Care and support
through terminal illness

A Place for Everyone - What stops people from choosing where they die?

A review of the barriers to good end of life care facing diverse groups in the UK

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1. Foreword

Marie Curie believes that everyone deserves the best possible experience at the end of their lives. The place where someone's cared for at the end of their life and whether this matches what they want – is an important part of this experience.

Even before the start of the coronavirus pandemic in early 2020, it was inevitable that services would have to change to cope with increasing complexity and numbers if there was going to be any chance of meaningful choice at the end of life in the future. The gaps in the system are more apparent now than ever before. It's clear that the service environment will need to be different in several ways – from where, what, when and how services are delivered, to how they are funded. This is vital in making sure everyone is able to access the services they need, at the right time for them.

This report is the first in our *Place for Everyone* series and explores the groups for whom choice in place of death is limited. It also looks at the reasons why home may not be the preferred place of death for some. More broadly, this report is part of the work we're doing to address the wider issues faced by people at the end of their lives, as well as those close to them. We'll be looking in detail at the role that place plays, and the challenges we face in delivering the best care while meeting people's preferences for where they receive that care and ultimately where they die.

If we think of dying at home as 'the achievement of a good death' and prioritise it accordingly, less choice and poorer experience[1] will inevitably follow. We have to do more detailed thinking on how to meet the complex clinical needs and diverse social circumstances of people approaching end of life. The focus must remain on choice, underpinned by more emphasis on people having early conversations about what they want, and avoiding planning in a crisis wherever possible. We need to hope for the best but plan for the worst.

Focusing on place in the context of future quantity and complexity of need has enormous implications for how end of life care services and social care, are designed, funded, and delivered. Such a focus also brings into play several other things outside the scope of health and social care such as private and social housing, employment policies and financial security. It means thinking again about the configuration of hospital services, the role of care homes, and the implications for primary care providers. It also means thinking about the role and impact on volunteers and family members as carers, among other important considerations.

It's vital to recognise that dying at home is not the simple indicator of a good experience at the end of life that it's often assumed to be. Failing to recognise this will mean people who don't have the option of being cared for and dying at home, or who choose not to, won't get the quality of experience they should expect.

Our work on place of death, what it means to people, and for priorities, policies, resources, planning and delivery across health and social care and beyond, will help

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to shape future thinking and actions. These, in turn, will mean a better experience at the end of life for many more people.

Against a backdrop of an ageing and growing population and ever tighter constraints on health and social care budgets, the aim of the *Place for Everyone* series is to inform and influence end of life policy. In doing so, we want to ensure practice is socially inclusive and delivers the best possible end of life experience for everyone across the UK.

Matthew Reed
Chief Executive, Marie Curie

> *It's vital to recognise that dying at home is not the simple indicator of a good experience at the end of life that it's often assumed to be.*

2. Executive summary

Everyone should have the right to express a choice on where they receive their end of life care and where they die. We also believe health and social care teams should have a duty to ensure that, where possible, this can be achieved. Despite national end of life care policies designed to encourage dying at home, research indicates that fewer people are able to die at home than would wish to do so and that the ability to die at home is unequally distributed depending on patient characteristics.[2]

There is an urgent need to improve end of life care services to ensure that everyone, regardless of circumstances, has the opportunity to receive the best possible personalised care. That includes ensuring that people can die in the place of their choice. In order to do this, we must better understand the barriers facing people from a diverse range of communities and take appropriate steps to make end of life care policy and practice is socially inclusive as possible.

The following groups are included for discussion in this report:

- People who are homeless
- People who are prisoners
- People from ethnically diverse backgrounds, including Gypsies and Travellers
- People who are LGBTQ+
- People with learning disabilities
- People from low socioeconomic groups
- Older people who are living alone
- People with dementia

Although the groups in this report all have different characteristics, there's a common theme. They all face barriers to getting the care they need, and quite often the barrier will be assumptions about who they are and what care they need. For some groups, to a greater or lesser extent, there are individuals within them who are inherently

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vulnerable, and it is their vulnerability that means we must take steps to increase the support and personalisation of services available to them.

For some people, dying at home isn't the preferred choice. Home might not be an appropriate place for death to occur. Or their home might not be what society recognises as a home. It's essential that we recognise the impact that individual circumstances have on experience at the end of life in the context of place and target our services accordingly.

If we're to ensure that everyone has the ability to have the best end of life care experience, or 'the death they choose', we must look at the reasons that the inequalities exist in the first place and how to implement meaningful changes to end them. If the principal reason people choose to die at home is that it's a safe, familiar and secure place, we must recognise that this isn't everybody's experience of home. Feeling unsafe or insecure at home has been identified as a key reason that people choose to seek care in a hospital or other institutional setting.[3]

There are countless interpretations of what constitutes a 'good death', but it's commonly thought that a person should have choice and control over where death occurs (at home or elsewhere) and have access to hospice care in any location, not only in hospital.

