

# Equity in the provision of palliative and end of life care in the UK

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# Introduction

Every day of your life matters – from the first to the last.

When you're living with a terminal illness, you feel that more than ever.

The right care and support at the right time can make all the difference.

Whether it's terminal cancer or any other terminal illness, Marie Curie is here to help people get the most from the time they have left.

Marie Curie Nurses work night and day, in people's homes across the UK, providing hands-on care and vital emotional support. Our hospices offer specialist round-the-clock care.

And we support people throughout their illness by giving practical information, support from trained volunteers and being there when someone wants to talk.

Over the last 60 years, we've helped hundreds of thousands of families get care and support.

But our ageing population means more and more people are living with a terminal illness.

Carers say seven out of every 10 people with a terminal illness in the UK don't get all the care and support they need.\*

We don't think that's good enough. We think more has to be done.

We commissioned the Personal Social Services Research Unit (PSSRU, [pssru.ac.uk](http://pssru.ac.uk)) at the London School of Economics and Political Science (LSE) to undertake a review of evidence relating to inequities in palliative care.

A palliative approach to care is often recommended for people with a terminal illness who are approaching the end of their lives. This is the active, holistic care of people with advanced progressive illness. A palliative approach to care can be delivered by a wide range of personnel and in a wide range of settings, including hospices.

Palliative care is often the recommended form of care and support for people towards the end of an illness, when there are no treatments that will stop a particular disease's progression.

However, people living with a terminal illness may have episodes, over a number of years, where a palliative approach to care is the most appropriate response, as it covers physical, emotional and spiritual needs. Palliative care, or indeed hospice care, is not necessarily just for people who are likely to die in the near future – it can be relevant at any stage of a terminal illness.

People should be able to access high quality palliative and end of life care, regardless of factors like who they are, where they live or the conditions they have.

The LSE review is summarised below and the full report is available at [mariecurie.org.uk/change](http://mariecurie.org.uk/change). It shows how these factors in practice often play a big role in how people experience living and dying with a terminal illness.

These inequities must be removed from the system. Everyone in the UK who is living with a terminal illness deserves to get the right care and support, at the right time and in the right place.

\* Ipsos MORI survey of 1,067 UK carers aged 16-75

# If you have a terminal illness, you may find it more difficult to access the right care if you...

## 1. ...have a terminal condition other than cancer

The roots of the modern hospice and palliative care movements developed in response to the needs of people with cancer.

However, palliative care can benefit people with many different illnesses, including dementia, motor neurone disease, multiple sclerosis or chronic obstructive pulmonary disease (COPD - lung disease). It can also be of use at different stages of those illnesses.

Murtagh et al (2013) estimate that “between 69% and 82% of deaths in high income countries are likely to have preceding palliative care needs”.

We know that not everyone who has terminal cancer and would benefit from palliative care will get access to it. Walshe et al (2009) identified particular barriers for those with haematological cancer, including the tendency for more aggressive treatments to be used, which delay or replace referral to palliative care.

We also know that it can be even more difficult for people with other terminal illnesses to access palliative care (Grande et al, 2006; NCPC, 2014a, Harrison et al, 2012):

- 88% of people in England and Wales using palliative care inpatient services and around 75% of new referrals to both hospital support and day services have cancer. However cancer currently accounts for around 29% of deaths (NCPC, 2014b).
- Two-thirds of people with cancer who died were on the palliative care register compared with 20% of people with non-malignant conditions (Harrison et al, 2012).
- Just 20% of people diagnosed with dementia or organ failure (heart, lung, liver or kidney) either requested or were identified for specialist palliative care at the end of life in Scotland (Zheng et al, 2013).

