



End of Life Evidence Review

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1 Introduction

We are all going to die someday, but many of us seem to have a lot of fear around the process. For example, in one recent survey the top four out of seven fears people admitted to were around death¹:

- Dying in pain (83%)
- Dying alone (67%)
- Being told they are dying (62%)
- Dying in hospital (59%)
- Going bankrupt (41%)
- Divorce/end of a long-term relationship (39%)
- Losing their job (38%)

NICE guidance defines the 'end of life' stage as people with advanced, progressive, incurable conditions; those who may die within 12 months; and those with life-threatening acute conditions.² End of life care covers any support and treatment for those nearing death, and includes palliative care.

'Palliative care' has been defined by NICE as:

'the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.'

Palliative care aims to³:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help the family cope during the patient's illness and in their own bereavement

This evidence review will discuss issues around the end of life for older people, including but not limited to palliative care.

Regardless of when we die or the cause, most of us would like a 'good death'. The End of Life Care strategy⁴ suggests that a good death is likely to include:

- Being treated as an individual, with dignity and respect;
- Being free from pain and other symptoms;
- Being in familiar surroundings; and
- Being in the company of close family and/or friends⁵.

However, while some people experience excellent end of life care in hospitals, hospices, care homes and in their own homes, many others do not. Research shows that many people experience unnecessary pain and other symptoms, being treated with a lack dignity and respect, and many people do not die where they would choose to.⁶

Unfortunately it is not common for people nearing the end of their lives to have discussions about dying or planning for death with clinicians, family, or carers.⁷

Research suggests that people want the following things at the end of life⁸

- Pain and symptoms controlled
- Spiritual/existentialist peace/acceptance
- Preservation of identity
- Dignity (wishes, cultural and religious traditions) respected
- Compassionate medical staff
- Die in place of choice – may be influenced by culture
- Not alone (with family present)
- Not to be a burden on family
- Some want to make their own decisions, others to delegate
- Some want to die – acceptance of life's natural course, loss of identity and independence

As the End of Life Care Strategy points out, "How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services."⁹

Key policy issues:

- Ageism and access to health care, referring to older people as 'bed blockers';
- Viewing older people's care needs as *only* social or *only* health rather than taking a personalised, holistic care approach;
- Preoccupation with portrayals of old age as healthy and positive, marginalising the ill and frail;
- Poor coordination between health and social care services, hospital and home/care home;
- Abusive practices such as physical and medical restraint;
- Domiciliary care packages restricted to people assessed as having severe levels of need, excluding those with moderate or low level needs and failing to provide preventative care;
- Gaps in specialist services for older people with mental health problems and sensory impairments;
- Lack of health professional training in end of life issues and older people's health and care issues;
- Poor communication between service users, carers and providers, particularly on issues surrounding death and dying;
- Very little data on palliative care or end of life care;
- Huge variability between local areas (and corresponding variation in spending);
- Poor understanding of *trajectory* of older people's health, i.e. transition from living well/with multiple conditions/frailty to end of life phase.

Few of these are solely end of life issues, but relevant to health and social care in general. Therefore addressing these issues would improve health and social care for older people regardless of proximity to death.

2 Age and cause of death

The age, cause, and place of death have changed dramatically over the last century. In the early 1900s, most people died at home, often from acute infections, and many more deaths occurred during childhood and early adulthood.¹⁰

Fortunately, in modern times medical progress, improved nutrition, hygiene, and other factors mean that most people die later in life. In 2010, 83% of deaths in England and Wales occurred in people aged 65 and over.¹¹ Two thirds (66.9 per cent) of people who died were aged 75 or over¹² and more than one third (36.8 per cent) were aged 85 and over.¹³

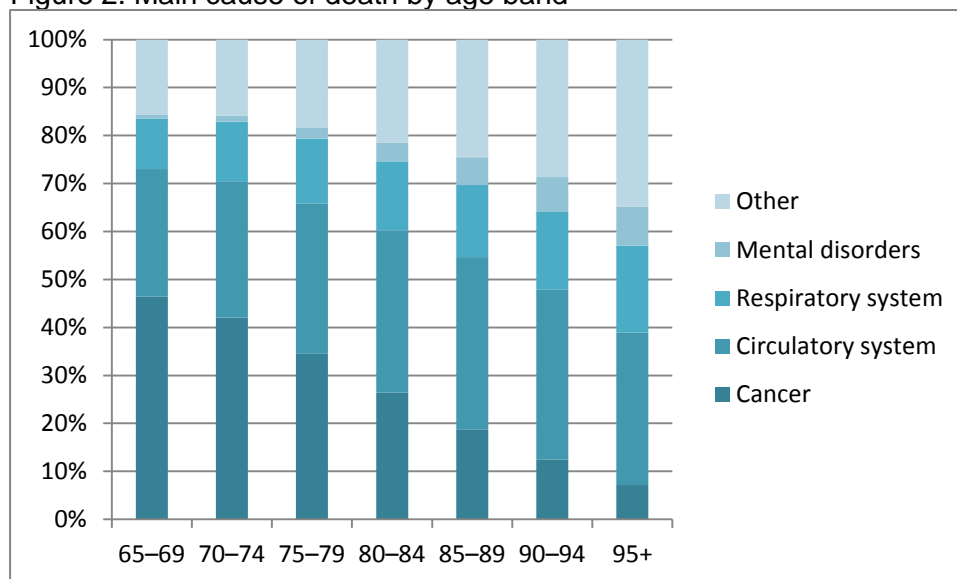
Figure 1. Mortality by age band

	65–69	70–74	75–79	80–84	85–89	90–94	95 and
% of all ages	7%	9%	13%	17%	19%	12%	6%
% of 65+	8%	11%	16%	21%	23%	14%	7%

ONS, *Mortality Statistics: Deaths Registered in 2010 (Series DR) Table 5, 2013*

The cause of death changes with age. In the 65-69 age group the leading cause is cancer, followed by diseases of the circulatory system. This gradually shifts as age increases so that by the age of 80, circulatory diseases are the most common and cancer the next most common causes. Deaths from respiratory illnesses (largely pneumonia) increase with age, as do deaths from mental disorders (mostly dementia).

Figure 2. Main cause of death by age band



ONS, *Mortality Statistics: Deaths Registered in 2010 (Series DR) Table 5, 2013*

NB 'Mental disorders' includes dementia. 'Other' includes infectious diseases, and other diseases of the digestive tract, skin, endocrine system, etc.

There has been discussion recently (July 2013) of an increase in the number of deaths in 2012 and early 2013 in people of 85 or over. The media have speculated about possible reasons, following publication of a paper by Public Health England, but it seems premature to attribute this to any cause or even to call it a trend.¹⁴

3 What are the key issues?

Health and care

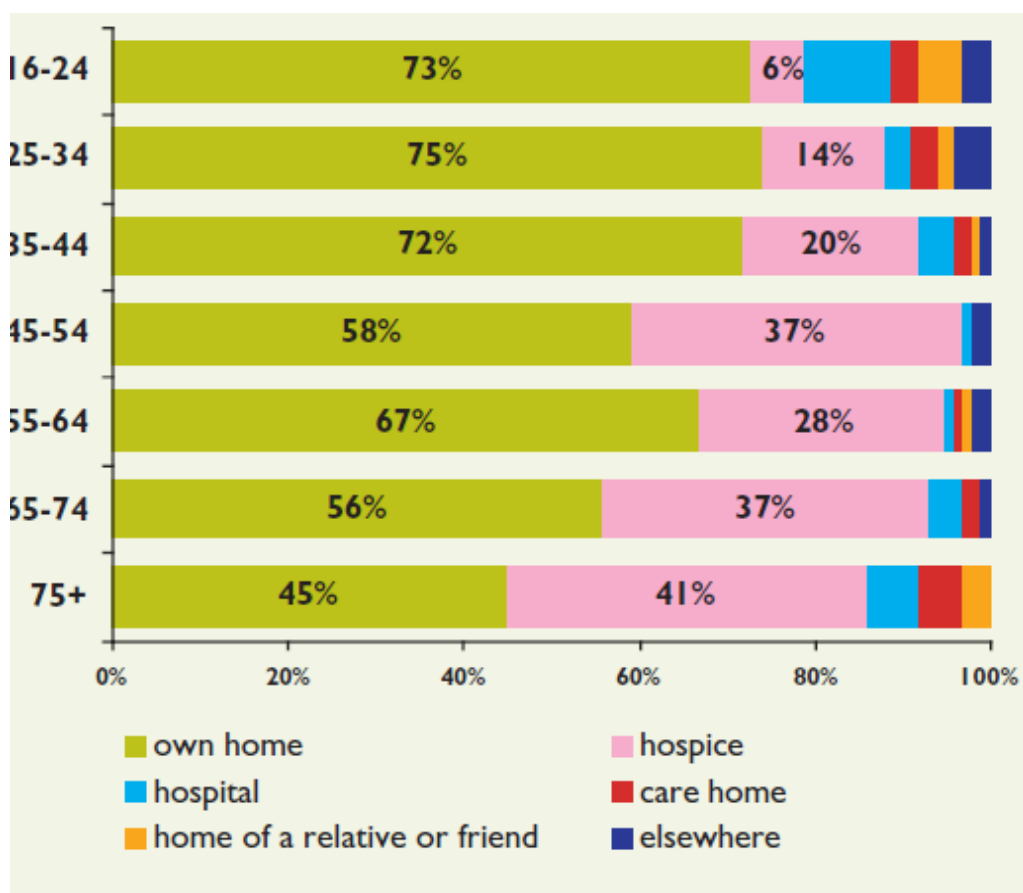
Older people often have special needs and issues at the end of life. Most older people die from chronic health problems and would benefit from palliative care during a slow decline. However, access to palliative care has traditionally been for younger people with cancer.¹⁵ The main problems with older people accessing palliative care are the lack of places, and huge variability and uncertainty about when death from chronic health problems will occur.