The idea of a good death is an important one in our system. It both reflects and creates our beliefs about how end of life should occur. Yet it's not without its flaws, since a good death requires awareness and agency,[4] which may not be the case for some of the groups discussed in this report. For example, people with dementia or learning difficulties.

For some people, having the ability to choose where to die isn't always possible. For some, home doesn't exist, it's unsafe, or the level of care they need is too great and the options for where they may choose to die are, or become, limited. There's a large body of evidence that suggests the majority of people prefer to die at home. This evidence is what end of life care policy has been based on, but such evidence if often problematic because it reflects the opinions of the general population. Surveys which ask healthy and younger people where they would like to die often emphatically show a preference for home. But those focused on older and sicker people show a trend towards hospital and hospice. This may be because, as people approach end of life and death is brought into focus, people worry that they won't be able to get the best pain relief at home. Tailoring of end of life care services to meet this presumed preference, based on general population evidence, isn't appropriate for some people and may be detrimental to their end of life experience.

We must try to address the reasons why place of death may not be the quality marker it's believed to be, and ensure that everyone, regardless of place, has the ability to have a 'good death'. Or rather, the best end of life experience possible for them. All end of life care settings must deliver high quality palliative care services that meet people's expectations for 'homeliness'. For many, the choice to die at home reflects a rejection of the 'institutionalised death' – dying in the unfamiliar, regimented surroundings of a hospital ward or in a nursing home. But when hospital equipment and staff take over a person's home, the sense of familiarity and privacy may already be lost.

Focusing too heavily on where we die risks paying too little attention to the other things that are important to us in our final days and weeks. Comfort, familiarity, social engagement and not feeling like we're becoming a burden to our families, and chiefly on making sure our symptoms are managed and we're pain-free. Often, clinicians know that it can be difficult to ensure that these other priorities are properly addressed when we're cared for at home.

With most of us likely not to die in our own homes – whether that's by choice or necessity – it's vital that death outside of the home isn't automatically seen as a failure. Rather than viewing this as a failure and resigning ourselves to the idea that people can't experience 'a good death' unless they meet certain criteria, we should give urgent consideration to how deaths in institutional settings – especially hospitals but also hospices and care homes – can take on the positive characteristics of home.

The number of people dying with a need for specialist palliative care is projected to increase by up to 42%. This is due to trends in life expectancy, but also the increasingly complex care needs of people with multiple health conditions towards the end of life. Our health and social care system has to be capable of meeting the needs of everyone, especially the most vulnerable. The enormity of the coronavirus pandemic, its disproportionate impact on the vulnerable groups discussed in this report, and the sheer volume of deaths in our hospitals and care homes across the UK show us what end of life care failings will look like if we don't act now to future-proof the system.

This report explores the systemic barriers to experiencing good end of life care that exist for a great number of people, from a diverse range of groups, across the UK, and the reasons why those barriers continue to exist. The intention is to better understand how we can address each individually and remove them so that in turn everyone is able to access the best possible end of life care regardless of where they are cared for.

Following this report we will be embarking on conversations with people from each of these groups to talk about what 'home' means to them as individuals and to reflect on the things that are most important to people, so that other care settings can offer end of life care experiences equivalent to the much sought after, idealised home death, for those for whom home isn't an option.

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3. Introduction

The right to express a choice on where we receive care and where we die is something we should all have. Health and social care teams should be duty-bound to ensure that, where possible, this can be achieved.

Population ageing presents a huge challenge for future end of life care.[5] Deaths are projected to increase across the UK; by 2040 it's estimated that there will be 160,000 more people dying in England and Wales, 9,029 more people dying in Scotland and 3,830 more people dying in Northern Ireland. Along with the trends in life expectancy, the increasingly complex care needs of people with multiple health conditions towards the end of life mean the number of people dying with a need for palliative care is projected to increase by up to 42%.

Despite national end of life care policies designed to encourage dying at home, research indicates that fewer people are able to die at home than would wish to do so. It also suggests the ability to die at home is unequally distributed depending on patient characteristics.[6] This scoping review considers existing literature exploring the challenges that people from minority groups experience in end of life care. It's intended as a starting point. Following this report, we're going to begin a programme of engagement across the many diverse communities identified to further understand the lived experience and identify real, tangible, changes that we can make to improve the experience of choice and place in end of life care.

