



Dying with Dementia

National Dementia Intelligence Network and National End of Life Care Intelligence Network briefing

Introduction

This briefing is written in the context of Dementia and the End of Life Care Strategy, where everyone, including people with dementia, approaching end of life should experience high quality, compassionate and joined-up care.¹

This intelligence briefing produced by the Dementia Intelligence Network (DIN) in collaboration with the National End of Life Care Intelligence Network (NEoLCIN), draws on national data to illustrate key information related to people who died with dementia in 2012-14. This briefing focusses on the setting and circumstances of death, discussing the data findings followed by the discussion and recommendations. This is with the purpose of informing key policies and commissioned programmes to deliver high-quality palliative care to people with end-of-life dementia.

The accompanying data report contains more detailed analysis and information. Other products in this release include data for local authorities and clinical commissioning groups, a presentation slideset and a summary infographic. Health intelligence related to other key themes for dementia, including the diagnosis process, are supported by the work of the DIN.

Key messages

- The mortality rate for deaths with a mention of dementia has increased significantly from 2001 to 2014
- Data suggests that people who reside in more deprived areas die younger with dementia; the relationship is small but significant
- More than half of dementia deaths for people aged 65+ occurred in care homes, compared with a quarter of the general population
- More than a third of dementia deaths also had a record of respiratory disease and more than a third had a record of circulatory diseases
- Recommendations include focusing on dementia specific palliative services, improving the adoption and quality of advanced care planning and advocating GP led holistic reviews for more co-ordinated care

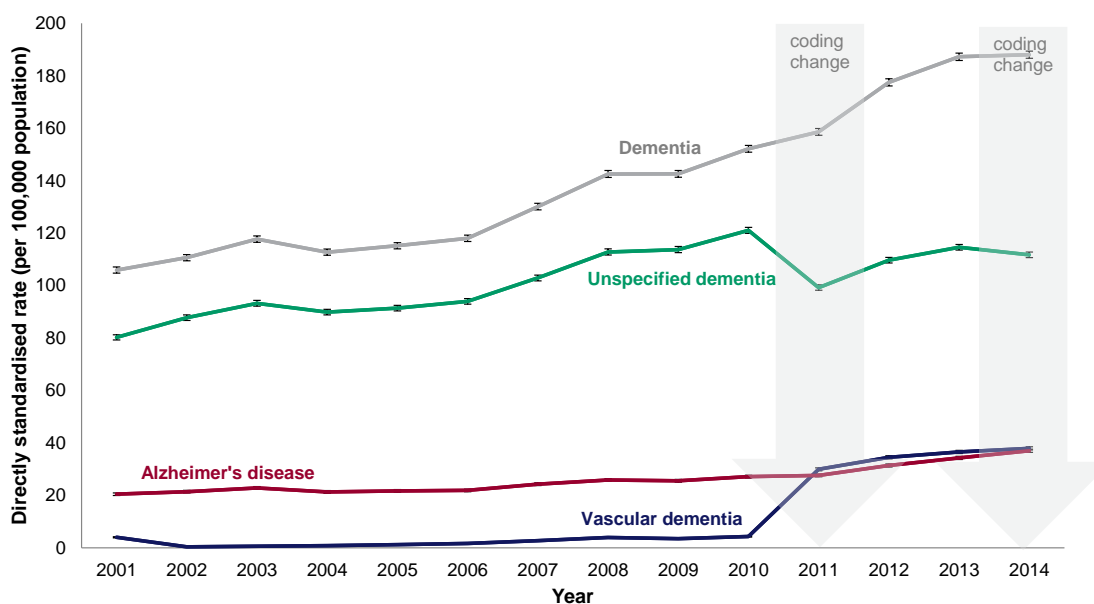
Deaths with a mention of dementia over time

In 2014, there were 73,189 deaths with a recorded mention of dementia. Nearly all of these deaths occurred in people aged 65 and over (72,504), representing 18% of all deaths in this age group. The mortality rate of deaths with a mention of dementia have increased significantly; from 106 deaths per 100,000 population in 2001 to 188 deaths per 100,000 population in 2014 (Figure 1), this is in contrast to overall mortality rate for all causes which is falling.² Overall, there is a higher age-standardised mortality rate of deaths with a mention of unspecified dementia subtype compared with other subtypes. The rate of deaths with a recorded mention of vascular dementia increased significantly in 2011 whereas deaths with Alzheimer's disease have increased steadily over the period.