We know that in each of the four nations of the UK the proportions of people dying from different terminal illnesses are broadly similar. As the LSE review shows:

*“In England and Wales, around 29% of deaths each year are due to cancer, 28% due to circulatory conditions and 15% due to respiratory illness (ONS, 2014a). In Scotland 30% of deaths are due to cancer, 28% due to circulatory conditions and 13% due to respiratory conditions (General Registrar Office for Scotland, 2013), and in Northern Ireland, 29% of deaths are due to cancer, 27% due to circulatory conditions and 14% due to respiratory disease.” (NISRA, 2013)*

New analysis undertaken for the LSE review shows that people with non-haematological cancer were more likely than people with other diagnoses to die at home. They were also more likely to get access to key support such as Marie Curie Nurses, other community-based nurses, spiritual and emotional care, hospice at home, rapid response services and care from a social worker or support worker.

Your illness doesn't just affect your access to palliative care. It can also affect your family's perceptions of the quality of care you received. The National Survey of Bereaved People (VOICES), 2013 in England found that 37.7% of bereaved relatives of people who died from cardiovascular disease rated the care their family member received as being excellent or outstanding. The figure was 50.5% for those who supported a family member with cancer (ONS, 2014).

The VOICES survey is important because it collates the views of recently bereaved relatives in England. It would be extremely useful for similar surveys to take place in Scotland, Wales and Northern Ireland so we can compare perceptions of experiences across the UK. We can then use this to ensure the right care is available for people with different terminal illnesses, regardless of where they are living or being cared for.

## 2. ...are 85 years of age or over

We have long known that there are significant differences in the proportion of people from different age groups using palliative care (Grande et al 2006). The LSE review makes clear that those who we might call 'the oldest old' – those who are 85 years old and over – are much less likely to access palliative care than younger people:

*“When mortality figures are compared to the proportions in receipt of palliative care, the levels of receipt for the oldest old (those aged 85 or over) appear disproportionately low.” (Dixon et al, 2015)*

The review looks at the latest available data for England, Wales and Northern Ireland to show that:

*“People aged 85 or over account for 39% of deaths (excluding deaths from external causes) but only 16.4% of people in this age group access specialist palliative care services (NCPC, 2014b), although this proportion has increased from 8.8% in 2000 (NCPC, 2014b) and 11% in 2012.” (NCPC, 2013)*

By comparison, the 25-64 age group accounts for 29% of those who use palliative care, but only 13% of deaths. The review concludes that:

*“Even in samples of people with cancer, older people have been found to access less palliative care.” (Burt et al, 2006)*

Walshe et al (2009) conclude that there is no evidence that the oldest old have different needs and preferences, so it could be these differences in access to palliative care can be explained by perceptions of older people and dying. Gott et al (2013) conclude that older people are:

*“commonly seen to have less need for specialist input as a consequence of death being ‘more expected’ and the view that older people will be more able to come to terms with a terminal diagnosis”. (Dixon et al, 2015)*

Gardiner et al (2011) suggest that different rates of access can be explained by a range of cultural and professional reasons:

*“The barriers to accessing palliative care for older people in hospitals are attitudinal barriers, lack of resources for both specialist and generalist palliative care, difficulties in switching from a curative or interventionist approach, and confusion over roles and responsibilities, in particular, a lack of clarity regarding the role of the geriatrician in providing palliative care.” (Dixon et al, 2015)*

### 3. ...are from a black, Asian or minority ethnic background

Research evidence suggests that there is poor care for people from black, Asian and minority ethnic (BAME) backgrounds, unmet cultural and religious needs and uncertainty and stress created for professionals (Calanzani et al., 2013).

Evidence on inequity in the provision of palliative care for people from BAME backgrounds is equivocal. However there is evidence that people from BAME backgrounds are less likely to experience high quality care in the last three months of life, overall and from care homes in particular.

A new multivariate analysis of data from the National Survey of Bereaved People in England (2013) sheds significant light on the experiences of people from BAME communities.