In 2015, the London School of Economics and Political Science (LSE), commissioned by Marie Curie, explored the issues surrounding the equity of palliative care services in the UK. That review found there's significant evidence that some people who would benefit from palliative care don't receive any at all, either from specialist palliative care professionals or generalists. They found that there were an estimated 92,000 people a year in England, 6,100 people a year in Wales, 3,000 people a year in Northern Ireland and 10,600 people a year in Scotland who would benefit from palliative care but who weren't getting any.[7]

The LSE review also found that although it's generally accepted that everyone should be equally supported to die in their usual place of residence if they want to and can, not everyone will do so. Some groups, such as people aged 80 or over, immigrant Black and Minority Ethnic groups, people without a spouse or carer, people who live in the most deprived areas and people with non-cancer diagnoses, are more likely to die in hospital than others.[8]

In 2016, the Care Quality Commission undertook a review titled *A different ending – Addressing inequalities in end of life care* to look more closely at 'how dying patients are treated across various settings' and looked particularly at end of life care for people who may be less likely to receive good care.[9]

The review found that people from a number of groups continued to face inequalities in end of life care. These included those with conditions other than cancer, older people, people with dementia, people from ethnically diverse groups, including Gypsies and Travellers, LGBTQ+ people, people with a learning disability, people with a mental health condition, people who are homeless, and those detained in a secure settings . The review also highlighted barriers that sometimes prevented these groups from experiencing good, personalised end of life care.[10]

The review noted that the reasons these inequalities persist may be due to a lack of understanding that each of these groups, and the individuals within them, had their own unique needs, which had to be considered for people to receive end of life care that reflects their wishes and choice in the last phase of their life.[11]

There's an urgent need to improve end of life care services to ensure that everyone, regardless of circumstances, has the opportunity to receive the best possible personalised care. That includes ensuring that people can die in the place of their choice. In order to do this, we must better understand the barriers facing some communities and take the appropriate steps to ensure end of life care policy and practice is socially inclusive and meets the needs of everyone.

The 2015 Ambitions for Palliative and End of Life Care Framework[12] highlighted the importance of delivering personalised palliative care and set out six ambitions to achieve this for everyone. The framework noted that the first national strategy for end of life care in England (2008)[13] identified three key challenges that the Ambitions Framework aimed to address:

- firstly, that people didn't die in their place of choice,
- secondly, that we needed to prepare for larger numbers of dying people, and
- finally, that not everybody received high-quality care, and called for the need to ensure that each death matters.[14]

The Ambitions Framework set out six ambitions for end of life care for everybody, but there are challenges to delivering on these for some disadvantaged populations, as follows:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

Not everyone has the agency to determine where they die, or the care and support required to do so, as set out in the Ambitions Framework. The challenges that arise for many are multi-faceted. To achieve the ambitions set out in the Framework, we have to understand the challenges for disadvantaged population groups, and the individuals within them.

Similarly, in Wales in 2008, the Palliative Care Planning Group published a report (known as the Sugar Report) for the Minister for Health and Social Services which noted that core palliative care services must be holistic, put the patient at the centre of care, and endeavour to enable patients to die in the place of their choice while offering support to families and carers through the illness and into bereavement.[15] The report also noted that meeting preferred place of death targets was vital as a mark of palliative care service quality.

In 1998, one study looked at place of death, access to home care services and whether some groups were disadvantaged. It found that, unless factors associated with home deaths are identified and interventions are targeted accordingly, further general improvements in care support may only help those already at an advantage.[16] Researchers found that patients with informal carer support were both more likely to die at home and to access palliative care home services, but that having home care didn't remove dependence on informal carers in achieving home death. They concluded that an important target in improving home death rates is therefore better support for informal carers overall.

The study found that older patients were both less likely to die at home and to access home care but that once they had palliative care home services, they were no longer less likely to die at home. Although age-related needs required consideration, improved access to home care is therefore likely to increase home deaths for older people.[17]

They also found that women were less likely to die at home than men, yet younger women may be more likely to access home care. There was also some evidence to suggest that men were less efficient as carers, which may help explain why women were less likely to achieve home deaths, while making their referral to home care more likely.[18] While home care may help redress the gender imbalance, men also needed to be encouraged and enabled to take on the carer role.

The researchers also found that cancer patients in higher socioeconomic groups were both more likely to die at home and to access home care. Hence home deaths may increase by improving access for lower socioeconomic groups to the services available.[19]

It's been more than two decades since the study was published and yet these inequalities experienced in end of life care persist, particularly around being able to die at home for disadvantaged populations. Yet end of life care policy across the UK continues to promote and prioritise home as the best place of death.

Although the groups in this report all have different characteristics, there's a common theme. They all face barriers to getting the care they need, and quite often the barrier will be assumptions about who they are and what care they need. In some groups, to a greater or lesser extent, there are individuals who are inherently vulnerable, and it's their vulnerability that means we must take steps to increase the support and personalisation of services available to them.