Box 1: Definition of study group

- 2012-14 deaths with a mention of dementia, ie recorded as an underlying cause of death or as a contributory cause of death
- Dementia is defined using ICD10 codes for the following subtypes; Alzheimer's disease (F00 & G30), vascular dementia (F01), unspecified dementia (F03) and other dementia subtypes (F02, F04 & G31)
- Deaths with a valid resident code for England, in the adult population aged 20 and over

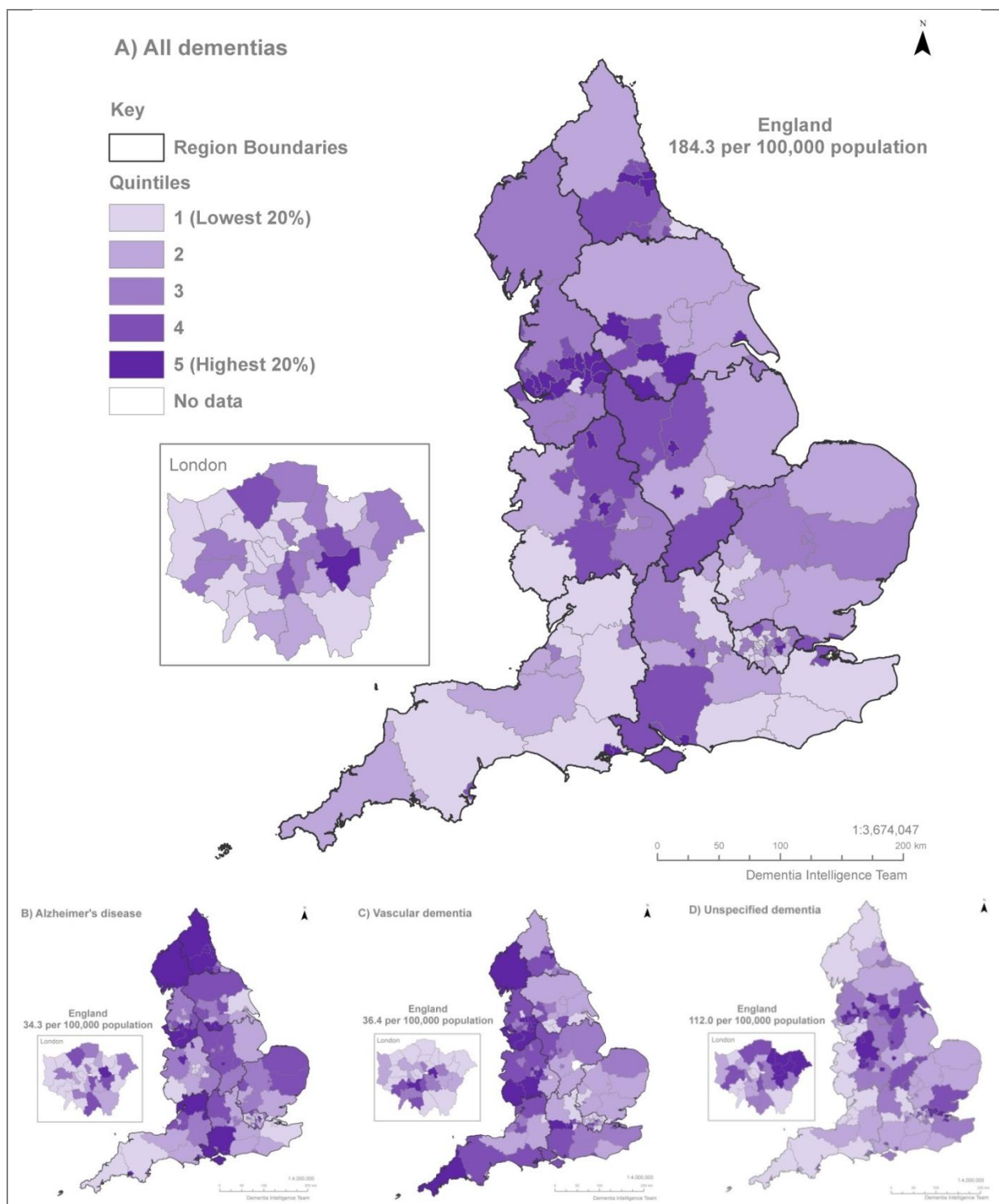
Figure 1: The directly age-standardised mortality rate for deaths with any mention of dementia (all subtypes) and dementia subtypes, persons aged 20+, England, 2001-2014