Respondents from BAME communities were less likely to report that they had received sufficient help and support to care for someone at home. They were also 26% less likely to rate overall care as 'outstanding' or 'excellent'. This varies according to where someone was cared for. For those who spent time in a care home, respondents from BAME communities were 55% less likely than those of white ethnicity to rate care as 'outstanding' or 'excellent' and half as likely to rate care in a hospice as 'outstanding' or 'excellent' as those of white ethnicity (Dixon et al, 2015).

It is important to note that the review's analysis also highlights some positive outcomes for BAME communities. It shows that people from BAME communities were equally likely to receive care from Marie Curie Nurses, social workers and hospice at home services. They are more likely to get some other services, including home help and meals on wheels (Dixon et al, 2015).

Clearly, we need stronger research to test which interventions and models of care actually improve access to and experiences of palliative care for people from BAME communities. Only then will we be able to respond positively to the needs and expectations of different communities, both now and in the future as demographic change means that more people from different BAME communities will need appropriate end of life care.

### 4 ...live in particular parts of the UK

A significant inequity identified by the review is the lack of universally available palliative care support for all those who need it. There are simply not the same levels of access to specialist palliative care services across all parts of England, Scotland, Wales and Northern Ireland. The relatively uneven spread of hospices across different parts of the country, as well as variations in the availability of 24/7 palliative care in hospitals, means that many people may be missing out simply because of where they live.

Gatrell and Wood's 2012 analysis of geographic variations in access to adult hospices in England and Wales suggests that:

*"Rural and more deprived areas were comparatively under-served compared to urban centres and more affluent areas."*

We also know there is considerable variation in levels of access to palliative care services in hospitals in England. Only 21% of hospital trusts in England have face-to-face palliative care services, seven days a week, and just 2% of sites provide 24/7 palliative care (Royal College of Physicians, 2014, National Care of the Dying Audit of Hospitals).

## 5. ...live in the most deprived areas of the country

Where you live, and the relative levels of deprivation in your area, can have a significant impact on how likely you are to access the right care and affect your family's views of the quality of care you receive.

The LSE's analysis of the VOICES survey shows that levels of deprivation have an impact on where people die. It found that people in the most deprived areas were more likely to die in hospital than at home. In particular, people who lived in the most deprived or second most deprived areas, compared to the least deprived areas (as measured using Index of Multiple Deprivation quintiles) were less likely (at the 99% significance level) to die at home rather than in hospital. Those living in the most deprived areas were 33% less likely to die at home and those in the second most deprived areas were 18% less likely. (Dixon et al, 2015)<sup>\*a</sup>

Campbell et al (2010), in a study of hospice at home referrals for people with cancer in Manchester, found significant differences in referral rates for people living different areas of the city:

*“Even though people had the same diagnosis, there were fewer referrals in areas with multiple and income deprivation.”*

A literature review on place of death for people with non-malignant conditions (Murtagh et al 2012) also found that “home deaths are associated with higher income households”.

The LSE review team's analysis of the VOICES survey data for England found that respondents in the most deprived areas were less likely to rate care received by their family member or friend in the last days and weeks of life as outstanding or excellent compared to those in the least deprived areas.

Respondents in the most deprived areas were also less likely to report that their family member had always been treated with dignity and respect than those in more affluent areas and less likely to feel that they had the right levels of support when caring for someone at home (Dixon et al, 2015).

It would be interesting to know whether this situation is replicated in Scotland, Wales and Northern Ireland, but we do not have the equivalent data.

## 6. ...are single or live alone

Whether you have a partner/spouse<sup>\*b</sup> or live alone can have a major impact on your experiences of end of life care.

The review found that having a spouse or partner had a clear protective effect (Dixon et al, 2015). Spouses/partners may act as advocates or coordinators, as well as carers, helping someone who is terminally ill to navigate their way through different services. Murtagh et al (2012) found that “having a carer was the single most important factor associated with home death, whereas living alone or being unmarried increased the likelihood of a hospital death”.