For some people, dying at home isn't the preferred choice. Home might not be an appropriate place for death to occur. Home for them might not be what society recognises as a home. It's essential that we recognise the impact that individual circumstances have on experience at the end of life in the context of place and target our services accordingly.

We must challenge the belief that dying at home is the simple indicator of a good experience at the end of life. If we're to ensure that everyone has the ability to have the best end of life care experience, or 'the death they choose', we must look at the reasons that the inequalities exist in the first place. Only then can we find ways to end them.

3.1. What does 'home' mean to different people?

Much of the discussion around supporting people to die in the place of their choice, and the widespread view among healthcare professionals and public policymakers that 'home is the best place to die', fails to look beyond the data that suggests people want to die at home. It fails to explore why, for some people, this is not preferable or practical.

Instead, research into place of death preferences is too frequently taken at face value, with little effort taken to examine what lies behind that choice or to understand why a patient may wish to die at home or elsewhere.

Aside from the desire to be pain-free, medical factors such as access to professional medical intervention or having professional carers nearby are regularly ranked far lower in people's priorities than social and personal factors.[20] This may explain why so many people express a preference for a home death over death in hospital. But it also indicates that people are making a more complex choice and considering far more than a mere physical 'location' or 'care setting' when they decide where they wish to be cared for.

3.1.1 Comfort and familiarity

For many people, home is more than a physical space. It represents familiarity, the presence of loved ones, and the possibility of enjoying "normal" life – reasons why well over half of people with a progressive illness want to die at home.[21]

Home is frequently described in symbolic terms as having a deeper meaning than simple bricks and mortar. Home is an expression of the familiarity of one's surroundings, the retention of one's independence at the end of life and especially the presence and closeness of family and loved ones.

A death at home is understood to be a place where people can be themselves and end their lives in a place of comfort, cared for by family.[22] It's not simply a care setting and a person's preference to die there is often profoundly bound up in these feelings of home.

People near the end of life often highlight the importance of having their personal possessions with them and others, especially those who have lived in the same place for years – having perhaps raised their family there – also describe 'home' as being synonymous with important and meaningful memories.[23]

In a poll of 2,127 people for Demos, for example, 31% cited the presence of family and friends as a reason to die at home, with 20% citing having their own things, 18% valuing the memories that home evokes and 13% citing the value of being in familiar, comforting surroundings when they die.[24]

3.1.2. Privacy and independence

For others, the choice to die at home is as much about a rejection of the perceived 'institutional' nature of more clinical settings as it is about perceived benefits and advantages of dying at home – even when they acknowledge the high quality of care on offer in a clinical setting.

Some aspects of hospital care can be very distressing for people at the end of their lives, with the perception that the very reasons people choose to die at home – familiarity, the presence of family, privacy and comfort – are difficult, or even impossible, to experience in a hospital setting.

For some, dying in hospital is perceived as being a death surrounded by 'strangers' in a 'disciplined' institutional setting where they aren't treated as an individual.[25] The quality of care in hospital is seen as unreliable and impersonal, and the hospital itself is seen as inaccessible to family, friends and other carers – in other words, the very opposite of the home.[26]

Similarly, nursing homes are also seen as a negative place to die even when standards of healthcare are known to be good. Again, they're seen as institutional environments that somebody 'goes into to die,' with some people living with advanced illness or nearing the end of life strongly rejecting this setting as an 'only as a last resort' option if no other place is available.[27]

If it's the very lack of an institutional, 'medicalised' atmosphere that most appeals to people about dying at home, we should be aware that the highly specialised, professional care often needed to enable somebody to live and die at home with a terminal illness can greatly compromise this feeling.

For some, the entry of professionals into the home represents an 'intrusion' into the privacy and familiarity people associate with a death at home[28] - this feeling will only be compounded when several different specialist professionals are needed to care for a person, or where there's no consistency or reliability in who's coming to deliver care.

The lack of 'informational continuity' – that is, having to explain the circumstances of your condition or care needs to a changing cast of nurses and healthcare assistants which may change from day to day – is especially disliked by people. It has a significant impact on the sense of familiarity and control that should be the hallmark of good quality care at home.[29] This is a particularly big issue for many LGBTQ+ people who either have to come out to a new person or have a discussion about their gender identity and every time feels like there is a risk of rejection or the potential to lose access to care.

Having several different professionals enter the home can also be a burden for family members and carers. Having to 'make an effort' or 'perform' in the presence of nurses, carers or other professionals can be very wearing for family members and compromise their view of home as a place where they can 'close the door to the outside world' and have time to themselves.[30]

This is especially true when care is being provided by 'new people' on a regular basis. The difficulty this causes for family caregivers in building relationships with professional carers is frequently as significant a frustration for them as it is for patients.[31]

3.1.3. Is home always the right place?

If the principal reason people choose to die at home is that it's a safe, familiar and secure place, we must recognise that this is not everybody's experience of 'home'.