Deaths with a mention of dementia across England

There is considerable geographical variation in the mortality rates for deaths with a mention of dementia. Overall mortality rates are highest in central England. However, this pattern varies by dementia subtype where mortality rates are highest in west of England for vascular dementia and highest in the north for Alzheimer's disease (Figure 2).

Figure 2: The directly age-standardised mortality rate of deaths with any mention of A) Dementia (all subtypes) B) Alzheimer’s disease C) Vascular dementia D) Unspecified dementia per 100,000 population, people aged 20+, LAs, England, 2012-2014

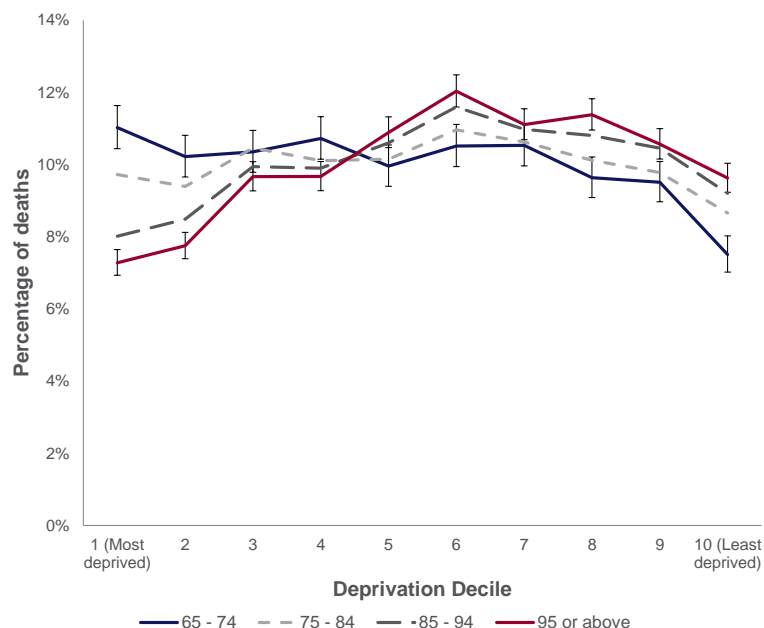


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The maps of directly age-standardised mortality rates by dementia subtype are also available at CCG level in the data analysis report. Note that populations are not distributed evenly across geographical areas. Data for these maps can be downloaded [here](#).