Older people are more likely to have complex needs and problems, which require the support of different medical specialists and other care professions.¹⁶ People in later life often have more than one medical condition, and are often taking a range of different drugs to treat these. There is a greater risk of adverse drug interactions, cumulative psychological effect of minor problems, other physical or mental impairment, economic hardship, and social isolation.¹⁷

Place of death

Most people are unlikely to die in their preferred place of death, regardless of where they live in England.¹⁸ The majority of people die in hospital. However, this becomes more common with age, as does dying in a care home (the second least-preferred place to die). Not only do home deaths decrease for people aged 65+, but so do deaths in hospices.

Figure 3: Most preferred place of death by age group (PRISMA 2011, England)



Age differences were statistically significant (Kruskal-Wallis test=43.287; p -value<0.001).

The overall picture from the PRISMA survey is not as clear as it should be as the all-age results are skewed in favour of younger people. Although over 80% of people who die each year in England are aged 65 or over, this age group made up only 28% of the total sample.¹⁹

Figure 4. Place of death by age group

Age	Total deaths	Home		Care Homes		Hospices		Hospitals	
65-74	78,591	22,669	29%	5,536	7%	7,388	9%	41,386	53%
75-84	143,422	31,315	22%	23,720	17%	7,670	5%	78,746	55%
85+	180,103	25,452	14%	61,125	34%	3,291	2%	88,424	49%
Total 65+	402,116	79,436	20%	90,381	22%	18,349	5%	208,556	52%

From ONS *Deaths registered in England and Wales, 2011*

Evidence suggests that the level of care, dignity, the environment, and peacefulness of the setting could all be improved in care homes and hospitals to make end of life care a better experience for people dying in these settings and their families.^{20 21}

Home

Although survey data suggest that the majority of people (approximately 66 per cent) would wish to die at home²², and this fact has had influence on the Department of Health's End of Life Strategy (2008), there is a need to take a more nuanced approach. The survey respondents were mostly middle-aged, healthy, middle income people.

Further research has shown that as age increases, a preference to die at home **decreases**. The PRISMA survey (2010) found that preferences for home death decreased from 75% (for those aged 25-34) to 45% (for those aged 75+)²³.

Also, another study found that when asked, 'Would you still prefer to die at home even if you did not have sufficient support from family, friends or the social and medical professionals?' 60 per cent of those who initially expressed a preference to die at home report that they would change this view if sufficient support from the various sources listed in the question was not available.²⁴

It is also not fully understood why people say they would prefer to die at home. One study suggests that people view it as the most likely place to be surrounded by family and friends, in a comfortable, familiar space, a peaceful atmosphere, and where they can experience dignity.²⁵ People are apparently willing to give up better pain control in a hospital setting to have these things.

With increasing age, older people become less likely to want to die at home, for a variety of reasons: most women outlive their partners and live alone; if people do have spouse carers, these spouses are usually also old and have health problems; there is great concern about being a burden on family and being dependent on others, especially for 'intimate' needs such as toileting and bathing.^{26 27}

Current research is being done on older carers and the realities of older people dying at home. In addition to their own health problems, other major issues are accessing services,

and turning the family home into a mini-hospital with many different specialists or carers coming in.²⁸ This can be overwhelming, and it negatively influences how the bereaved feel about their home in the aftermath.

Plus as people get older, they are less likely to have spacious middle-class homes; they may have to turn the living room into a bedroom or put a commode in the kitchen. Older people are also more likely to live in homes which are in bad repair or poorly insulated.²⁹

Pros

In theory, people say they would prefer to die at home, surrounded by family, because it is familiar and more comforting than a hospital room, surrounded by medical equipment and strangers.³⁰

Cons

Concerns about dying at home include dying alone, being a burden, needing intimate care, lack of pain control, becoming disabled, and turning the home into a mini hospital. In short, romanticised ideas about dying at home do not always match the reality.

Hospital

In surveys, most people say they do not wish to die in a hospital, yet in fact most do.

Figure 5: Deaths in hospital by cause

Underlying Cause of death		Age Standardised Proportions	England Average
All Causes	Highest	63%	52%
	Lowest	30%	
Cancer	Highest	68%	48%
	Lowest	23%	
Cardiovascular disease	Highest	64%	53%
	Lowest	31%	
Respiratory disease	Highest	72%	62%
	Lowest	36%	
Stroke	Highest	66%	54%
	Lowest	27%	
Other	Highest	62%	51%
	Lowest	29%	

Source: *Linked Mortality File, Office for National Statistics, annual mortality file and NHS Information Centre, Hospital Episode Statistics, England 2004-2008*

In 2010, 54% of those aged 75 and over died in hospital.³¹

89% of those who die in hospital do so following an emergency admission. 32% of these people die after a stay of 0-3 days, 18% after a stay of 4-7 days and 50% after a stay of 8 days or longer.³²

12% of those who die in hospital will have been admitted from a care home.³³

Over 200,000 emergency admissions end in death per annum. This compares with 24,000 planned admissions which end in death. The 24,000 planned admissions ending in death account for around 500,000 bed days. The length of stay for most of these individuals is 8+ days.³⁴

The 86% of all admissions in the last year of life (106,000) which are emergency admissions have an average length of stay of 27 days (cancer 24 days, stroke 30 days) and account for 2.8 million bed days.³⁵

While it has been argued that hospital death rates in older people should be higher, because they are more likely to have multiple and complex health issues, this is not necessarily the case. A study comparing place of death in New York and London found that older people with cancer were more likely to die in hospital and less likely to die at home in London. This was not accounted for by differences in symptoms or family structure (such as living alone). Instead, it seemed to be largely due to more intensive home support provided by Medicare in the US, which allowed more older people in New York to die at home.³⁶

Pros

Hospitals provide better access to necessary medical diagnosis and care, and 24-hour care by professionals. For some people, this is the most appropriate place to be.³⁷

Cons

For many people the last hospital admission before death may have been preventable.³⁸ There is a risk of both over- and under-treatment.³⁹ “The reasonable expectation that an older person or their family may have of dignified, pain-free end of life care, in clean surroundings in hospital, is not being fulfilled”.⁴⁰

Hospital staff can be overly focused on curative treatments within hospitals, and a lack of resources means that good care is not always provided. There is also some uncertainty over the roles of palliative care providers in hospitals.⁴¹

Care Home

Many older people who move to care homes acknowledge these as a last resting place before death.⁴² However, this is the second least-preferred place to die.⁴³ It could be that this is because people do not wish to go into care homes in the first place.

Care home deaths increase with age, from 7% of people aged 65-74 to 34% of people 85+.⁴⁴

With increasing numbers of people living alone towards the end of life and with a complex condition and comorbidities, more may need to be cared for in care homes.⁴⁵ It is therefore important to understand why people do not wish to die in these places and what improvements people would like to see made to these settings to provide them with appropriate end of life care. An example might be the development of home and hospice-like environments within care homes.⁴⁶

Pros

Access to professional care staff 24 hours per day; can be the familiar, 'usual place of residence'; less medicalised environment than a hospital.