For some people, especially those in disadvantaged circumstances, the reality of their home life is less secure and conducive to home care than the idealised, vision of the home that models of palliative and end of life care frequently assume. Feeling unsafe or insecure in the home has been identified as a key reason that people choose to seek care in a hospital or other institutional setting.[32]

In one study of clinicians with experience in end of life care, 89% agreed that a patient's socioeconomic status had an impact on their ability to die at home,[33] while other studies looking at older people's views on home care show that people recognise if a person lives in poor material circumstances, their home may be an unsuitable place to live and die with advanced illness.[34]

This can relate both to the person's immediate physical environment – the home not being able to accommodate medical equipment, for example, being challenging for care providers to access, or being prone to health hazards such as damp or mould – as well as precarity. People who are on lower incomes are also more likely to be renting their home and are less likely to have a secure tenure,[35] especially if their illness means they're unable to work and may be struggling financially.

Where a person's home is can also affect the ability – or willingness – of care providers to enable care at home. In the above study, physicians reported higher perceived concerns about providing care and their own safety in lower-income areas, those with more run-down buildings or the presence of substance abuse or mental health issues.[36] These perceived concerns may ultimately lead to some care providers not participating in home care, and especially in out-of-hours care, for patients in lower-income areas or who live in deprived areas where they may have concerns for safeguarding their staff members.

Where a person's home is may also be a barrier for people living in rural areas compared to those in more densely populated urban areas. The challenge for services providing palliative care to people in the community in sparsely populated rural areas include a lack of GPs, nearby hospital services, and out-of-hours care. For example, in the Shetland Isles there has recently been a call for people to have the right to have full care at home for the last few days of life,[37] with one local GP quoted in the Shetland Times saying, "Shetland patients dying at home don't have access to overnight carers, and there is only one district nurse for the whole of the mainland, and they can't be there all night with a patient. There is also no cover at short notice at weekends". These are all barriers for people dying at home.

In January 2020, a motion was debated before the Scottish Parliament which called for there to be an automatic right for people to have full care at home, day or night, for their last few days of life, so that they could have their wish fulfilled by being able to die at home with suitable palliative care. Since the debate, NHS Shetland published its Palliative and End of Life Care Strategy which includes in its Action Plan a number of items to improve access to 24/7 palliative care services.[38]

In the chapters that follow, we'll explore the reasons why some groups are disadvantaged by end of life care policies that prioritise home deaths. Following this report, we'll be embarking on conversations with people from each of these groups to talk about what 'home' means to them as individuals. We'll also reflect on the things that are most important to people, so that other care settings can offer end of life care experiences equivalent to the much sought-after, idealised home death, for those for whom home isn't an option.

4. Who is excluded by prioritising home in EOL policy?

Layton Thompson/Marie Curie

Everyone with a life-limiting illness should be able to die, when the time comes, with dignity and in a manner and place of their own choosing. While most of us say that we wish to die at home, an important minority chooses to die elsewhere and many feel they are denied the option to die at home due to their personal circumstances – whether this is due to living alone, having a lack of family carers or their socioeconomic, or other, circumstances.

In order to be able to be able to improve end of life care services, it's important to understand the unique challenges and barriers faced by various groups.

In the following sections, we'll look in more detail at the reasons why for some groups, dying at home isn't an option, either because people don't have their own home, people don't want to be at home, or people simply can't be cared for at home.

This review gathered evidence through existing literature and discussion with clinical and other experts, both internal and external to Marie Curie. Following publication of this review we will be meeting with people with lived experience of the groups discussed in the sections that follow so that we can build recommendations that meet their true needs.

Marie Curie recognises that, regardless of gender, sexual orientation, relationship or family status, faith, ethnicity, age, disability or socio-economic background, everyone's needs and preferences at end of life will be unique. While we're discussing people's needs and experiences in this report, it's important to recognise that not all people within a group will have the same needs and experiences at the end of their lives.

Everyone with a life-limiting illness should be able to die, when the time comes, with dignity and in a manner and place of their own choosing.

4.1. People who are homeless

Being homeless or vulnerably-housed is associated with death at a young age and is frequently related to medical problems complicated by drug or alcohol dependence. Homeless people frequently experience high symptom burden at the end of life and yet use of palliative services is limited.[39]

Official figures across the UK for people experiencing homelessness vary, because often these people don't show up in official statistics at all. When they do, the population figures are calculated differently in each of the nations. In 2017 the Care Quality Commission noted that to address inequalities, providers and commissioners must first be aware of them, and the very lack of local awareness of the extent of homelessness is itself a major barrier to understanding the needs of this group.