Relationship between deprivation and age for dementia deaths

Figure 3: Percentage of deaths with a mention of dementia by deprivation decile and age group, England, 2012-14

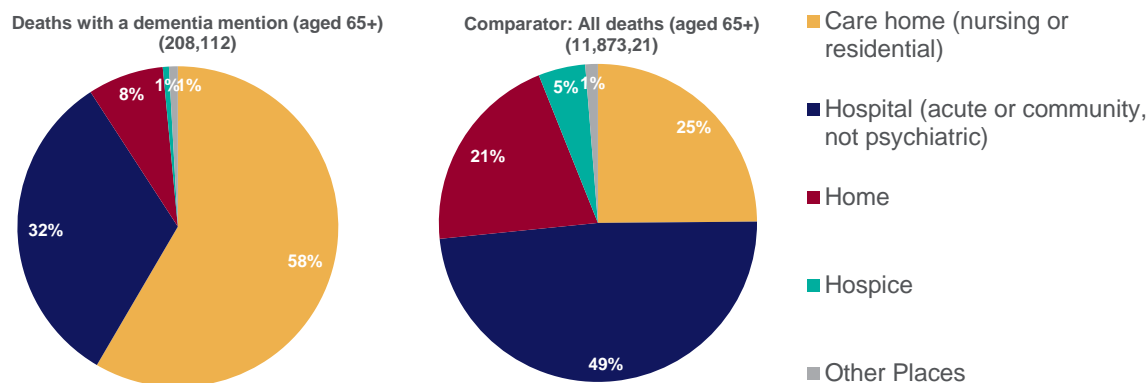


A higher proportion of deaths for people aged 65 to 74 with dementia occurred in more deprived areas compared with the least deprived areas. Although the proportion difference is small it is statistically significant (Figure 3). This suggests that people who reside in more deprived areas die younger with dementia. Analysis by dementia subtype revealed that this difference is greater for deaths with a mention of vascular dementia, with 15% of deaths in people aged 65 to 74 occurring in the most

Place of death

The place of death profile for people who have died with dementia is markedly different compared with the general population. For those aged 65+, the majority of deaths with a mention of dementia occurred in care homes (58%), nearly a third of deaths in hospitals and less than a tenth at home. In contrast, in the general population aged 65+, nearly half of all deaths occurred in hospitals, a quarter in care homes and one fifth at home. A very small proportion of people who have died with dementia do so in hospices (1%) compared with the general population (5%).

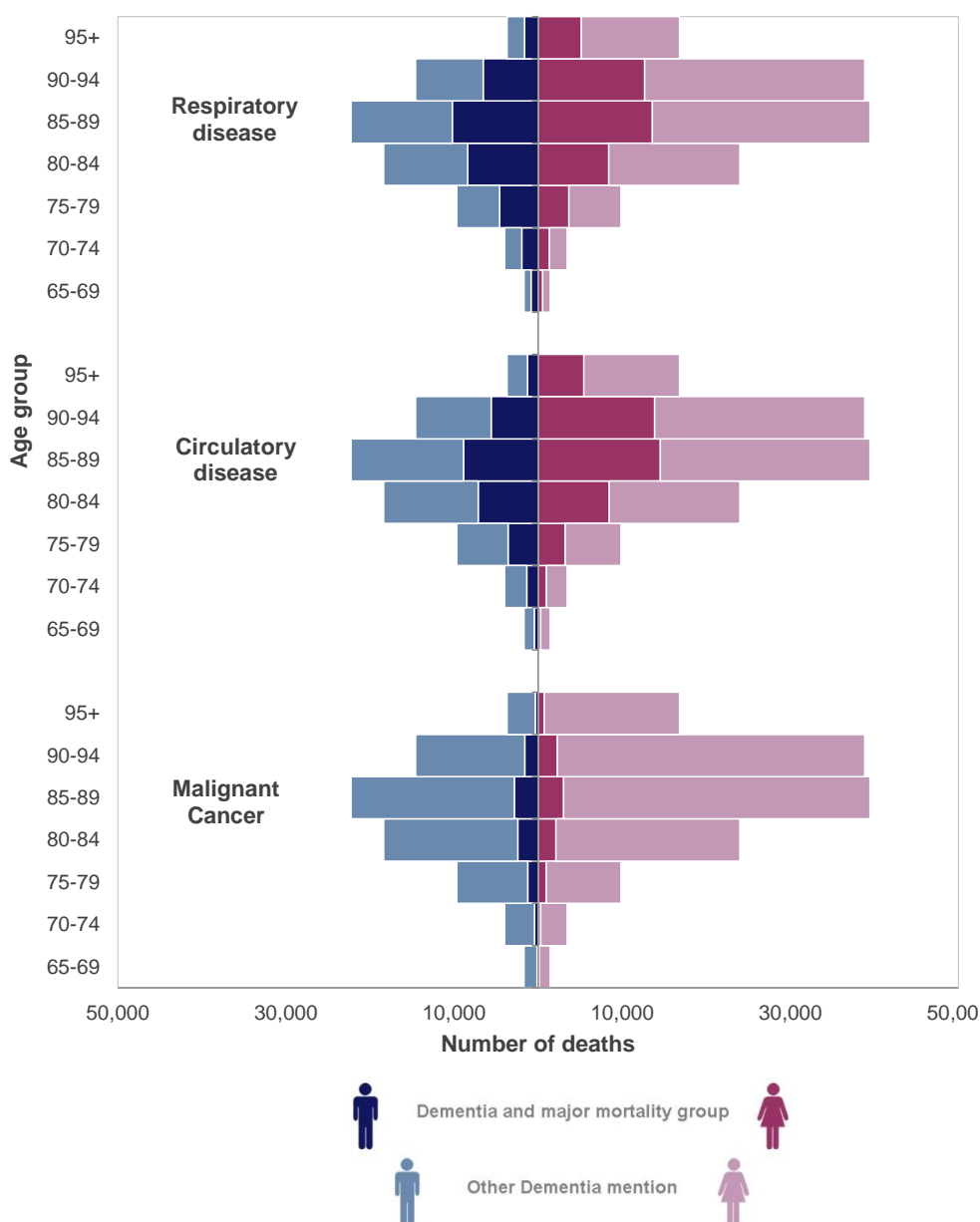
Figure 4: The proportion of deaths with a mention of dementia compared with all deaths by place of death, deaths of people aged 65+, England, 2012-14