Cons

People over 65 in care homes have a poorer experience with regards to dignity and respect at the end of life compared with other age groups⁴⁷.

Hospice

People's second-highest rated preferred place of death is a hospice. And as people age, their preference for a hospice as a place to die increases, from 28% of those aged 55-64, to 37% of the 65-74 age group and 42% of people 75 and over.⁴⁸

However, only 5% of older people die in a hospice, falling from 9% of 65-74 year olds to only 2% of people 85+ (see Fig X).⁴⁹

More research is needed, but the problems appear to be:⁵⁰

- Not enough hospice spaces
- Time limit to care, which may be too short for many older people
- Too few referrals from community services and hospitals

Health and social care professionals

Physicians, nurses, and other health professionals often do not have sufficient training to meet the demands of end of life care – of the patient, or their families. They also often find this work very stressful and emotionally taxing.⁵¹

However, they do have to deal with deaths. For example, the average GP cares for around 20 people who die each year with the following causes:⁵²

- Frailty/Comorbidity/Dementia: (average 8 deaths)
- Cancer: average 5 deaths
- Organ failure: average 5-6 deaths
- Sudden unexpected death: average 1-2 patients

Clinicians can be unsure how to discuss the uncertain prognosis and risk of sudden death, fearing causing premature alarm and destroying hope.⁵³ For example, conversations between people with heart failure and healthcare professionals largely focus on disease management, and end of life care is rarely discussed.

In addition, many practitioners are reluctant to use strong pain medication (such as opiates), or are not qualified to do so, or do not have sufficient training in using delivery devices (such as syringe drivers). This leads to more hospitalisations for pain control for those nearing end of life.⁵⁴

Many of these issues exist for social care practitioners as well, even though they may expect to work more with people who are dying. One major issue is the lack of support and training for these professionals, for example in detecting signs that warrant medical attention.⁵⁵

Informal carers (family and friends)

The needs of caregivers need to be considered; the caring burden is physical, mental, emotional, and financial.⁵⁶ Also, as most caregivers are spouses, they are often older themselves, with their own health issues.⁵⁷

Family, especially spouses, have to cope with many issues which grow and intensify over time including 'pre-death grief', increasingly physical aspects of care, and increasing levels of decision-making which may be compounded by lack of knowledge and experience, and poor communication with professionals. They often fear discussing end of life issues 'prematurely', leading to a tendency for 'active' interventions such as hospital admission, antibiotics and other treatments which have little use or may be against the older person's wishes.

Changes in the nature of the relationship between the caregiver and the person nearing the end of life can cause high levels of anxiety and stress over a long period of time.^{58 59 60}

Caregivers need and should get a lot of support throughout caring for someone at the end of life, and beyond through bereavement.

Costs

A study with health and social care practitioners highlighted funding as a major issue around poor end of life care.⁶¹ They felt that the two or more competing budgets around health and social care leads to chaos and 'cost-shunting' between health and social care teams, causing delays, confusion, and poor care. In addition, the complexities of various means and non-means testing, with differing levels of eligibility and awards not only between local authorities, but within them as well.

Other studies have given some evidence across all age groups that higher social care costs at the end of life tend to be associated with lower inpatient costs. While a direct causal link has not been proven, it does suggest that reducing local authority-funded social care might increase demand on hospital services.⁶²

It is not possible to examine here all the various claims and estimates of the benefits of prevention (or the extra costs of doing nothing), but an example would be a recent estimate that, if all people who die in hospital stayed only a maximum of eight days, then the total estimated cost to commissioners would be lower by approximately £357million per year.⁶³

The estimated total cost of acute admissions ending in death in 2010-11 was over £520m. In England a 10% reduction in the number of hospital admissions ending in death could potentially result in a saving of £52m.⁶⁴

Taking a midpoint of the estimated inpatient end of life care costs (£3,065.50) and community-based end of life care costs (£2,107.50), there is an estimated potential net saving of £958 per person who dies in the community (assuming they do not need expensive medical equipment to be provided in the home or care home).⁶⁵

However, any reduction in hospital bed days must be based on clinical need, quality of care and individuals' preferences.

Also, reducing time and costs in hospital does shift some costs to the community, raising the question of who would pay for it.⁶⁶ Importantly, dying people should not be discharged to the community with little or no support. Having medical equipment and care support in the home,

for example, would be very expensive for people to bear if the local authority will not pay for it. This would further limit the choice of a home death to people who could afford the expense.

Advance Care Plans

An Advance Care Plan (ACP) is a documented plan covering all aspects of a patient's care as they approach the end of life, including information about the illness and prognosis, the wishes of the patient, family, and other relevant carers.⁶⁷ A trusted person can be appointed to make decisions through a Lasting Power of Attorney legal document.

A specific subset of the ACP regards medical treatments: **Advance Directives** (Advance Decisions, Living Wills). This is a statement explaining what medical treatment the individual would not want in the future, should that individual 'lack capacity' as defined by the Mental Capacity Act 2005. An Advance Decision or Living Will is legally binding.⁶⁸

An Advance Decision enables an individual to think about what they would like to happen to them in the event that they lose the capacity to make or communicate decisions about their care. Examples of such decisions include:

- The use of intravenous fluids and parenteral nutrition.
- The use of cardiopulmonary resuscitation.
- The use of life-saving treatment (whether existing or yet to be developed) in specific illnesses where capacity or consent may be impaired - for example, brain damage, perhaps from stroke, head injury or dementia.
- Specific procedures such as blood transfusion for a Jehovah's Witness.

Even if an ACP or Advance Decision is not immediately issued, the topic may motivate the individual to discuss future arrangements with their doctor, family and friends.

Only five per cent of all ages report having a living will or advance care plan, from 1% of 18-34-year olds to 12% of people 75+.⁶⁹

An analysis of the British Social Attitudes survey⁷⁰ found that 70 per cent of respondents say they feel comfortable talking about death, while only 13 per cent say they feel uncomfortable doing so. However, only 31% actually had spoken to someone about their wishes at the end of life, and only 12 per cent of respondents have ever discussed with anyone their end of life wishes relating to their preferred place to die.

The main reason respondents provided for not discussing any of these issues was feeling that death is a long way off. Even among those aged 75+, the proportion of those who have not discussed any aspects of their deaths and gave this reason is 23 per cent. The main reason people in this age group gave was 'people don't want to talk to me about my death' (28%).

Family relationships often affect whether or not an ACP will be drawn up; for example, older parents with difficult relationships with their adult children are much less likely to complete an ACP; whereas marital satisfaction is positively associated with completion of both advance directives and discussions.⁷¹

Pros

- People with ACPs or Advance Decisions will be more likely to experience the type of care prior to death that they would prefer, with plans acknowledged by medical and social care staff, family, and other informal carers.

For example, of people receiving hospice care who have engaged in advance care planning, only 10% die in hospital compared to 26% of those who have not engaged in ACP. The home death rate for people receiving hospice care with ACP is 40%, compared to 23% for those who have not engaged in ACP.⁷²

Cons

- The majority of people haven't discussed these issues with family and do not have an ACP or Advance Directive.
- Health care professionals find it difficult to discuss end of life issues and death with patients.
- Some older people do not want to consider death as a near outcome and prefer not to participate in discussions for ACPs.⁷³

Mental capacity

An issue that could prompt ACP discussions is a decline in mental capacity, such as through dementia or delirium.

The Mental Capacity Act (MCA 2005)⁷⁴ governs decision-making on behalf of adults who lack the capacity to make some or all decisions for themselves. The Act came into force during 2007.

The Ministry of Justice website states:

"the underlying philosophy of the MCA is to ensure that those who lack capacity are empowered to make as many decisions for themselves as possible and that any decision made, or action taken, on their behalf is made in their best interests."⁷⁵

Assisted dying

When a person's health has deteriorated to a degree that they feel they are constantly suffering, they may wish to have a doctor (or family member/friend) help them end their life. However, in England, participating in euthanasia (deliberately ending someone's life to end suffering) and assisting a suicide attempt, either actively (providing assistance and/or means to end life) or passively (allowing it to happen), are against the law.⁷⁶

Instead, the NHS encourages people to use other methods to retain control over the process of dying, such as:⁷⁷

- Refusing treatment (such as chemotherapy)
- Do not resuscitate orders (for CPR)
- Withdrawing life-sustaining treatments, such as nutrition, hydration and/or ventilation
- Palliative sedation (administering medication in high enough doses that the person is unconscious and unaware of pain)

The patient needs to be either 'mentally capable' of making these decisions, or have their wishes set out in an ACP or Advance Decision. Otherwise, others (such as family) may be asked to make decisions regarding these options.