A number of challenges exist around delivering good primary healthcare, let alone personalised end of life care, for people who are homeless. People in this group often underuse such services because of a mistrust of healthcare providers, perceived stigma and discrimination, competing priorities, and difficulties registering with a general practitioner (GP) and keeping appointments.[40]

Where healthcare services tailored to people experiencing homelessness do exist, they're fragmented and work in relative isolation – so there's little continuity of care, and deteriorating health or circumstances are often missed.[41]

The ONS[42] has recently produced statistics for homeless deaths in England and Wales, as follows:

- There were an estimated 726 deaths in 2018, the highest year-to-year increase (22%) since the ONS time series began.
- Most of the deaths in 2018 were among men (641 estimated deaths; 88% of the total).
- The mean age at death was 45 years for males and 43 years for females in 2018; in the general population of England and Wales, the mean age at death was 76 years for men and 81 years for women.
- Two in five deaths were related to drug poisoning in 2018 (294 estimated deaths), an increase of 55% since 2017.
- London and the North West had the highest numbers of deaths in 2018, with 148 (20% of the total number) and 103 (14% of the total number) estimated deaths respectively.

By comparison, in Scotland in 2018, there were an estimated 195 deaths of people experiencing homelessness, the highest rate of homeless deaths for all GB countries at 35.9 per million.[43]

In Northern Ireland, 205 homeless people died in the 28-month period before March 2019. Of those who died, 82 people were aged 65 and over, while 26 were under the age of 30.[44]

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When people who are homeless do access healthcare services, it's usually through hospital Accident and Emergency department admissions. Too frequently this is followed by people being discharged without taking into account the environment they are going to, or without being linked to support services, or even accommodation to return to.[45]

Evidence suggests that due to the lack of alternatives, people experiencing homelessness with advanced ill health often remain in hostels. But the conflict between the recovery-focused nature of services and the realities of health and illness, for often young homeless people, result in a lack of person-centred care,[46] and significant burden on hostel staff who mostly have no medical experience or support for such situations.

For example, one study found that it was very difficult for staff to talk about palliative care preferences with people who were young and who had, for example, advanced liver disease, knowing that if they were to stop drinking the disease progression may stop and they could potentially live for many more years. With one healthcare professional quoted as saying:

> *They could be classed as palliative, but they are also reversibly palliative. So if you don't stop drinking, if you don't stop doing these things, then you are probably going to die in six months. And it's a little bit difficult sometimes to class them as palliative, when you have a reversible cause to it.*[47]

Gemma's story

Gemma, 28, and her partner had been street homeless for a number of years. They were both addicted to alcohol and heroin. There were safeguarding concerns about their relationship as her partner was very controlling. Gemma had been offered hostel places, but never together with her partner, due to these concerns. This resulted in Gemma never taking up her place in the hostel.

Gemma had had frequent emergency hospital admissions over the last couple of years, as a result of decompensated liver disease. She had advanced cirrhosis as a result of alcohol misuse and hepatitis C. Following admission, as soon as she was beginning to recover, her partner came to the hospital and took her away. As a result, she rarely completed her treatment.

On one occasion when she'd been admitted to hospital, a doctor working with the Pathway team, which helps NHS hospitals support homeless people, heard she'd been admitted and knew she was likely to self-discharge quickly, so went to find her and attempted to build rapport with her. Gemma had said she was bored, so the doctor went to get her a card for the hospital TV and a magazine, but in the short time frame that she was gone, Gemma's partner arrived and she self-discharged before the doctor returned.

The team communicated with the outreach services and an emergency meeting was arranged where it was made clear that it was essential that Gemma needed to come back as she had septicaemia and needed to finish her treatment urgently. It was also made clear that Gemma was likely to be in the last months of her life – particularly if she were to continue to live on the street, drinking and using heroin. It was decided that though there were safeguarding concerns regarding the coercive and controlling nature of her partner, she and her partner would be supported to live in the same hostel. The homelessness outreach team were able to get Gemma to come back into hospital and to complete treatment and subsequently got her into a hostel with her partner.

Despite improvements, two months later Gemma unexpectedly collapsed and died at the hostel. Gemma had no palliative care involvement. Though her death should not have been unexpected, it was sudden and shocked the staff and other residents at the hostel. Her partner was devastated. There had been no opportunity for advance care planning.

Peter's story

Peter, 59, came into hospital with lung cancer and bone metastases. He'd been in denial about his deteriorating health, due to fear of health services and fear of what may be wrong with him. He was admitted following collapsing while picking up his methadone from the local pharmacy.

Peter had been homeless for a number of years following a relationship breakdown. He'd been addicted to heroin, but now was stabilised onto methadone, and before his illness rarely used heroin. However, as the pain in his back increased, he'd started topping up his methadone with heroin to try and make the pain bearable.

