



INTRODUCTION

Nursing and residential care homes play an important role in the care of many people at the end of life. Collectively they are referred to as care homes. Each year over 100,000 people die in these settings and approximately 29,000 other people normally resident in a care home die elsewhere.

Care homes provide accommodation and personal care for people who may not be able to live independently either permanently or temporarily. Temporary admission to a care home may occur when someone needs short term support recuperating from an illness, for a trial period to decide whether they want to live permanently in a care home, or following discharge from hospital during a terminal illness.

According to the Care Quality Commission there are 462,035 care beds in England in 16,765 care homes (2016). The number of beds has decreased from 466,317 in 2012 this overall decrease contrasts with an increase in nursing home beds.

METHODS

Information on deaths in care homes and care home residents who died elsewhere was extracted from the Office of National Statistics (ONS) Annual Deaths Extract which is itself compiled from death certification data. Deaths in care homes (both residential and nursing homes) were identified within this dataset using the method of categorising place of death described in <http://www.endoflifecare-intelligence.org.uk/resources/publications> Analysis focused on deaths of England residents registered in the 10 years 2005 to 2014, excluding neo-natal deaths.

The mortality data includes a residential address as well as a place of death. Temporary residence in a care home was inferred if the postcode of residence of someone who died in a care home did not match a care home (as listed in the ONS Communal Establishment database which is used to categorise place of death). A limitation to this method is that the mortality dataset contains no information on how long people had been temporarily living in a care home; for some this may be a few days, for others this may have been months.

RESULTS

- The numbers of people dying in care homes (permanent and temporary residents) and the proportion of deaths occurring in care homes is increasing (Figure 1). In 2014, 22% of all deaths in England (101,203) occurred in a care home, up from 16% (76,997) in 2005. Each year between 2005 and 2014 around 34% of deaths in care homes were associated with temporary residents.
- The majority of deaths of permanent care home residents occur in a care home (70% in 2014 up from 58% in 2005) (Figure 2), however a further 28,892 permanent care home residents died elsewhere, most often in hospital.
- The majority of deaths among temporary and permanent care home residents are associated with females, the largest numbers being with those aged 85+ (Figure 2).
- The distribution of broad underlying causes of death for care home residents are summarised in Table 1.
 - The most common underlying causes of death in care homes are dementia and diseases of the nervous system (31% of deaths in care homes).
 - Circulatory disease was the most common underlying cause of death group for care home residents who die elsewhere (27% of these deaths).
 - Cancer as an underlying cause of death was disproportionately common for temporary residents, compared to permanent residents; 61% of deaths from cancer in a care home were temporary residents.
- An analysis of underlying cause of death together with contributory causes of death recorded on death certificates shows that considerably more who die in a care home die with dementia or Alzheimer's disease or senility significant enough to be recorded (62%) than were identified in Table 1 by underlying cause alone (Figure 3). The figure also shows that most (57%) of all deaths where dementia are recorded as underlying or contributory cause of death occur in a care home

Figure 1. The number and percentage of deaths in care homes, England 2005-2014

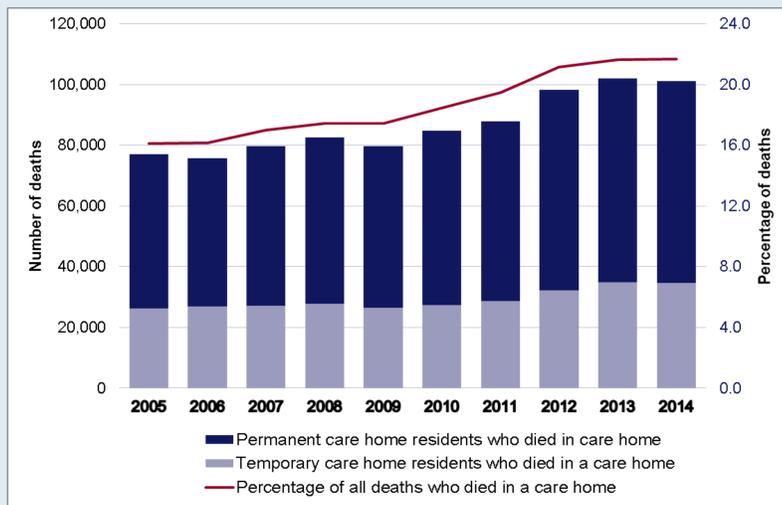


Table 1. Broad underlying causes of death for permanent and temporary care home residents, England 2014