There are many arguments both for and against assisted dying. Some say that people should have the right to choose when to die, and that the 'alternatives' above are simply cloaked methods of assisting death but in a prolonged manner, potentially causing unnecessary suffering.

Very limited research has shown that a small number of doctors admit to taking action to hasten death and carry out euthanasia when they consider it to be in the best interests of their patients;^{78 79} the worry is that this is unregulated because it is illegal.

Others argue that if palliative care is done correctly, there need not be any suffering or hastening of death. Furthermore, there are worries that if assisted death becomes legal, the quality of palliative care will decline.⁸⁰ There are also fears that vulnerable people will be targeted and 'encouraged' to end their lives.

Inequalities

The following factors have been shown to affect the quality of end of life care for older people:

Age

The Review of the Liverpool Care Pathway, as one model of end of life care (described in more detail later), found evidence of age discrimination against older people. Old age is sometimes taken as a proxy for lack of mental capacity in patients who are dying, and is also used to justify withholding treatment or care.⁸¹

As mentioned earlier, palliative care is often difficult for older people to access; instead, it tends to be reserved for younger people, usually those with cancer, partly because impending death is more easily recognised in this group.⁸²

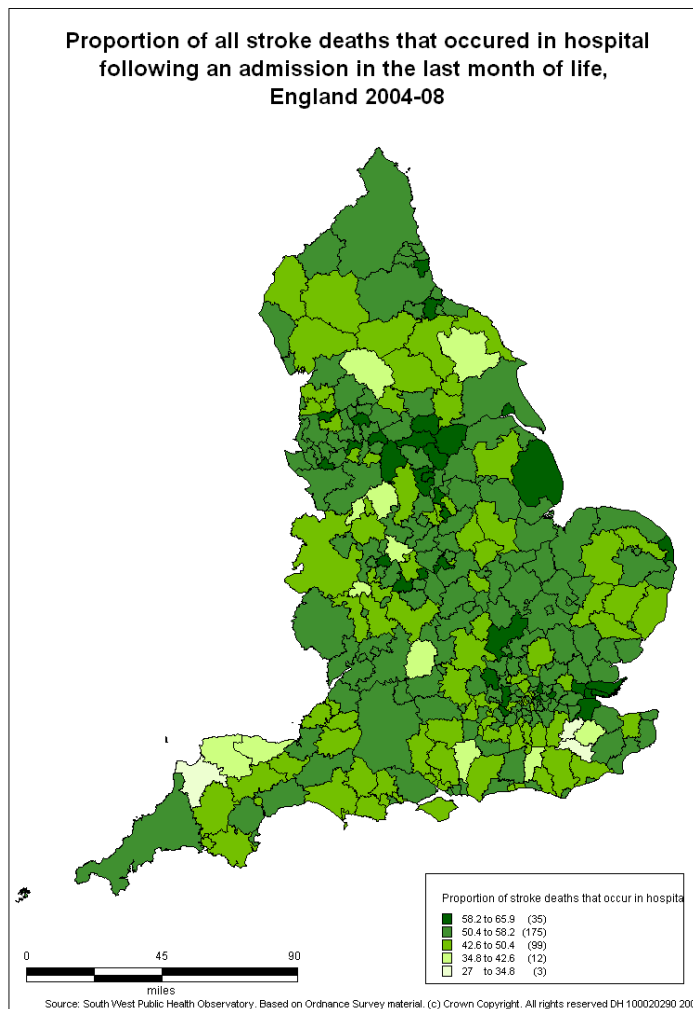
It is also noteworthy that hospice care decreases as age increases. Even though hospices are the second most preferred place to die (42% of people over 75)⁸³ only 5% of older people die in a hospice, falling from 9% of 65-74 year olds to only 2% of people 85+.⁸⁴

Locality

Dying in your preferred place varies depending on where you live. Regions where local preferences are likely to be more often met are the West Midlands (for those wishing to die at home) and the North West (for those wishing to die in a hospice); however, even in these regions there is still a large gap between preferences and reality.⁸⁵

The largest gap between local preferences and place of death is in the North East for those wishing to die at home, in the East of England for those wishing to die in a hospice.⁸⁶

Figure 6: Geographic variation in deaths in hospital; example: strokes



More can be found at http://www.endoflifecare-intelligence.org.uk/profiles/2/Place_of_Death/atlas.html

Physicians/nurses

Physician age, race, religion, attitude to risk, and personality factors have been associated with end of life care decisions⁸⁷. While sometimes this may be unavoidable or even appropriate, such as when the patient's wishes are unknown, and could never be entirely eliminated, it is potentially an ethical problem. Some strategies to reduce the 'physician roster lottery' are below in the 'Solutions' section.

Ethnicity

People from minority ethnic and/or religious groups potentially have additional challenges when dealing with end of life issues. For example, different values and expectations (such as the best place to die, gender and care, and the role of family in care and decisions), attitudes to death, responsibility, and medical treatment, not to mention complications arising from language barriers.⁸⁸ These are exacerbated by the low numbers of ethnic minority care workers and nurses.⁸⁹

There is also quite a lot of variation in where people die when ethnicity is factored in. For example, Pakistani and Bangladeshi elders are far more likely than white Britons to die in

hospital, and far less likely to die in a care home or hospice. It is not understood why this is the case.

Figure 7: Where people die

	UNDER 65						65 or older					
	Hospital	Home	Care home (nursing or residential)	Hospice	Other	Total	Hospital	Home	Care home	Hospice	Other	Total
British (White)	56.3	25.3	2.5	12.9	3.0	100.0	62.4	14.3	17.2	5.2	1.0	100.0
Irish (White)	56.1	25.6	2.2	12.9	3.3	100.0	62.1	17.1	12.2	7.2	1.3	100.0
Any other White background	60.0	21.7	2.1	12.9	3.4	100.0	63.7	14.3	15.4	5.3	1.3	100.0
White and Black Caribbean (Mixed)	66.2	19.2	1.4	9.6	3.6	100.0	63.3	17.5	10.9	7.4	1.0	100.0
White and Black African (Mixed)	69.6	15.7	1.3	11.0	2.3	100.0	67.3	14.6	7.5	9.7	0.9	100.0
White and Asian (Mixed)	75.9	12.8	0.9	7.9	2.5	100.0	64.8	14.1	14.5	5.3	1.4	100.0
Any other Mixed background	68.5	16.2	1.3	10.3	3.7	100.0	66.3	13.1	13.0	6.4	1.1	100.0
Indian (Asian or Asian British)	75.1	16.3	1.0	5.7	1.9	100.0	76.8	14.9	4.6	2.6	1.0	100.0
Pakistani (Asian or Asian British)	80.8	12.8	0.4	4.2	1.8	100.0	76.4	18.6	1.5	2.0	1.5	100.0
Bangladeshi (Asian or Asian British)	78.8	14.1	0.3	5.0	1.8	100.0	78.2	16.0	1.9	3.1	0.8	100.0
Any other Asian background	74.3	13.1	1.9	8.3	2.4	100.0	74.9	14.8	5.2	4.2	0.9	100.0
Caribbean (Black or Black British)	65.7	17.9	1.6	12.0	2.7	100.0	65.6	16.5	10.2	6.9	0.8	100.0
African (Black or Black British)	76.6	10.9	1.6	8.9	2.1	100.0	67.5	14.0	10.5	7.1	1.0	100.0
Any other Black background	70.4	14.5	2.1	10.0	3.0	100.0	67.0	16.1	10.0	5.7	1.2	100.0
Chinese (other ethnic group)	63.5	16.8	1.7	16.8	1.2	100.0	69.1	12.2	10.4	7.4	0.9	100.0
Any other ethnic group	68.8	16.9	1.8	9.9	2.7	100.0	67.1	14.1	12.9	5.1	0.9	100.0

Source: *Linked Hospital Episode Statistics - Office for National Statistics mortality dataset*⁹⁰

4 What are the main interventions?

Current policy and practice guidance espouses advanced planning, good communication and choice around place of care and death, appropriate symptom control and referral to specialist palliative services. However, older people experience a lack of advance planning, more repeated hospital admissions, and lower access to specialist palliative care than their younger counterparts.^{91 92}

There is growing evidence that providing palliative care, plus coordinated care across specialists and advanced planning, gives more positive outcomes to patients and caregivers/families.⁹³

Guidance

There already exist several well-researched pieces of guidance for providers and practitioners of end of life treatment, care and services. These set out good practice including identifying people at the end of life, communicating with patients and carers, coordinating care across organisations, making decisions on treatment, and education and training.

