

Ageing Well

End of Life Care

Revised: 30/08/2017

Introduction

End of life care can be a sensitive and intrusive subject for many who are seriously ill and need to consider what choices they have. People at the end of life are cared for and supported in a variety of settings including; acute hospitals, hospices, in their own home by their GP practice, and in care homes. End of life care provides support and care for people who are recognised as possibly being in last months of life. It can allow patients and those important to them to be able to express their wishes and goals and as a result enables them to have choice. It can also support people who are caring for people who are dying. End of life care helps people live their last days as comfortably as possible, and as far as possible in their chosen circumstances. Specialist palliative care can also be provided and help reduce symptoms towards the end.

The government (2016) has made [6 commitments](#) to the public to end variation in end of life care across the health system by 2020. These are:

- Honest discussions between care professionals and dying people
- Dying people making informed choices about their care
- Personalised care plans for all
- The discussion of personalised care plans with care professionals
- The involvement of family and carers in dying people's care
- A main contact so dying people know who to contact at any time of day

What do we know?

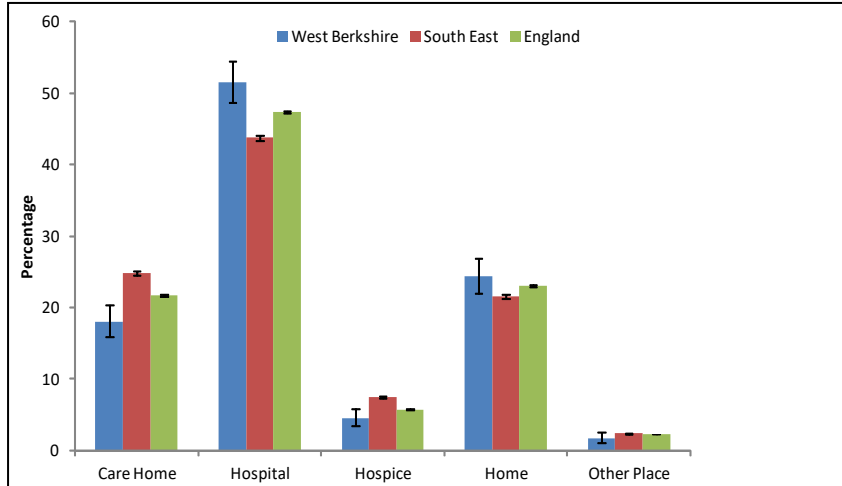
According to the [Office for National Statistics](#), there were 529,655 deaths registered in England and Wales in 2015, an increase of 5.6% compared with 2014. Cancer was the most common broad cause of death (28% of all deaths registered) followed by circulatory diseases, such as heart disease and strokes (26%).

There has been a year on year increase in the number of deaths since 2011 and this reflects not only an ageing population but also advances in medicine and technology that help people live longer lives. Over time, we can expect the number of deaths to increase.

Although many people would prefer to die at home or in a hospice, hospitals remain the most common place of death. Figure 1 shows that in West Berkshire, more

people die in hospital, with 51.5% of deaths across all ages. In addition, when looking at hospital deaths by age group, the highest percentage of deaths is for the age group 75 to 84 with 59.0%. Both of these figures are significantly higher than England's percentages (47.4% and 50.9% retrospectively).

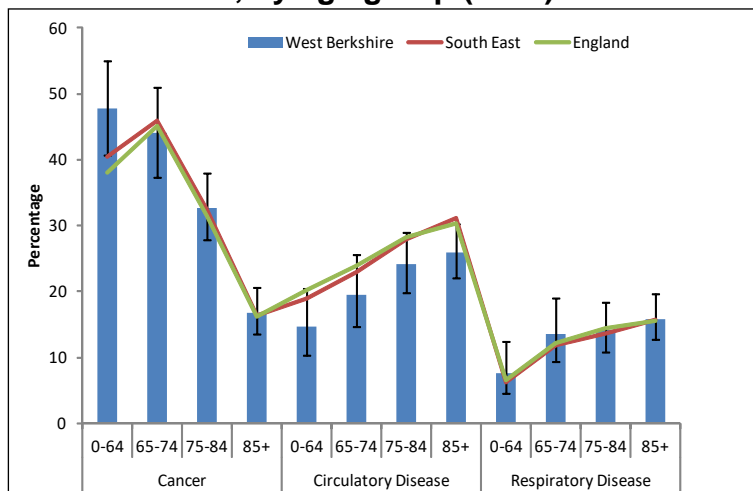
Place of death – West Berkshire 2014



Source: Public Health England: [End of Life Profiles](#)

West Berkshire (26.0%) have a significantly lower percentage of deaths from the underlying cause of circulatory disease in persons aged 85+ than England (30.3%) in 2014, and a significantly higher percentage of deaths from the underlying cause of cancer in West Berkshire (47.8%) than England (38.0%) for people aged under 65.