Fresh analysis of the VOICES Bereavement Survey data in England shows that having a partner/spouse<sup>\*b</sup> increases access to care. Data from 2013 shows that people who died without a partner or spouse “were far less likely to access a range of community-based services” (Dixon et al, 2015). Similarly those who responded to the National Survey of Bereaved People who were someone other than a spouse/partner were 52% less likely to report that they had “sufficient help and support from health and social services to be cared for at home” (Dixon et al, 2015).

<sup>\*a</sup> Based on odds ratios and controlling for age, sex, diagnosis, whether the decedent had a spouse or partner and ethnic background

<sup>\*b</sup> using the proxy of whether a questionnaire is completed for the deceased by a spouse or partner

Those with a spouse or partner\* were more likely to be perceived as having had excellent or outstanding overall care in the last months of life. These differences extended to care provided by GPs, care homes and from out-of-hours services (Dixon et al, 2015).

Finally, the families of those without a spouse or partner were more likely to perceive pain management as worse (Dixon et al, 2015).

Again, it would be helpful to establish whether this picture is replicated in Scotland, Wales and Northern Ireland.

We also need further research into the experiences of single people who have no partner and no carers living at home, but are supported by others such as adult offspring or other family members.

The LSE review shows that who you are, how old you are, where you live, the conditions you experience and whether you live alone all have the potential to impact on both your access to, and experiences of, different types of care for people living with a terminal illness.

\*using the proxy of whether a questionnaire is completed for the deceased by a spouse or partner

# What do we need to do?

We need to understand what has to change to ensure that everyone can access the right care.

The first step must be to acknowledge that people with all terminal illnesses can benefit from access to palliative and end of life care. We know that good palliative and end of life care can make a significant difference to those who have access to it.

However, the Palliative Care Funding Review estimated that every year in England around 92,000 people who would benefit from palliative care services are missing out. The LSE review team has used the same assumptions and calculations to estimate that around 10,600 people in Scotland, 6,100 people in Wales and 3,000 people in Northern Ireland who need palliative care are currently unable to access such care (Dixon et al, 2015).

People with cancer have fewer emergency admissions in the last year of life if they have access to palliative care (Henson et al, 2014). We know that people with a range of terminal illnesses are more likely to die at home with access to palliative care (Gomes et al, 2013).

Greater availability of palliative care could help reduce ongoing pressures on key NHS services such as accident and emergency (A&E) departments. Most importantly, it can enable more people to die in their place of choice. While this may require extra short-term funding, more appropriate community services are likely to lead to a longer term shift in demand for acute care services.

The LSE review team has estimated that providing palliative care to those who need it could potentially generate net savings of more than £30 million in England, at least £2 million in Wales, more than £1 million in Northern Ireland and more than £4 million in Scotland.

Given its potential impact, we must ensure that those who need and would benefit from it are able to access palliative and end of life care. The second step is to think through how we make this access a reality.

# To ensure that everyone can access the right care, we must:

## 1. ...acknowledge that people with all terminal illnesses can benefit from access to palliative care and end of life care

The LSE review underlines that people with a range of different conditions could benefit from greater access to palliative care and more equitable access to other forms of end of life care (Dixon et al, 2015).

The review team acknowledges the importance of recognising that the experiences and needs of people with conditions such as dementia, chronic obstructive pulmonary disease (COPD) or heart failure will be very different to those with conditions such as cancer.

Different diseases have different trajectories. Many of these may be longer or less predictable than those associated with cancer, with a less obvious onset of the terminal phase. This has clear implications for how we provide palliative and end of life care. Specifically, we must determine how we ensure that people with different terminal illnesses are referred to palliative care services as soon as they need it.

It is also important to acknowledge the overlap in symptoms between most terminal illnesses, including cancer. Moens et al (2014) found that “pain, fatigue, anorexia, dyspnea and anxiety were highly prevalent across all of the conditions”. We need to build a consideration of both the differences and similarities between conditions in order to provide the right care for people living with a terminal illness.