Examples include:

*Liverpool Care Pathway (LCP) for the Dying Patient*⁹⁴

The LCP is a framework for guiding and managing treatment and care in the last days and hours of a patient's life. It requires senior clinical decision making, communication, a management plan and regular reassessment.

The LCP was developed by the Royal Liverpool & Broadgreen University Hospitals NHS Trust and the Marie Curie Palliative Care Institute Liverpool, with the intention of replicating quality hospice care in the hospital setting.⁹⁵ It is recognised⁹⁶ as a model of good practice, and aims to support clinical judgement through consideration of the person's physical,

psychological, social, and spiritual needs. It recommends communication, care, and compassion from all healthcare workers for the individual and their family.

However, the LCP has become the centre of controversy following claims of inappropriate use: these include doctors failing to inform families that their relatives have been put on the pathway, misuse by hospitals receiving financial payments for using it, patients put on the pathway when they are not in the last days or hours of life, sometimes for weeks without follow-up.⁹⁷ An independent review was ordered by government which found that, when properly used, the LCP works well. However, it recommended that, because of evidence of inappropriate use, the LCP should be phased out over the next year, and replaced with individualised care plans. The review also recommended that a single, named physician should be assigned to and held accountable for every person at the end of life, that age discrimination should cease, funding should be available to make palliative care accessible at all times, financial incentives for using the LCP should cease, and clinicians should be better trained in end of life issues and communication.⁹⁸

Gold Standards Framework⁹⁹

GSF is a systematic, evidence-based end of life care accredited training programme for front line staff.

It is delivered by the National Gold Standards Framework (GSF) Centre in End of Life Care, the national training and coordinating centre for all GSF programmes, enabling generalist frontline staff to provide a gold standard of care for people nearing the end of life.

End of Life Care Strategy 2008 (Department of Health)¹⁰⁰

The End of Life Care Strategy aims to improve the provision of care for all adults at the end of life, and their families and carers.

The Strategy covers all levels of health care management to general practice, and sets out guidance for: identifying people at the end of life, planning care, coordinating health and social care at all levels, delivering high quality care, managing the person's last days, and supporting family and carers.

It also recommends education and training for all levels of practitioner delivering health and social care, gathering evidence and research to further best practice, and improve funding for end of life care. The Fourth Annual Report outlines progress on these recommendations.¹⁰¹

Quality Markers and Measures for End of Life Care (DH, 2009)¹⁰²

These Quality Markers were designed for commissioners and providers, to accompany the DH's End of Life Care Strategy. There are markers for commissioners, primary care, acute and primary hospitals, care homes, palliative care facilities, community services, ambulance services, and out of hours services. The markers encourage communication across all of these sectors.

Quality Markers include, for example: ensuring that patients nearing the end of life are identified, a plan is developed for them with their input and wishes, care is coordinated across health and social services, plans and treatments are recorded, and quality monitoring takes place.

General Medical Council guidance: Treatment and care towards the end of life: good practice in decision making (2010)¹⁰³

This guidance for doctors from the General Medical Council provides a framework for good practice when providing treatment and care for patients who are reaching the end of their lives.

The guide defines 'end of life' as within 12 months of death. It covers not only treatment and decision-making, but including communicating with patients and families, and recommends training to keeps skills and knowledge up to date.

NICE End of life care for adults guidance (QS13)¹⁰⁴

This National Institute for Clinical Excellence quality standard defines clinical best practice within this topic area. It provides specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care.

This quality standard "covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. This includes adults who die suddenly or after a very brief illness. The quality standard does not cover condition-specific management and care, clinical management of specific physical symptoms or emergency planning and mass casualty incidents."

Find your 1%¹⁰⁵

The Find your 1% campaign aims to support GPs and other health and social care staff in identifying the 1% of people who are likely to be in their last 12 months of life, in order to talk about, plan for and meet their end of life care needs and preferences.

By identifying people who are in their last year of life and talking to them about their preferences and wishes, GPs can ensure their patients are more likely to receive high quality end of life care, have fewer emergency admissions to hospital and have a good death in the place of their choosing.

Advance Care Plans and Directives

Encourage take-up of Advance Care Plans and Advance Directives.¹⁰⁶ These support better planning and care that reflects individual preferences. These could also reduce health care costs by avoiding unwanted or non-beneficial medical intervention at end of life.

Palliative care

Alongside policy changes and service developments to help prevent avoidable hospital admissions, it is crucial to secure good palliative care for the large number of older people who die in hospitals. Mobile hospital palliative care teams are key champions of good practices and care across hospital wards, helping to identify people who need palliative care and to ensure a safe return home if they wish.¹⁰⁷ Concerns with the lack of peacefulness in hospital can in part be addressed by the existence of wards of dedicated palliative care in quieter and family-friendly areas within hospitals.¹⁰⁸ Palliative care also needs to be available in evenings, on weekends, and during bank holidays.¹⁰⁹

Education

Professionals, people receiving care, informal carers, and the general public need to be educated about palliative care and end of life issues.¹¹⁰

Talking about death and end of life issues needs to become more public and normalised.¹¹¹

Communication between patients, families, and care professionals

When family members have good communication with health/care professionals and understand the patient's condition and prognosis, they are less likely to opt for unnecessary interventions and instead focus on comfort.¹¹³

Doctors and nurses need to be trained to discuss end of life issues as a regular, normal part of consultations.¹¹⁴ As part of this, training should include communication about patients' fears about death and dying, wishes for control, and involving family/other care-givers.¹¹⁵

Policy

Age UK's policy in relation to end of life care is underpinned by the following principles:

- Everyone has the right to expect services and support that helps to achieve a good death and offers choice in how they are cared for in their final months and days.
- Diagnosis, place of residence, care setting or individual circumstances should not act as a barrier to receiving high quality end of life care.

All of the policy proposals below can be summarised as: all health and care staff need training in the treatment and care of older people at the end of life; communication among organisations/professionals and between professionals and patients and carers is paramount; care needs to be coordinated across all organisational boundaries (including into the patient's home); and advanced planning for end of life should be encouraged more widely.

Public Policy Proposals

- GPs should work closely with Clinical Commissioning Groups (CCGs) in coordinating end of life care in the community. CCGs should drive take up of existing good practice such as the Gold Standards Framework and the *Find your 1%* toolkits, particularly the elements that encourage and support advance care planning.
- The government, health professional bodies and commissioners should systematically incorporate end of life care into the wider narrative on multiple morbidity and frailty. This should include establishing and disseminating a stronger evidence base on the progression of poor health in later life and living with multiple conditions.
- All health and wellbeing boards should have a strategy on end of life care. This must incorporate the promotion of long-term planning and ensuring all relevant health and care services merge seamlessly with palliative care pathways.

- As part of this, health and wellbeing boards should take a leading role in formally incorporating end of life care into social care planning and delivery.
- End of life support commissioned by CCGs should include comprehensive support for care home residents.
- Pre-registration training of all health and social care professionals should include sufficient time devoted to palliative care and the needs of people in late old age. Professionals should be expected to keep up to date with these issues throughout their careers and have the support to do so.
- There should be an investment in new approaches to advance care planning and talking about end of life care. Health and care services should explore how to use key transition points to promote these conversations e.g. changes in living circumstances.

The World Health Organisation recommends:¹¹⁶

- Addressing the need for palliative and primary care clinicians to receive training in the health of older people and to know about syndromes affecting older people that are not typically included in palliative care textbooks or terminal diseases, such as urinary incontinence and falls;
- better knowledge about the age-related changes of the pharmacokinetics of opiates for pain management and the polypharmacy (more drugs are prescribed than clinically indicated or there are too many to take) associated with comorbidity;
- a holistic approach by health professionals to explore any problems that may reduce people's quality of life, not just those directly related to the life-limiting disease;
- addressing the need for palliative physicians to improve their familiarity with long-term care, such as the administrative and clinical issues associated with older people living and dying in care homes.