Comorbidities for people who have died with dementia

More than a third of all deaths in 2012-14 with a recorded mention of dementia in those aged 65+ also have a mention of respiratory disease (38%). A similar proportion of deaths have a recorded mention of dementia and circulatory disease (36%). The age and gender profile for those dying with dementia and respiratory disease or circulatory disease is similar to that observed for dementia overall (Figure 5). A comparatively smaller proportion of deaths had a recorded mention of dementia and cancer (9%), perhaps due to the younger age profile of those who have died with cancer. The relationship between place of death and long-term conditions is further explored in the data report.

Figure 5: Deaths with a mention of dementia (all subtypes) with and without a mention of three major mortality groups, by age and gender, England, 2012-14



Discussion

Dementia mortality rate

Reporting of deaths associated with dementia has significantly increased over the period 2001 to 2014, even when using age-standardised mortality rates that have been adjusted for an ageing population. Other than demographic changes, key contributors to the increase in mortality rates are likely to be health policy drivers, clinical practice and changes to coding on death certificates.

Increased awareness

The 2009 National Dementia Strategy set out the ambition in England through objective one to increase the public and professional awareness and understanding of dementia.³ Around this time the dementia prevalence indicator to the Quality Outcomes Framework was introduced in primary care and in 2013 the Dementia Commissioning for Quality and Innovation (CQUIN) was introduced to encourage practitioners to identify those who potentially have dementia in a secondary care setting.⁴

In terms of evidence provided in this briefing and early findings of a study by the Office for National Statistics (ONS), where this increase in deaths associated with dementia has continued into 2015,⁵ there clearly has been a step change in the level of awareness of the general public and professional groups towards the symptoms of dementia and the push to increase the diagnosis rate, although better understanding of the condition may require additional exploration.