Peter had been in hostels in the past but had been moved into semi-independent accommodation two years before becoming ill. Following his admission to hospital, his keyworker was clear that it wasn't safe for Peter to return to the current accommodation. There were no staff on site and Peter had stairs which he couldn't manage. Peter knew he needed some support and was really keen to go into extra-sheltered accommodation. He wanted to have somewhere he could call home, so that he could start the process of reconnecting with his daughter – who he had not seen for over 20 years. He didn't want anyone to help with that reconnection while he was in hospital.

His key worker and a social worker gathered all of the information for an application into extra sheltered accommodation, but as Peter had used heroin recently, he was refused, based on the panel believing he would pose too much of a risk to other vulnerable residents.

Peter was supported to go back to his semi-independent accommodation with a package of care and meals on wheels, but he collapsed when leaving his room to go to the pharmacist for his methadone. This was within a week of his previous discharge from hospital. Peter was readmitted to hospital and it was absolutely clear that he could no longer live alone as his needs were too great.

One of the local homeless hostels was approached by the local authority, but the hostel managers deemed Peter's needs to be too great, and the risks too high for him to live there, due to his need for high doses of prescription opiates.

Doctors advocated for him to be able to go to a local hospice to try and get his pain under control. As he was on methadone, it was challenging to address his pain adequately. He went into the local hospice and while they were trying to find some other appropriate place of care for him, his health deteriorated. He had now become fast-track fundable. While trying to identify a nursing home that would be suitable for Peter, he died in the hospice. He never reconnected with his daughter.

The environment in hostels and supported accommodation projects is often not appropriate to care for someone at the end of their life. It can be noisy and chaotic, without access to a private bathroom or there may not be space for necessary medical equipment, such as beds. However, the reality is that there are very few suitable alternatives available for this group of people.[48] Hospices for example, struggle to support people with active addictions on an inpatient basis because of concerns regarding disruption to others and the level of care required, while nursing home support is also problematic because access to such services often requires a person to be over 65.[49]

The provision of palliative care can be complicated for all populations. But delivering palliative care for people who are homeless is influenced by a potentially greater and more varied range of factors, on both individual and systemic levels, than providing palliative care for the housed population. Careful consideration and potentially great changes will be needed within health care systems to ensure homeless populations have equitable access to palliative care.[50]

Many terminally ill people experiencing homelessness are dying in unacceptable situations, with services unable to anticipate or meet their needs in places where people would choose to die. As we've seen in the case studies, social services support is desperately lacking for people in this group, with assessments missing vital warning signs for support requirements and leading to hostel staff picking up the increased care burden alone. We must make changes to ensure that people who are homeless are able to be supported to die in the place of their choice, with the appropriate care and support in place and readily mobilised.

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Homeless Palliative Care toolkit [51]

Current evidence suggests increasing numbers of people with significant health needs and terminal conditions are being cared for in hostels and other homelessness services by staff who are not equipped to provide this care. Housing status should not be a barrier to accessing healthcare and Marie Curie wants to reduce the inequalities this group faces.

In January 2019, Marie Curie, UCL, Pathways, and St Mungo's launched the online Homeless Palliative Care toolkit. Based on research and joint working with residents and staff at St Mungo's hostel, as well as health and social care providers, a training course focusing on palliative care was developed and tested on a small scale with frontline staff in two London homeless hostels. The toolkit includes the training content and practical resources to help professionals plan and provide person-centred care for homeless people whose health is deteriorating.

Although Marie Curie accepts referrals for people who are homeless into our hospices or our nursing services, we rarely receive them in Wales. A scoping exercise in Cardiff and the Vale in late 2017 identified no palliative care services specifically for people who are homeless.

Some health boards provide health services for people who are homeless, including walk-in or hostel-based clinics and street health teams, but evidence of joint working between these teams and palliative care services is lacking. A common perception amongst local homeless services was that their clients would not be able to access our services due to challenges faced accessing other healthcare services, their living circumstances, or complex needs (ie drug/alcohol issues).

Many of the inequalities people who are homeless face in their end of life experiences centre on lack of awareness and identification of their needs by the professionals they encounter. The instability that homelessness presents can make accessing general healthcare services difficult, and research suggests that in the UK the rates of A&E usage and admission to hospital are four times higher for people who are homeless, while primary care services are underused. For many people who are homeless, their primary professional support will not be health professionals but homelessness services, including hostels, housing support, and day centres.

4.2. People who are prisoners

In the UK, the number of older prisoners has rapidly increased in recent years, and the need for palliative and end-of-life care has grown accordingly.[52] While there may be a fear from within the prison service that prisons aren't the right place for people to die, it's clear that a significant portion of those dying in prison would prefer to remain there.