Cause of death, by age group (2014)

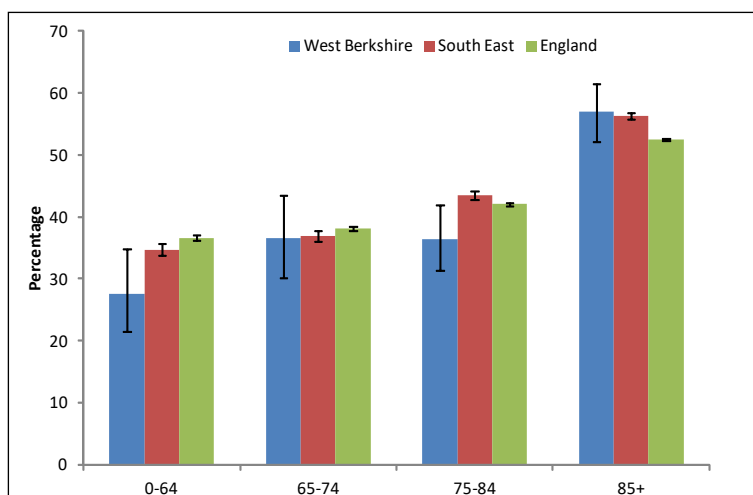


Source: Public Health England: [End of Life Profiles](#)

There is a significantly lower percentage of deaths in usual place of residence within West Berkshire, 27.6% of people aged 0-64, compared to England, 36.7%.

Death in usual place of residence, by age, 2014

West Berkshire Council Joint Strategic Needs Assessment



Source: Public Health England: [End of Life Profiles](#)

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, this is in contrast to overall mortality rate for all causes which is falling.

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%).

In August 2016, Public Health England published an [intelligence briefing](#), produced jointly by the [National Dementia Intelligence Network](#) and the [National End of Life Care Intelligence Network \(NEOLCIN\)](#) that illustrated key information related to people who have died with dementia between 2012 and 2014. It focuses on the setting and circumstances of death for people with dementia.

In West Berkshire, the rate of deaths from vascular dementia was significantly higher than England. The rate of deaths from dementia, Alzheimer's disease and unspecified dementia were lower than England.

Number and rate per 100,000 Mortality in persons aged 20+, recorded with any mention of dementia (all subtypes), Alzheimer's Disease, Vascular Dementia and Unspecified Dementia, West Berkshire, 2012-2014

	Dementia		Alzheimer's Disease		Vascular Dementia		Unspecified Dementia	
	Number	Rate	Number	Rate	Number	Rate	Number	Rate
West Berkshire	512	170.7	105	35.6	157	51.6	238	79.4
England	210,187	184.3	39,200	34.3	41,558	36.4	127,551	112.0

Source: [PHE: Dying with Dementia - dataset by local authority](#)

One of the key findings from a report by the [National End of Life Care Intelligence Network \(2015\)](#) was that the factors of most importance to people at the end of their life were: having pain and other symptoms managed effectively, being surrounded by loved ones and being treated with dignity. They also found that more GPs are having conversations with people about their end of life care wishes but 25% still say they have never initiated such a conversation.

What is the data telling us?

[Research has shown](#) that being single, widowed, or divorced was associated with a higher likelihood of dying in hospital than being married. As meeting people's preferences for place of care and place of death is an important measure of the quality of end of life care, this group of people need to be supported to ensure they are able to choose where they die.

People are reluctant to talk about death, dying and bereavement which can impact upon how people experience death. Consideration needs to be given on how to enable people to talk more openly about death, dying and bereavement and how to plan for the end of life. This means that people are empowered to die as they wish and family and carers can be given support.

Recommendations for consideration

Each person is seen as an individual – that patients who may be entering last months of life are recognised as early as possible, so that they may have the opportunity to have open and honest discussions about their wishes. These discussions should involve those people who are important to the patient as well, and can help inform a personalised care plan that should be reviewed regularly.

Each person gets fair access to care –that patients with palliative care need have equal access to care, both health and social, no matter their diagnosis.

Maximising comfort and wellbeing –to ensure that patients symptoms are well controlled and that there is 24/7 access to specialist palliative care for those who need it.

Care is coordinated – that with permission of the patient, information is shared and easily accessible to all health and social care professionals who may give care to that patient via the electronic palliative care co-ordination system (EpaCCs)

All staff are prepared to care – via regular education and training programmes for staff in all care settings including social care and care homes that involve recognising dying, initiating and conducting conversations about patient's wishes, and developing personalised care plans

Each community is prepared to help - involving voluntary and third sector organisations to support those in last months of life. Encouraging co-design of services with patients and carers. Ensuring high quality provision of bereavement support.

Outcome measures are identified and collected to provide assurance to Health and Wellbeing Board that our patient population are receiving high quality well integrated end of life care.

Other services and partner organisations

[Cruse Bereavement Care West Berkshire Branch](#) - CRUSE offers support to bereaved adults and children. The branch has a team of trained volunteers who will listen to the feelings that bereavement can bring. Visits can be arranged at home or in our office in central Newbury. An understanding bereavement course is held every two years, followed by a training course for potential bereavement volunteers.

National and local strategies

[The National End of Life Care Strategy 2008](#)

[Action for End of Life Care 2014-16](#)

[NICE \(2013\) Quality Standards \(QS13\) End of life care for adults](#)

[Department of Health \(2012\) End of Life Care Strategy: fourth annual report](#)

[Department of Health \(2013\) Improving care for people at the end of their life](#)

[Parliamentary and Health Service Ombudsman \(2015\)](#)

[GOV.UK: 'Government commits to high quality end of life care' \(July 2016\)](#)

Other chapters you might be interested in

Excess Winter Deaths

Mental Health (Old Age)

Preventable Sight Loss

If you have any questions about this chapter, please contact Public Health and Wellbeing Team on publichealthandwellbeing@westberks.gov.uk or 01635 503437