Changes to coding practice

During the study period of this briefing there have been two important methodological changes in the way mortality data is collected in relation to the underlying cause of death. In 2011, deaths previously coded with an underlying cause of unspecified cerebrovascular disease were to be reclassified as vascular dementia⁶ and in the 2014 revision, dementia was to be coded as the underlying cause of death whereas previously this was assigned to chest infections and aspiration pneumonia.⁷

However, in this study the cohort being investigated were defined with a broader definition of a mention of dementia on the death certificate that incorporates either an underlying or a contributory cause of death. Consequently, the methodological changes outlined above are likely to have had little impact on the overall numbers/rates for dementia, although the 2011 revision appears to have increased the reporting of vascular dementia and decreased unspecified dementia reporting.

Recording of the unspecified dementia subtype

The National Institute for health and Care Excellence (NICE) pathway for the diagnosis of dementia states that a formal diagnosis should include the subtype of the underlying disease and thus should lead to the appropriate care and treatment being provided to an individual while it remains socially and clinically appropriate.

Around 70% of cases in this study cohort with dementia reported a mention of unspecified dementia on their death certificate, while more than one-quarter related to both Alzheimer's disease and vascular dementia. However, it has been estimated that 62% of all cases of dementia is related to Alzheimer's disease and the analysis of the study suggests that there could be a significant number of cases with Alzheimer's disease that may have not been formally diagnosed during the lifetime of the individual.⁸ These individuals may have potentially missed out on condition-modifying treatments and other relevant care.⁹

It is unclear at this time if the issue is a symptom of any or all the following:

- Death certificates not being completed with full access to primary care records which should contain details of the formal diagnosis of dementia
- The formal diagnosis of dementia in the primary care record not including a specification of subtype
- The diagnosis of dementia being complex, ie multiple causes and thus the coder using the code for unspecified dementia to describe this

Recommendation

- Improvement of communication across the dementia care pathway - consistently recording the dementia subtype in line with a formal diagnosis process in primary care, secondary care and on death certification

Geographical variation of deaths recorded with dementia

The mortality rate of dementia subtypes varies across England; the pattern of variation is similar to that reported for emergency admission rates for people with dementia.¹⁰ Environmental differences and behavioural risk factors may explain some of this variation. Other contributing reasons include inequalities in access to diagnostic facilities, variation in clinical practice and different routes to a formal dementia diagnosis. These factors are likely to impact on the dementia subtype diagnosis recorded on the death certificate.

Recommendation

- Commissioners and providers to review the routes to access, capability and service configurations of their diagnostic facilities

Relationship between dementia, deprivation and age of death

A higher proportion of the 'young-old' (those aged 65-74) who have died with dementia resided in the more deprived areas compared to the least deprived areas, the reverse is the case for people aged 95 and over. This suggests that people who reside in more deprived areas die younger with dementia. This relationship was more notable for deaths with vascular dementia, perhaps due to a higher prevalence of vascular risk factors such as smoking and obesity in more deprived areas.¹¹ A comparable relationship has been observed previously, with higher reported dementia incidence rates in more deprived areas.¹²

Recommendations

- Commissioners and providers to take account of the level of need in their population based on factors such as deprivation, because the needs of people with dementia and their carers will vary accordingly
- Researchers to further investigate the link between deprivation and dementia

Place of death profile

People with dementia were more likely to die in care homes and less likely to die at home or in hospices. This most probably reflects the complex needs of people with dementia, for example, significant changes in a person's function, capacity and behaviour.

Dementia deaths in hospitals

Although the proportion of deaths that occur in hospital has decreased over time, a third of people with dementia are still dying in hospital. Research suggests that the majority of people would prefer to be cared for at home and prefer not to die in hospital.¹³ Work from the DIN has shown emergency admissions for people with dementia are increasing and that a large proportion of admissions are considered avoidable for reasons such as respiratory and urinary infections.¹⁴ Overall, the evidence suggests that hospitalisation can be unfavourable for people with dementia causing significant distress and deterioration.