Improving care for older people in hospitals

Recommendations to improve end-of-life care in hospitals include:¹¹⁷ educating staff members, identifying and assessing the people who need care, implementing care pathways and ensuring access to specialist palliative care teams, and coordination between specialists, including geriatricians, oncologists, cardiologists, palliative care clinicians, pharmacists, psychologists, social workers, dieticians, nursing staff, speech therapists and chaplains, at different stages of the illness.

Improving palliative care for older people living in nursing and residential care homes

Specialist and generalist palliative care should be available for all residents. Residents often have multiple health conditions, and there are high levels of impaired cognition, sight and hearing. Many residents experience pain, which is often not well treated and sometimes not treated at all. Care home staff need to be trained and competent in recognising and dealing with these issues.¹¹⁸

Improving palliative care for older people at home

To increase high-quality care at home until the end of life, services and policy-makers should develop initiatives that address important issues such as providing intensive home support, support for the family and assessing and addressing risk factors.¹¹⁹

The World Health Organisation recommends that health professionals need to do the following:¹²⁰

1. Ensure they are adequately trained and up to date in both geriatrics and the palliative care of older people, including assessing and treating pain and other symptoms, communication skills and coordination of care.
2. Measure the outcomes of their routine care regularly, including for older people.
3. Ensure that older people with palliative care needs are regarded as individuals, that their right to make decisions about their health and social care is respected and that they receive the unbiased information they need without experiencing discrimination because of their age.
4. Ensure that their organizations work in coordination and collaboration with other statutory, private or voluntary organizations that may provide help or services for older people needing palliative care.
5. Participate in research, education and auditing that seek to improve palliative care.

Figure 6: Strategies for reducing physician-related variability in ELDM¹²¹

Strategy	Advantages	Disadvantages
Guidelines	“Process” guidelines may help promote a consistent approach	Difficulty in reaching agreement/consensus; problems with vagueness or arbitrariness
Advance care planning/patient decision aids	Improve knowledge and communication of patient values	May reflect physician values; only helpful for patients who have undertaken advance planning
Practice audit/feedback	May improve awareness of own practice in comparison with others	May not be effective in the absence of defined best practice
Consensus/collaboration	Less variation where there is team-based practice; ethics consultation may reduce use of life-sustaining treatments of little benefit	Differences between teams/units may persist; impractical to involve in every case of ELDM

5 What can Age UK/Third Sector organisations do?

It is as yet unclear what practical steps the national Age UK and third sector organisations should now take, but a recent policy paper¹²² makes the following recommendations:

- Incorporate end of life care into all policy on long-term conditions and integration.
- Promote evidence on healthcare savings through use of specialist and coordinated care at end of life.
- Promote end of life issues amongst patient and public involvement (PPI) channels e.g. GP Patient Participation Groups.
- Collaborate with other organisations on work to improve identification of end of life needs.
- Promote advance care planning through work on co-morbidities and frailty (in parallel with work on improving communication around death and dying).
- Promote the use of advance care planning at key transition points in older people’s care (in collaboration with older people).

- Work with sector partners to promote this issue nationally, e.g. National Council for Palliative Care
- Promote best practice e.g. My Home Life.
- Call on Government to build wider audit of health care quality in care homes
- Try to influence medical education of these issues.
- Collaborate with Dying Matters on public facing material.
- Support enhanced shared decision-making at the end of life.
- Review organisational services materials to examine where appropriate information can be included in end of life and advance care planning.

6. What are local Age UKs doing?

Quite a few local Age UKs are providing services for people at the end of life and their carers.

While a comprehensive survey of Age UKs has not been carried out, examples of services are:

- Bereavement Counselling service;
- support for older Lesbian, Gay, Bisexual and Transgender people;
- Hospital Aftercare Service for people in last few months of life;
- support, information, and signposting of services for people at end of life and their carers; and
- befriending support.

One comprehensive example is from Age UK Northamptonshire's End of Life Care Service (Extra Help Service).

NHS Northamptonshire and Nene Commissioning commissioned Primecare, a private healthcare provider, in partnership with Age UK Northamptonshire to deliver a three year End of Life Care Service in the county with the aim to:

- Increase the proportion of all deaths that occur at home by 9.34%
- Reduce the rate of hospital deaths in the county by 9.7% by 2013
- Improve patient choice at end of life

Older people and their carers, in the last days or weeks of life, are provided with a range of high quality home care services to enable them to die with dignity in their own home. The service allows people to remain in their communities and prevents unnecessary admission to hospital or institutional care. On average each month they receive around 58 new referrals, of these they are able to accept 35 and approximately 18 people die in their own home. (These figures purely relate to Age UK Northamptonshire services – Primecare have their own statistics).

This is an Enhanced Community Service to meet the needs of both individual patients at the end of their lives and their carers.

- Age UK Northamptonshire's part of the service is 24 hours, 365 days a year
- Accessible by any health care professional (GP, District Nurse, hospice, acute hospital, community beds) via the Co-ordination Centre for End of Life care

- Provides day and night sitters (and other care packages as required) to provide low level support for patients and carers, which may be pre-booked but may also be unplanned and therefore require an urgent response. This includes:
 - Sensitive, appropriate response to the needs of patients/carer;
 - Maintaining the safety and comfort of the person receiving care;
 - Undertaking personal and domestic care tasks as required; and
 - Undertaking tasks to support the patient's carer.

Where the low level End of Life support has been provided to married or co-habiting couples, support continues to be provided after the death of the client.

A Rapid Response service manages any unexpected deterioration in the patient or carer situation, which would otherwise lead to admission into hospital at the end of life. Age UK Northamptonshire aims to keep older people in their own homes.

Supporting people at End of Life also involves accompanying patients or carers to GP and hospital appointments, ensuring that food, medication and other essentials are available, and supporting carers by helping to re-establish the infrastructure of their lives, including social networks and mechanisms to cope with their dependents condition and circumstances.

Feedback, including interviews with clients for a DVD, has been overwhelmingly positive. Relatives, friends and carers are fulsome in their praise for the service and the words 'professional', 'caring', 'kind', 'wonderful' appears on so many cards and letters. They speak of the fact that their loved ones were able to die with dignity in their own homes which would simply not have been possible without the team. Staff turnover has been extremely low, with many of the same staff currently working who began three years ago.

The service provides 550 hours per week low level community support to patients at the end of life and is delivered by 22 part time care workers, each working an average of 25 hours per week. However, it is not enough to meet the needs of the community.

"The service took great efforts to set up, we had to learn so many new things, develop new policies and procedures, get CQC registration and run the gauntlet of the NHS toolkit. We were very much a partnership with our health and social care colleagues and Primecare but whereas they had a diverse range of managerial experts to call on for aspects of the service (e.g. medicine management, Clinical Governance, communications etc.), there were only two of us and it was a steep learning curve but well worth the effort and it helped our organisation grow in confidence about what we could achieve."

