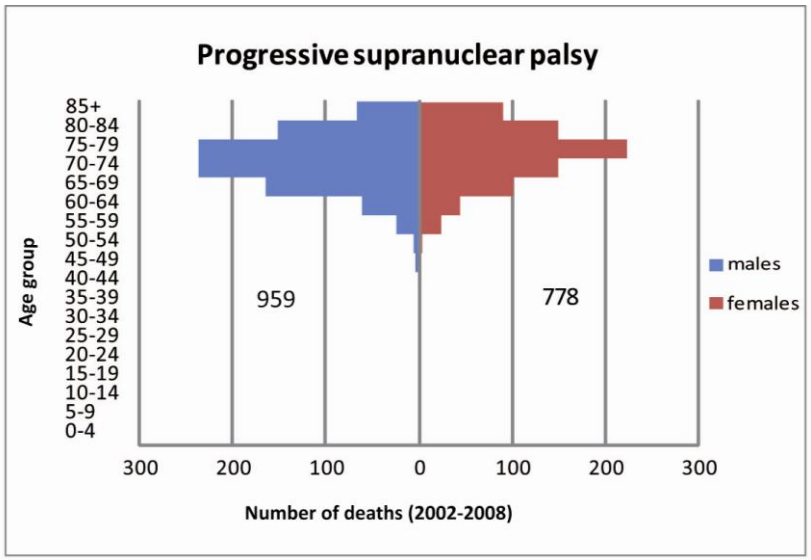
Source: Office for National Statistics, annual mortality extracts

- The numbers of recorded deaths where multiple system degeneration is **'mentioned'** are higher for males than for females.
- Multiple system degeneration deaths principally occurring in late 'middle age' and early 'older age', and deaths largely declining in the very oldest age-groups. There are similar percentages of males and females in each age-group, except for the 65-69 year age-group, where almost twice as many males as females die.

Recent information from ONS indicates that multiple system degeneration deaths between 2002 and 2005 were coded to ICD-10 R68.8 'Other specified general symptoms and signs' rather than ICD-10 G90.3 as was the case in the years 2006 onwards. Consequently ONS are extracting the death certificates that were previously coded to 'Other specified general symptoms and signs' and re-coding those that mention multiple system degeneration to ICD-10 G90.3 so that the tables in future versions of this bulletin show consistently coded numbers for the whole time period 2002 to 2008.The online version of this bulletin will be updated when this information becomes available.

3.3.6 Progressive supranuclear palsy 'mentions' by age and sex

Figure 6: Age and sex distribution of people who died with a 'mention' of progressive supranuclear palsy, England 2002 to 2008 (total for all years shown)



Source: Office for National Statistics unpublished MND and PSP reclassified deaths

- The number of people who die with a **'mention'** of progressive supranuclear palsy on their death certificate is much higher than previously reported in official statistics (please see Table A at the beginning of this bulletin). Recorded deaths are approximately 24% higher in males.
- There were very few recorded deaths with a **'mention'** of PSP in anyone under the age of 55 in the 2002 to 2008 time period. There were, however, differences between males and females with respect to the age of death, with males who have a 'mention' of PSP dying at an earlier age than females.

3.4 Place of death

The place where someone dies is influenced by the nature of their final condition and associated complications, the age of the person and their usual place of residence, i.e. own residence or nursing or old people's home. A high proportion of people with a neurodegenerative disease (approximately half) die in hospital (please see Tables 6 and 7). Both the total number and percentage are higher for males. The overall proportion of deaths in hospital for neurodegenerative diseases is lower than for all conditions (58%)[3] and may reflect both the age profile of the people who die of, or with, neurodegenerative diseases as well as their needs for care at the end of life and their place of residence prior to death.

Tables 4–7 give some insight into place of death for people with these conditions.

[3] Data for England, 2005-07 from *Variations in Place of Death in England* (SWPHO, 2010)

Table 4: 'Underlying' cause of death from neurodegenerative diseases by place of death, males, England, 2002 to 2008 (total for all years shown)

	Hospital		Hospice		Nursing home		Old people's home		Own residence		Else-where		Total
	n	%	n	%	n	%	n	%	n	%	n	%	n
Parkinson's disease	8,473	53	84	1	4,063	25	2,013	12	1,411	9	72		16,116
Motor neurone disease	2,463	50	614	12	343	7	99	2	1,399	28	42	1	4,960
Multiple sclerosis	1,291	58	56	3	340	15	108	5	356	16	73	3	2,224
Huntington's disease	270	44	16	3	181	30	47	8	74	12	23	4	611
Multiple system degeneration	135	51	15	6	34	13	14	5	65	24	3	1	266
Progressive supranuclear palsy	360	46	40	5	181	23	67	9	135	17	2		785
Total	**12,992**	**52**	**825**	**3**	**5,142**	**21**	**2,348**	**9**	**3,440**	**14**	**215**	**1**	**24,962**