Dementia deaths in the community

We have shown that less than a tenth of people with dementia die at home, this is significantly lower than those dying with other conditions. In this context it is important to consider the extent of community care support that is available to both people with dementia and their carers and to challenge whether they have the same choice as people dying from other long-term conditions. The Alzheimer's Society reports that 49% of carers do not receive enough support to care for their relatives.¹⁵ Community support could enable carers to continue caring for their relatives at home and should they choose, allow for people with dementia to die at home.

This report has shown that the majority of people aged 65 and over with a mention of dementia die in care homes. Therefore, it is essential to focus on the quality of end-of-life care provided in these settings. Evidence-based recommendations highlight the importance of equipping care home staff with the knowledge, skills and behaviours required to deliver co-ordinated, compassionate and person-centred end-of-life care for people with dementia.^{16 17}

Reasons for place of death differences

A possible reason to explain the inequalities we observe may be that dementia is not routinely identified as a terminal illness for end of life care and as a result people have less access to specialist palliative care services compared to people with other terminal illnesses.^{18 19} This factor may influence where people with dementia die. It is reasoned that the disease trajectory for people with dementia makes it harder to identify the terminal phases. However, end-stage dementia predictors have been identified such as more frequent infections and physical decline.²⁰

These differences in the place of death for people with dementia compared with other conditions may also be due to a potential gap in advance care planning discussions. This process is important for ascertaining the responsibilities of different professional groups and ensuring that people's preferences are expressed and where possible adhered to.²¹

Recommendations

- Commissioners and providers to review capacity and capability of community support services (ie care co-ordinators) for people with dementia and their carers, so that people with dementia can be cared for at home in the advanced stages if this is their preference
- Commissioners and providers to include a specification to target care home and hospital settings for tailored specialist palliative care programmes for people with dementia with targeted outreach teams, creating greater parity of esteem with other long-term conditions
- Health professionals to customise their application of palliative care guidance to meet the needs of people with advanced dementia reaching the end of life and their carers, engaging with both parties to understand what works well and what could work better
- Health professionals to offer early opportunity to complete advance care plans for people with dementia while they have capacity for these discussions, so, for example with the aim that more people with dementia are able to die in their place of choosing
- Commissioners and providers to review services and initiatives which improve the transition for people with dementia from secondary care back into the community

Comorbidities for people with dementia

More than a third of deaths with a recorded mention of dementia also had a recorded mention of respiratory disease (38%) or circulatory disease (36%). Due to the nature of recording on death certificates, the actual numbers of people with dementia and other comorbidities is estimated to be higher. This is because conditions will only be recorded on death certificates if they are considered a direct or important factor at death. Comorbidities have additional implications for people with dementia, with the loss of cognitive function impacting on the capability for self-management of other conditions. Evidence suggests that this cohort of people will experience complex challenges, with delays in the recognition of symptoms and increased risk of hospitalisation.²² The scale of comorbidities highlighted in our report supports the need to address care coordination for people with dementia. More information is required to understand whether people with dementia are receiving appropriate care management for their additional conditions and whether staff are equipped to deal with these additional challenges.

Recommendation

- Development of the All-Party Parliamentary Group recommendation to introduce of a GP-led holistic review to address all conditions a person may have rather than individual reviews for each condition, so that the physical and mental health needs of a person with dementia are met

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Find out more:

The dementia intelligence network (DIN) was launched in June 2014 with the purpose of providing and disseminating health intelligence products to enable local systems to take an intelligence-driven approach to planning and commissioning, resulting in measurable improvements in the quality and outcomes for local communities.

The DIN will provide these health intelligence products in ways designed to support and enable local improvement work aimed at developing local community's dementia services.

The ambition of the DIN is to develop a strategic approach to the development of the health intelligence products around dementia. This will include a new focus on risk reduction and living well with dementia. This will be approached thematically around five "pillars" of health intelligence – prevalence; prevention and risk reduction; the diagnosis process; living well with dementia and post-diagnosis support; end of life care. The approach also includes cross-cutting themes such as user and carer experiences and system financials.

The DIN website contains more information and resources related to dementia intelligence www.yhpho.org.uk/default.aspx?RID=198136

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

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