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References

- ¹ ComRes Opinion Poll for Dying Matters' 'No Dress Rehearsals', Aug 2011; as cited in 'What do we know now that we didn't know a year ago? New intelligence on end of life care in England.' National end of life care Intelligence Network. 2012 (reviewed 2013).
- ² QS13: Quality standard for end of life care for adults
- ³ The National Council for Palliative Care, <http://www.ncpc.org.uk/palliative-care-explained>
- ⁴ End of Life Care Strategy (2008) Department of Health
- ⁵ End of Life Care Strategy, Department of Health, 2008
- ⁶ End of Life Care Strategy (2008) Department of Health
- ⁷ More care, less pathway: a review of the Liverpool Care Pathway. Baroness Julia Neuberger and others. July 2013. Accessed 17 July 2013
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf
- ⁸ Ethical challenges in end of life care in a pluralist society. Presentation by Professor Julia Verne, National End of Life Care Intelligence Network. 2013
- ⁹ End of Life Care Strategy (2008) Department of Health
- ¹⁰ End of Life Care Strategy (2008) Department of Health
- ¹¹ ONS, *Mortality Statistics: Deaths Registered in 2010 (Series DR) Table 5, 2013*
- ¹² Variations in Place of Death England 2010 and End of Life Care Profiles, NEoLCIN
- ¹³ Variations in Place of Death England 2010 and End of Life Care Profiles, NEoLCIN
- ¹⁴ Weekly and monthly provisional figures on deaths registered in England and Wales; outline of reported deaths in 2013 to week ending 5th July, Public Health England, 2013
- ¹⁵ Palliative care for older people: better practices. WHO, 2011
- ¹⁶ Palliative care for older people: better practices. WHO, 2011
- ¹⁷ Palliative care for older people: better practices. WHO, 2011
- ¹⁸ Local preferences and place of death in regions within England 2010.' Gomes, B, Calazani, N, and Higginson, IJ. Cicely Saunders International. 2011.
- ¹⁹ PRISMA survey data, as published in 'Local preferences and place of death in regions within England 2010.' Gomes, B, Calazani, N, and Higginson, IJ. Cicely Saunders International. 2011
- ²⁰ *Local preferences and place of death in regions within England 2010.* Gomes, B, Calazani, N, and Higginson, IJ. Cicely Saunders International. 2011.
- ²¹ A time and a place: What people want at the end of life. Claudia Wood and Jo Salter of Demos, for Sue Ryder Hospice. 2013
<http://www.sueryder.org/About-us/Policies-and-campaigns/Our-campaigns/Dying-isnt-working/-/media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx>
- ²² PRISMA survey data, as published in 'Local preferences and place of death in regions within England 2010.' Gomes, B, Calazani, N, and Higginson, IJ. Cicely Saunders International. 2011
<http://www.csi.kcl.ac.uk/files/Local%20preferences%20and%20place%20of%20death%20in%20regions%20within%20England.pdf>
- ²³ PRISMA telephone survey of the general population aged 16 and over, 2010; As cited in 'What do we know now that we didn't know a year ago? New intelligence on end of life care in England.' National end of life care Intelligence Network. 2012 (reviewed 2013).
- ²⁴ Dying: Discussing and planning for end of life. Janet Shucksmith, Sarit Carlebach and Vicki Whittaker; British Social Attitudes 30, 2013
- ²⁵ A time and a place: What people want at the end of life. Claudia Wood and Jo Salter of Demos, for Sue Ryder Hospice. 2013
<http://www.sueryder.org/About-us/Policies-and-campaigns/Our-campaigns/Dying-isnt-working/-/media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx>
- ²⁶ End of life care. Seymour, J., Witherspoon, R, Gott, M., Ross, H., and Payne, S., with Owen, T. Help the Aged:Bristol, 2005
- ²⁷ A time and a place: What people want at the end of life. Claudia Wood and Jo Salter of Demos, for Sue Ryder Hospice. 2013
<http://www.sueryder.org/About-us/Policies-and-campaigns/Our-campaigns/Dying-isnt-working/-/media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx>

- ²⁸ End of life care. Seymour, J., Witherspoon, R, Gott, M., Ross, H., and Payne, S., with Owen, T. Help the Aged:Bristol, 2005
- ²⁹ English Housing Survey Household Report 2010-11 Annex Table 6.2, DCLG 2012
- ³⁰ *Local preferences and place of death in regions within England 2010*. Gomes, B, Calazani, N, and Higginson, IJ. Cicely Sounders International. 2011.
- ³¹ HES data – Deaths in hospital 2010
- ³² HES data – Deaths in hospital 2010
- ³³ ONS data – Deaths in hospital 2010
- ³⁴ QIPP and NeoLCiN data, as cited in 'What do we know now that we didn't know a year ago? New intelligence on end of life care in England.' National end of life care Intelligence Network. 2012 (reviewed 2013).
- ³⁵ QIPP and NeoLCiN data, as cited in 'What do we know now that we didn't know a year ago? New intelligence on end of life care in England.' National end of life care Intelligence Network. 2012 (reviewed 2013).
- ³⁶ *A tale of two cities: factors affecting place of cancer death in London and New York*. Decker SL, Higginson IJ. *European Journal of Public Health* 2007;17(3):285-290
- ³⁷ *How common are palliative care needs among older people who die in the emergency department?* Beynon T, Gomes B, Murtagh FE, Glucksman E, Parfitt A, Burman R, et al. *Emergency Medicine Journal* 2011;28(6):491-495.)
- ³⁸ *How common are palliative care needs among older people who die in the emergency department?* Beynon T, Gomes B, Murtagh FE, Glucksman E, Parfitt A, Burman R, et al. *Emergency Medicine Journal* 2011;28(6):491-495.)
- ³⁹ End of life care. Seymour, J., Witherspoon, R, Gott, M., Ross, H., and Payne, S., with Owen, T. Help the Aged:Bristol, 2005
- ⁴⁰ *Care and compassion?*, Parliamentary and health service ombudsman, 2011
- ⁴¹ Gardiner, C., et al, *Barriers to providing palliative care for older people in acute hospitals*, Age and Ageing, 2011
- ⁴² *Palliative care for older people: better practices*. WHO, 2011
- ⁴³ *Local preferences and place of death in regions within England 2010*. Gomes, B, Calazani, N, and Higginson, IJ. Cicely Sounders International. 2011.
- ⁴⁴ ONS *Deaths registered in England and Wales, 2011*
- ⁴⁵ *Palliative care for older people: best practices*. World Health Organization; 2011
- ⁴⁶ *Local preferences and place of death in regions within England 2010*. Gomes, B, Calazani, N, and Higginson, IJ. Cicely Sounders International. 2011
- ⁴⁷ First national VOICES survey of bereaved people: key findings report, Department of Health, 2012
- ⁴⁸ PRISMA survey data, as published in 'Local preferences and place of death in regions within England 2010.' Gomes, B, Calazani, N, and Higginson, IJ. Cicely Sounders International. 2011
- ⁴⁹ ONS *Deaths registered in England and Wales, 2011*
- ⁵⁰ *Local preferences and place of death in regions within England 2010*. Gomes, B, Calazani, N, and Higginson, IJ. Cicely Sounders International. 2011
- ⁵¹ 'Viewing in slow motion': patients', families', nurses' and doctors' perspectives on end-of-life care in critical care. Pattison N, Carr SM, Turnock C, Dolan S. *J Clin Nurs*. 2013 May;22(9-10):1442-54. doi: 10.1111/jocn.12095. Epub 2013 Mar 19.
- ⁵² Prognostic Indicator Guidance 4th Edition Sept 2011; as cited in 'What do we know now that we didn't know a year ago? New intelligence on end of life care in England.' National end of life care Intelligence Network. 2012 (reviewed 2013)
- ⁵³ End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis. S Barclay et al., *Br J Gen Pract* 2011; DOI: 10.3399/bjgp11X549018
- ⁵⁴ Ways and means. Paget, A and Wood, C. 2013. For Demos.http://www.demos.co.uk/files/Ways_and_Means_-_web.pdf?1371658165
- ⁵⁵ Ways and means. Paget, A and Wood, C. 2013. For Demos.http://www.demos.co.uk/files/Ways_and_Means_-_web.pdf?1371658165
- ⁵⁶ *Palliative care for older people: better practices*. WHO, 2011
- ⁵⁷ *Palliative care for older people: better practices*. WHO, 2011
- ⁵⁸ Approaching the end of life and dying with dementia in care homes: the accounts of family carers. Hennings, J, Froggatt, K, and Keady, J. *Reviews in Clinical Gerontology* 2010 20; 114–127
- ⁵⁹ *Palliative care for dementia—time to think again?* Crowther J, et al. *Q J Med* 2013; 106:491–494; doi:10.1093/qjmed/hct078