Underlying cause of death (ICD-10)	All deaths in care homes	Deaths in a care home		Permanent care home residents who died elsewhere
		Permanent residents	Temporary residents	
Dementia and Alzheimer's disease (IF01, F03, G30)	31% (31,585)	37% (24,714)	20% (6,871)	18% (5,195)
Circulatory disease (I)	22% (22,368)	22% (14,964)	21% (7,404)	27% (7,945)
Cancer (C)	18% (18,676)	11% (7,193)	33% (11,483)	12% (3,438)
Respiratory disease (J)	10% (10,325)	11% (7,036)	9% (3,289)	18% (5,195)
Other	18% (18,249)	19% (12,658)	16% (5,591)	25% (7,119)
All causes	100% (101,203)	100% (66,565)	100% (34,638)	100% (28,892)

Figure 2. Ages and sex distribution of deaths in care homes and of care home residents who died elsewhere, England 2005-2014

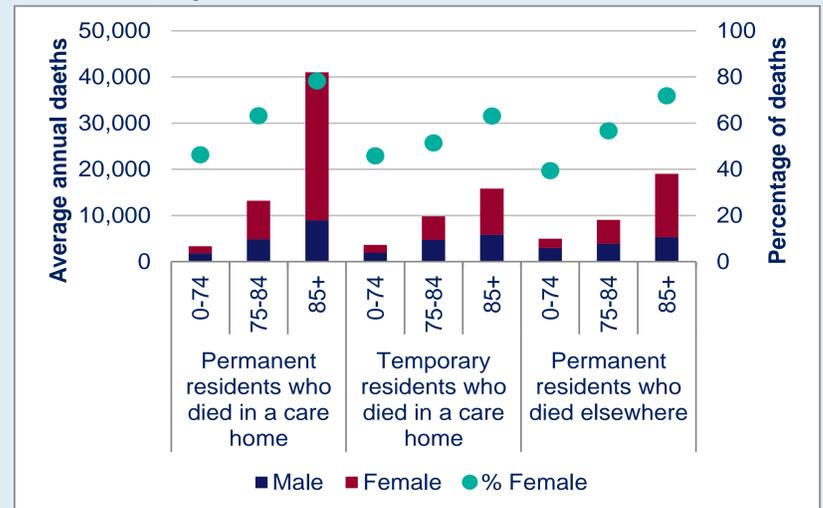
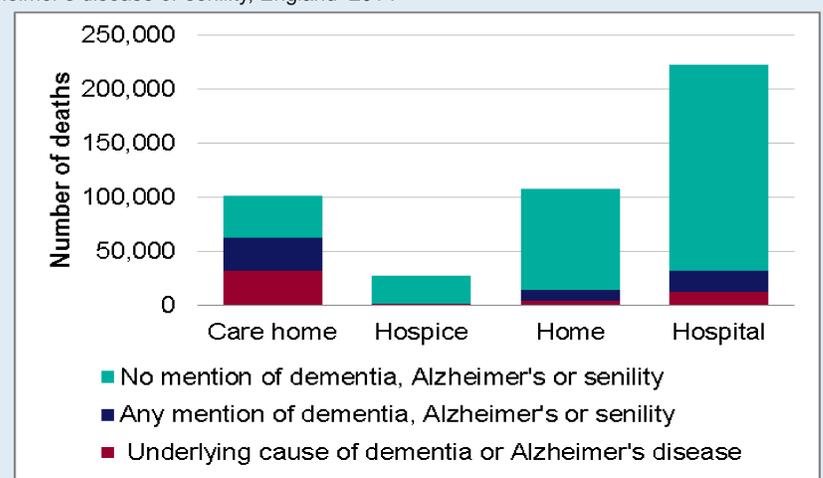


Figure 3. Number of deaths by place of death and causes of death including dementia, Alzheimer's disease or senility, England 2014



DISCUSSION

A Key Performance Indicator for End of Life Care has been the proportion of Deaths in Usual Place of Residence (DiUPR)^{1, 8}; designed to encourage care providers to support people to die in a place of their choosing, a place that for many would not be a hospital. The design of this indicator assumes that all deaths occurring either at home or in a care home are in the usual place of residence. The data presented here illustrates that for many people who die in a care home, perhaps as many as a third are not permanent care home residents, or are not in their usual place of residence.

Over recent years England has seen an increasing proportion of deaths occurring in care homes or private homes and a decreasing proportion in hospital¹. This has been encouraged by research indicating that, when asked, many people would prefer not to die in hospital^{2, 3, 4, 5, 6}.

People in a care home are some of the most vulnerable in society, many living with multiple co-morbidities. Dementia, Alzheimer's disease or senility is significant enough to be mentioned as an underlying or contributory cause of death for 60% of people who die in a care home. This increasing role for care homes comes at a time of huge pressure on social care provision.⁷

CONCLUSIONS

- Some of the most vulnerable in our community will receive care towards the end of their life in a care home.
- Most of those in a care home near the end of their life will die there, although there are a significant number who die elsewhere, mostly in hospital.
- Care homes are a major provider of care for people at the end of life and living with Alzheimer's or Dementia.

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Office for National Statistics, UK: Public Health England Annual Births and Mortality Extracts

CONFLICTS OF INTEREST

None