Source: Office for National Statistics, annual mortality extracts, and unpublished MND and PSP reclassified deaths

Table 5: 'Underlying' causes of death from neurodegenerative diseases by place of death, females, England, 2002 to 2008 (total for all years shown)

	Hospital		Hospice		Nursing home		Old people's home		Own residence		Else-where		Total
	n	%	n	%	n	%	n	%	n	%	n	%	n
Parkinson's disease	4,162	35	36		3,934	33	2,611	22	1,056	9	59		11,858
Motor neurone disease	1,694	41	627	15	484	12	167	4	1,084	26	50	1	4,106
Multiple sclerosis	2,285	55	83	2	736	18	208	5	696	17	127	3	4,135
Huntington's disease	199	34	5	1	233	40	52	9	69	12	22	4	580
Multiple system degeneration	89	40	22	10	36	16	16	7	60	27	1		224
Progressive supranuclear palsy	225	35	29	4	174	27	96	15	118	18	8	1	650
Total	**8,654**	**40**	**802**	**4**	**5,597**	**26**	**3,150**	**15**	**3,083**	**14**	**267**	**1**	**21,553**

Source: Office for National Statistics, annual mortality extracts, and unpublished MND and PSP reclassified deaths

Table 6: 'Mentions' of death from neurodegenerative diseases by place of death, males, England, 2002 to 2008 (total for all years shown)

	Hospital		Hospice		Nursing home		Old people's home		Own residence		Else-where		Total
	n	%	n	%	n	%	n	%	n	%	n	%	n
Parkinson's disease	16,449	56	239	1	6,378	22	3,211	11	2,713	9	155	1	29,145
Motor neurone disease	2,913	52	634	11	401	7	118	2	1,537	27	49	1	5,652
Multiple sclerosis	2,086	60	96	3	451	13	154	4	599	17	92	3	3,478
Huntington's disease	364	47	17	2	215	28	54	7	97	12	30	4	777
Multiple system degeneration	183	55	15	5	40	12	15	5	75	23	3	1	331
Progressive supranuclear palsy	470	49	41	4	204	21	77	8	164	17	3		959
Total	**22,465**	**56**	**1,042**	**3**	**7,689**	**19**	**3,629**	**9**	**5,185**	**13**	**332**	**1**	**40,342**

Source: Office for National Statistics, annual mortality extracts, and unpublished MND and PSP reclassified deaths

Table 7: 'Mentions' of death from neurodegenerative diseases by place of death, females, England, 2002 to 2008 (total for all years shown)

	Hospital		Hospice		Nursing home		Old people's home		Own residence		Else-where		Total
	n	%	n	%	n	%	n	%	n	%	n	%	n
Parkinson's disease	8,599	42	112	1	6,035	29	4,038	20	1,770	9	113	1	20,667
Motor neurone disease	1,955	43	640	14	546	12	186	4	1,133	25	54	1	4,514
Multiple sclerosis	3,771	58	178	3	997	15	310	5	1,074	17	158	2	6,488
Huntington's disease	271	37	9	1	267	37	66	9	91	12	25	3	729
Multiple system degeneration	124	45	23	8	43	16	19	7	65	24	2	1	276
Progressive supranuclear palsy	292	38	31	4	210	27	105	13	132	17	8	1	778
Total	**15,012**	**45**	**993**	**3**	**8,098**	**24**	**4,724**	**14**	**4,265**	**13**	**360**	**1**	**33,452**

Source: Office for National Statistics, annual mortality extracts, and unpublished MND and PSP reclassified deaths