- ⁶⁰ 'Viewing in slow motion': patients', families', nurses' and doctors' perspectives on end-of-life care in critical care. Pattison N, Carr SM, Turnock C, Dolan S. *J Clin Nurs*. 2013 May;22(9-10):1442-54. doi: 10.1111/jocn.12095. Epub 2013 Mar 19.
- ⁶¹ Ways and means. Paget, A and Wood, C. 2013. For Demos.http://www.demos.co.uk/files/Ways_and_Means_-_web.pdf?1371658165
- ⁶² Understanding patterns of health and social care at the end of life, M Bardsley, T Georghiou, J Dixon. Nuffield Trust, 2012
- ⁶³ Ian Blunt Analysis of Hospital Cost data – Nuffield Trust unpublished; as cited in 'What do we know now that we didn't know a year ago? New intelligence on end of life care in England.' National end of life care Intelligence Network. 2012 (reviewed 2013).
- ⁶⁴ CMG42 Guide for commissioners on end of life care for adults. NICE, 2011; as cited in 'What do we know now that we didn't know a year ago? New intelligence on end of life care in England.' National end of life care Intelligence Network. 2012 (reviewed 2013).
- ⁶⁵ QIPP and NeolCiN data, as cited in 'What do we know now that we didn't know a year ago? New intelligence on end of life care in England.' National end of life care Intelligence Network. 2012 (reviewed 2013).
- ⁶⁶ QIPP and NeolCiN data, as cited in 'What do we know now that we didn't know a year ago? New intelligence on end of life care in England.' National end of life care Intelligence Network. 2012 (reviewed 2013)
- ⁶⁷ NHS Advance Care Planning Guide; accessed 28-06-13
http://www.endoflifecare.nhs.uk/assets/downloads/pubs_Advance_Care_Planning_guide.pdf
- ⁶⁸ From Patient.co.uk <http://www.patient.co.uk/doctor/advance-directives-living-wills>
- ⁶⁹ Dying: Discussing and planning for end of life. Janet Shucksmith, Sarit Carlebach and Vicki Whittaker; *British Social Attitudes* 30, 2013
- ⁷⁰ Dying: Discussing and planning for end of life. Janet Shucksmith, Sarit Carlebach and Vicki Whittaker; *British Social Attitudes* 30, 2013
- ⁷¹ End-of-Life Planning in a Family Context: Does Relationship Quality Affect Whether (and With Whom) Older Adults Plan? Carr D, Moorman SM, Boerner K. *J Gerontol B Psychol Sci Soc Sci*. 2013 Jul;68(4):586-92. doi: 10.1093/geronb/gbt034. Epub 2013 May 20.
- ⁷² NHS South West review of 960 records in last 2.5 years; as cited in 'What do we know now that we didn't know a year ago? New intelligence on end of life care in England.' National end of life care Intelligence Network. 2012 (reviewed 2013)
- ⁷³ Advance Care Planning in terminally ill and frail older persons. Piers, RD, et al. *Patient Education and Counseling* 90 (2013) 323–329
- ⁷⁴ <http://www.legislation.gov.uk/ukpga/2005/9/contents>
- ⁷⁵ <http://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act>
- ⁷⁶ <http://www.nhs.uk/Conditions/Euthanasiaandassistedsuicide/Pages/Introduction.aspx>
- ⁷⁷ <http://www.nhs.uk/Conditions/Euthanasiaandassistedsuicide/Pages/Alternatives.aspx>
- ⁷⁸ End-of-life decisions in the UK involving medical practitioners. Seale C (2009) *Palliative Medicine* 23: 198-204
- ⁷⁹ Hastening death in end-of-life care: A survey of doctors. Seale C (2009) *Social Science & Medicine* 69(11): 1659-66
- ⁸⁰ <http://www.nhs.uk/Conditions/Euthanasiaandassistedsuicide/Pages/Arguments.aspx>
- ⁸¹ More care, less pathway: a review of the Liverpool Care Pathway. Baroness Julia Neuberger and others. July 2013. Accessed 17 July 2013
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf
- ⁸² Palliative care for older people: better practices. WHO, 2011
- ⁸³ PRISMA survey data, as published in 'Local preferences and place of death in regions within England 2010.' Gomes, B, Calazani, N, and Higginson, IJ. Cicely Saunders International. 2011
- ⁸⁴ ONS *Deaths registered in England and Wales, 2011*
- ⁸⁵ *Local preferences and place of death in regions within England 2010*. Gomes, B, Calazani, N, and Higginson, IJ. Cicely Saunders International. 2011.
- ⁸⁶ *Local preferences and place of death in regions within England 2010*. Gomes, B, Calazani, N, and Higginson, IJ. Cicely Saunders International. 2011.
- ⁸⁷ The luck of the draw: physician-related variability in end-of-life decision-making in intensive care. Wilkinson, DJC, and Truong, RD. *Intensive Care Medicine*, June 2013, Volume 39, Issue 6, pp 1128-1132

- ⁸⁸ Ethical challenges in end of life care in a pluralist society. Verne, J. Presentation for National End of Life Care Intelligence Network
- ⁸⁹ Centre on Migration, Policy and Society (COMPAS) (2008)
- ⁹⁰ Health and Social Care Information Centre
- ⁹¹ The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review. Burt, J., & Raine, R. (2006). *Age and ageing*, 35, 469-476.
- ⁹² Dying in older age: end-of-life care. Seymour, J., Witherspoon, R., Gott, M., Ross, H., & Payne, S. (2005). Bristol: Policy Press.
- ⁹³ *Better palliative care for older people*. WHO, 2004
- ⁹⁴ <http://www.endoflifecare.nhs.uk/care-pathway/step-5-care-in-the-last-days-of-life/liverpool-care-pathway.aspx>
- ⁹⁵ More care, less pathway: a review of the Liverpool Care Pathway. Baroness Julia Neuberger and others. July 2013. Accessed 17 July 2013
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf
- ⁹⁶ Recognised in the End of Life Care Strategy 2008, Quality Markers and Measures for End of Life Care (DH, 2009), General Medical Council guidance (2010), and NICE quality standard for end of life care for adults (2011)
- ⁹⁷ <http://www.bbc.co.uk/news/health-23068424>
- ⁹⁸ More care, less pathway: a review of the Liverpool Care Pathway. Baroness Julia Neuberger and others. July 2013. Accessed 17 July 2013
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf
- ⁹⁹ <http://www.goldstandardsframework.org.uk/>
- ¹⁰⁰ http://www.cpa.org.uk/cpa/End_of_Life_Care_Strategy.pdf
- ¹⁰¹ <https://www.gov.uk/government/news/end-of-life-care-strategy-fourth-annual-report>
- ¹⁰² http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101684.pdf
- ¹⁰³ http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp
- ¹⁰⁴ <http://guidance.nice.org.uk/QS13>
- ¹⁰⁵ <http://www.endoflifecare.nhs.uk/care-pathway/step-1-discussions-as-the-end-of-life-approaches/find-your-1.aspx#sthash.eJQ7oRVh.dpuf>
- ¹⁰⁶ End-of-Life Care Issues: A Personal, Economic, Public Policy, and Public Health Crisis. Morhaim, DK, and Pollack, KM. *Am J Public Health*. 2013; 103:e–e10. doi:10.2105/AJPH.2013.301316
- ¹⁰⁷ *Do hospital-based palliative teams improve care for patients or families at the end of life?* Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AG, et al. *Journal of Pain & Symptom Management* 2002;23(2):96-106
- ¹⁰⁸ *Local preferences and place of death in regions within England 2010*. Gomes, B, Calazani, N, and Higginson, IJ. Cicely Saunders International. 2011.
- ¹⁰⁹ More care, less pathway: a review of the Liverpool Care Pathway. Baroness Julia Neuberger and others. July 2013. Accessed 17 July 2013
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf
- ¹¹⁰ *Palliative care for older people: better practices*. WHO, 2011
- ¹¹¹ *End-of-life care issues: A personal, economic, public policy, and public health crisis*. Morhaim, DK, and Pollack, KM. *Am J Public Health*. 2013; 103:e–e10. doi:10.2105/AJPH.2013.301316
- ¹¹² More care, less pathway: a review of the Liverpool Care Pathway. Baroness Julia Neuberger and others. July 2013. Accessed 17 July 2013
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf
- ¹¹³ Approaching the end of life and dying with dementia in care homes: the accounts of family carers. Hennings, J, Froggatt, K, and Keady, J. *Reviews in Clinical Gerontology* 2010 20; 114–127
- End-of-life care issues: A personal, economic, public policy, and public health crisis*. Morhaim, DK, and Pollack, KM. *Am J Public Health*. 2013; 103:e–e10. doi:10.2105/AJPH.2013.301316
- ¹¹⁵ Advance Care Planning in terminally ill and frail older persons. Piers, RD, et al. *Patient Education and Counselling* 90 (2013) 323–329
- ¹¹⁶ *Palliative care for older people: better practices*. WHO, 2011
- ¹¹⁷ *Palliative care for older people: better practices*. WHO, 2011

¹¹⁸ Palliative care for older people: better practices. WHO, 2011

¹¹⁹ Palliative care for older people: better practices. WHO, 2011

¹²⁰ Palliative care for older people: better practices. WHO, 2011

¹²¹ The luck of the draw: physician-related variability in end-of-life decision-making in intensive care. Wilkinson, DJC, and Truong, RD. Intensive Care Medicine, June 2013, Volume 39, Issue 6, pp 1128-1132

¹²² Policy recommendations for Age UK (unpublished), 2013