## 2. ...change the way we decide who would benefit from access to palliative care

The review found that a number of groups have lower rates of access to palliative care. It highlights a tendency for doctors and nurses to often “under-estimate distress”, particularly among older people who are less likely to be referred to palliative care.

It would appear that because death is seen to be more normal and acceptable for this group, and because they are less likely to report symptoms, they are less likely to be referred for palliative care.

There is a similar tendency to under-estimate distress for those who are undergoing aggressive disease-modifying treatments, in what Epstein (2012) describes as a ‘no-pain, no-gain’ framework. In other words, healthcare professionals may view a level of distress as acceptable because the treatment is necessary to extend the person’s life.

We can begin to address this by changing the way we assess needs. Standardised measures of need, rather than professional judgment in isolation, may be one way to improve identification and assessment of need (Gardiner et al, 2013; Gott et al, 2001; Barclay, 2000). People reporting real-time data about their symptoms and concerns (Trotti et al, 2007) could also help identify those requiring palliative care.

## 3. ...build links between specialists and palliative care

Links between oncologists and specialist palliative care teams are well established.

However, this does not appear to be the case for other healthcare professionals, including specialists in dementia, chronic obstructive pulmonary disease, motor neurone disease and other terminal illnesses.

We need to work with specialists, GPs, district nurses and other community colleagues to strengthen these links and demonstrate the role that palliative care can play alongside other aspects of treatment and care. We must demonstrate the value of palliative care for people with terminal conditions other than cancer, by evaluating interventions and undertaking health economic assessments. It is only by building a stronger understanding of the role of palliative care that we will begin to break down the barriers which currently prevent access.

#### **4. ...acknowledge that palliative care can be delivered alongside other types of treatment**

There is a widespread lack of understanding or acceptance among clinicians that specialist palliative care may be provided at the same time as disease-modifying treatments (Gibbins et al, 2009). As the review notes:

*“An audit of a hospital trust managing 1,500 deaths a year concluded that, instead of asking healthcare professionals to make accurate prognoses or to diagnose dying, an environment needs to be created where teams feel comfortable in actively managing patients alongside considering their symptom control and planning for possible end of life care.”* (Dixon et al, 2015)

#### **5. ...broaden the way we think about palliative care**

Much of the literature focuses on a very narrow, medicalised view of palliative care. However so much that underpins inequity lies in people’s social circumstances (Gott, 2014). Understanding

these social aspects is vital in ensuring everyone gets the right type of care.

Professionals such as social workers, counsellors and therapists can help build a greater understanding of someone’s personal circumstances. They can use this knowledge to help people navigate and access services and support. These allied health professionals often provide the glue which ensures people affected by a terminal illness can access the support they need. Their role underlines the need for a holistic approach to delivering care. Palliative care must be seen to be everyone’s business.

#### **6. ...ensure greater clarity about who does what**

The literature identifies a lack of clarity about the roles and responsibilities of a range of health and social care professionals working with people with a terminal illness. In particular, there can be confusion between the roles of specialist and generalist practitioners in primary and acute settings. These include the role of geriatricians in providing palliative care and the roles of GPs and community nurses in delivering care in care homes.

This confusion is underlined by the Care Commission’s report (2009) of its inspections of Scottish care homes, which found:

*“Only 44% of care homes had policies in place to guide staff on when and how to contact members of the primary healthcare team. The inspections also found that 43% of care homes claimed not to provide palliative care, apparently considering palliative care to be solely that given in the last days of life, and 54% of care homes provided no training at all to staff on end of life care.”* (Care Commission, 2009)

## 7. ...improve care in all settings

People living with a terminal illness should be able to choose where and how they are cared for and die.

Most people say when asked that they would rather die somewhere other than in hospital. However, the reality is that older people, people without a spouse, those living in the most deprived areas and those who have a condition other than cancer are more likely to die in hospital. We need to better understand why this is the case. What are the barriers which prevent people from accessing support in their preferred place of care?