- For each disease, in almost all instances, the place of death where most deaths occur is in hospital. The proportion of deaths in hospital across all diseases are higher for males; however, the actual number of deaths is higher amongst women where multiple sclerosis is **'mentioned'**. Over 50% of males and 40% of females who had a neurodegenerative disease as the **'underlying'** cause of death died in hospital. The proportions are slightly higher if all mentions of deaths involving a neurodegenerative disease are included (please see Tables 6 and 7).
- Between one in four and one in five deaths from neurodegenerative diseases occur in a nursing home but the proportion varies with condition and age of the person and is higher for females than males, possibly reflecting their older age at death.
- Between 9% and 15% of deaths from neurodegenerative diseases occur in old people's homes, but the proportion varies with condition and age of the person and is higher for females than males, possibly reflecting their older age at death.
- Hospice deaths, overall, are comparatively rare, with only approximately 3% of deaths occurring in a hospice. This varies according to the disease involved. Where motor neurone disease was the **'underlying'** cause of death, between 12% (males) and 15% (females) died in a hospice.
- The percentage of deaths occurring in a person's 'own residence' are similar for males and females when all diseases are considered together, but varies considerably when the diseases are looked at separately. For example, around 25% of deaths associated with either motor neurone disease or multiple system degeneration occurred at home (own residence).
- People dying from or with Parkinson's disease are least likely to die in their own home, when compared to the other diseases. This is true for both males and females, with 9% dying in their own home. The reasons for this are unclear but might be associated with age – more than half are aged 80 or older – and management of the disease in the later stages of life. For males, more than 50% of the deaths occurred in hospital and a further 20% to 25% of all the deaths associated with Parkinson's disease occurred in a nursing home. For females the equivalent proportions were between 35% and 42% for hospital deaths, and between 29% and 33% for deaths in a nursing home, possibly reflecting longer life expectancy for females.

4 Note for Primary Care Trust commissioners

In 2008, there were 475,763 deaths in England, of which 7,364 (1.5%) were recorded as deaths with an underlying cause of one of the neurodegenerative diseases discussed in this report.

To support commissioning decisions, an interactive spreadsheet with PCT level data has been produced to accompany this report – see http://www.endoflifecare-intelligence.org.uk/resources/dataandtools.aspx. This enables commissioners to examine the number and rate of deaths registered for their PCT for the group of neurodegenerative diseases as a whole, per year and for the seven year period 2002–2008. Data for both 'underlying' cause or any 'mention' on a death certificate are given. The numbers for individual diseases have not been provided as these are often very small and subject to yearly fluctuation. Even for the group as a whole, the lowest number of deaths with a neurodegenerative disease recorded as the 'underlying' cause was one death in a year, and with a 'mention' was seven in a year.

The number of deaths per PCT is greatly dependent on population size, which varies from 92,000 to 1,300,000 people. For this reason rates are also given.

The six-fold variation in rates is currently under investigation. The influence of age profile of the Primary Care Trusts on the number of deaths for neurodegenerative diseases will be examined along with other factors.

5 Summary and next steps

This report is the first to provide a high level overview of deaths from neurodegenerative diseases in England. It shows the absolute numbers of deaths, where these are recorded as the **'underlying'** cause of death and where these are listed as **'mentions'** on either the death certificate or the official statistical records, and therefore contributed to the death. It highlights how important it is to search for **'mentions'** of these conditions in death records to get a clearer picture of how many people may be dying of these conditions, and where they contribute to the specific needs of people at the end of their life.

The report also, through the use of population pyramids, illustrates the different age profiles of people dying with neurodegenerative diseases. These differences in age profile are important to take into consideration in terms of the needs of the person, family and carers, and where the person is likely to be resident at the time of their final illness.

This report is one of a series produced by the SWPHO for the National End of Life Care Intelligence Network. Subsequent analyses will examine:

- in more depth, the influence of **'underlying'** cause of death and age on place of death for each of the main neurodegenerative diseases, comparing, for example, place of death for those who die of a neurodegenerative disease as the **'underlying'** cause with those who die of some other **'underlying'** cause where a neurodegenerative disease is cited elsewhere on the death certificate as a **'mention'**;
- the pattern of admissions to hospital and type of care received in hospital during the last year of life for those with neurodegenerative diseases.

Further information

This bulletin is available online at:
www.endoflifecare-intelligence.org.uk

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About the National End of Life Care Intelligence Network

The Department of Health's National End of Life Care Strategy, published in 2008, pledged to commission a National End of Life Care Intelligence Network (NEoLCIN). The Network was launched in May 2010. It is tasked with collating existing data and information on end of life care for adults in England. This is with the aim of helping the NHS and its partners commission and deliver high quality end of life care, in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families.

Key partners include the National Cancer Intelligence Network (NCIN), which will work closely with the Network to improve end of life care intelligence; and the South West Public Health Observatory, lead public health observatory for end of life care, which hosts the NEoLCIN website. The SWPHO has been commissioned to produce key outputs and analyses for the Network, including the national End of Life Care Profiles.

See www.endoflifecare-intelligence.org.uk for more information about the Network and its partners.