Gott (2014) suggests that we should identify what we value about care at home and seek to reflect this in how we provide care for people with a terminal illness in hospital. For others the solution lies in creating alternatives to hospitals for those who do not wish to die at home (Leadbeater and Garber, 2010). There is a potentially enhanced role for hospices in training hospital and community-based healthcare professionals.

## 8. ...improve generalist care for people with different terminal illnesses

One of the most intriguing findings of the LSE review was that people who had a terminal illness other than cancer not only experience poorer access to palliative care, but also have less access to generalist care than people with cancer (Dixon et al, 2015). Burt et al's (2010) random sample survey of people registering a death of someone over 65 years of age found that people with conditions other than cancer were:

*“significantly less likely to receive district nursing, general practitioner care and other health and social care services, and were likely to report less satisfaction with the quality of this care.” (Dixon et al, 2015)*

This is reinforced by the findings of the Nuffield Trust's own analysis of this area (Georghiou and Bardsley, 2014).

It is important that everyone, regardless of the conditions they experience, not only have access to high quality palliative care, but are also able to access the right levels of generalist care, particularly at home and in other community settings.

## 9. ...ensure the health and social care workforce has the right skills

We need to develop existing staff, and recruit future staff, to ensure we have the right balance of understanding, expertise and experiences of dealing with people with all terminal diagnoses. While some knowledge and skills will be transferrable, we'll need to undertake specialist training, models of integrated care and greater collaborative working to ensure we have the expertise and capacity to deliver for all (Dharmasena and Forbes, 2001). This is particularly important given the changing nature of disease profiles.

Over recent years we have seen an increase in the numbers of people dying in care homes, as we have seen a reverse in the numbers of people dying in hospital, particularly among those with dementia (Sleeman et al, 2014). We have also seen a rise in the proportion of people in care homes who die within their first year in the home:

*“Three studies in England show that the proportion of care home residents that die within a year of entering a care home has increased from around 28% in 1997 (Sidell et al, 1997), to 47% in 2006 (Froggatt et al, 2006), and to 56% in 2014 (Kinley et al, 2014).” (Dixon et al, 2015)*

Care homes have a growing role in providing care for people who are terminally ill and, given our ageing population, this appears set to

increase significantly over the coming decade. It is therefore vital we equip those working in care homes with the skills needed to deliver the highest possible care and that we build links with other health and social care professionals.

### **10. ...match services to local needs**

The evidence highlights “unclear and variable local resourcing decisions” (Dixon et al, 2015). There is a lack of connection between local commissioning decisions and assessments of local palliative and end of life care needs. While this remains the case, care will remain uneven across the UK.

The review underlines that there are significant resourcing and capacity issues in particular settings and for specific groups of people, including:

- people in hospital, particularly older people
- people in the community with conditions other than cancer
- people living in care homes (Dixon et al, 2015)

We need to explore and evaluate different models of community-based care to determine which ones are most effective. Commissioners must fund those services which provide the most appropriate support for people with a terminal illness in their own homes and care homes.

### **11. ...use limited resources more effectively**

Evidence suggests that extending and improving access to palliative care not only provides better outcomes but can also be cost effective. As well as delivering care which meets the needs of people with complex issues, palliative care specialists can also support other health and social care colleagues to deliver better generalist services.

# Conclusion

Access to palliative and end of life care in the UK is not equal or equitable. The LSE review demonstrates this clearly in many areas and shows more research is urgently needed in others.

We believe everyone living with a terminal illness should have access to high quality care and support, which meets all of their needs.

Our already stretched health and social care system is failing to deliver that now and the demands on it are only set to grow.

So we must change the conversation about terminal illness, to tackle these major issues, and find solutions.

If we don't, we as a society will be failing vulnerable people at the time they need us most.

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