Historically, the number of offenders aged 50 and over in custody had been increasing steadily largely as a result of an increase in the proportion of sexual offence prosecutions being pursued, which typically have an older age profile than the general prison population.[53]

The latest available data show a current prison population of approximately 92,400 in the UK, comprising

- 83,516 in England and Wales[54] (of those,1,759 were 70 or older[55])
- 8,205 in Scotland, and
- 1,487 in Northern Ireland (at the end of June 2019)[56].

People in prison are reported to age more rapidly due to their lifestyles, healthcare access, substance misuse and the stress of imprisonment. So while the definition of an 'older prisoner' varies, such as 70 or older as above, it's typically considered to be at least 10 year younger than that of the general population.[57]

The prison population is made up of a wide range of people from different backgrounds, often with large proportions of people who would otherwise fit into one of the other groups included in this report, particularly people who are homeless, gypsy or travellers, or low socioeconomic backgrounds. For example, more than 95% of UK prisoners are male, and a disproportionate number are from minority ethnic backgrounds (26% compared with 10% of the general population [58]).

With an aging population comes increasing ill-health, and there is now a growing population of frail, older prisoners who have multiple comorbidities, disabilities, or life-limiting conditions. Some have limited mobility, some use wheelchairs, and a few are unable to get out of bed. Their health care needs are frequently complex and include assessment and monitoring, medication and other treatments, and specialist intervention from clinicians outside the prison, others require assistance on a daily basis with personal care such as bathing, toileting, eating, and drinking.[59]

There's also a hidden dementia crisis in prisons that has so far been largely ignored. Prison staff are expected to understand a number of health conditions and forms of disability and to respond appropriately under massive pressure. But most lack the training required to spot the signs of dementia and to make the relevant referrals.[60] Due to the regimented nature of prison life, older inmates with early dementia may go unnoticed because they can get by on the regularity of the prison timetable without raising any concerns and it's therefore often very late when staff finally recognise that there's a problem.

Despite the ageing prison population and the increasing need for dementia care and other end of life care, UK prisons are not built to deliver this type of care to an elderly population of inmates. For example, a lot of prisons are Victorian buildings, with steps into and out of wings, and yet there are an increasing number of prisoners with limited mobility housed in them on long term sentences.

Improving prisoner care in Edinburgh

Following experience of the challenges of looking after terminally ill patients, the Marie Curie Hospice, Edinburgh now have protocols in place to ensure prisoner care is supported. This is achieved through joint meetings, a palliative care register, and a focused effort on anticipatory care planning, adapted from Healthcare Improvement Scotland. This all aims to make sure all prisoners on the palliative care register have an advanced care plan and have had a chance to say where they would prefer to die, so that support can be put in place where appropriate.

Recently, the Marie Curie Hospice, Edinburgh also developed a partnership with the local prison at HMP Edinburgh. This prison has one of the highest populations of older, long-term prisoners in Scotland, which in part is due to the increase in convictions for historical offences . The team found that there are specific challenges to ensure high quality palliative and end of life care for this group, which are applicable to prisons across the UK. Those challenges included:

- effective and timely identification of prisoners with palliative care needs
- lack of 24/7 health and social care available in the prison setting, especially overnight
- safe and timely access to medication
- a prison environment not built for those with significant health needs or disability
- a fixed regime of prison life compromises ability to deliver flexible care, for example prisoners being locked in cells over night
- staff confidence and competence both in the hospice and prison setting
- concerns for other residents in hospices and their families when increased uniformed security is present
- stigma surrounding all offenders
- not all prisoners are eligible for compassionate release but end of life care in the prison setting is not currently possible.

Following the experiences in Edinburgh and across the UK, Marie Curie is seeking to offer services that would mean people dying in prison aren't excluded from being able to receive pain medication and other care 24/7.

Example summarising a PPO Report into the anticipated death of a prisoner[66]

Mr E was sentenced to life imprisonment in 1989. In June 2015, he collapsed and was admitted to hospital. A chest x-ray identified possible lesions in his left lung and a CT scan revealed cancerous tumours in Mr E's left lung and right kidney.

After his return to prison, healthcare staff discussed the cancer diagnosis with Mr E and explained that, once his condition deteriorated, he would need 24-hour medical care. Mr E agreed and staff contacted HMP Parc, where care could be provided. He was not accepted for transfer.

In the following months, Mr E attended hospital regularly for treatment, returning to Usk on each occasion. The prison made further attempts to transfer Mr E in November, when his health began deteriorating. Despite their efforts, a transfer could not be arranged.

Mr E lived on a normal accommodation wing at Usk and shared a cell with another prisoner who assisted him with daily activities as his condition declined. His cell was suitable for his needs until it became evident that he was seriously ill and the prison attempted to transfer him to another establishment with 24-hour healthcare.

Initially, clinicians managed Mr E's pain with codeine. However, as his condition deteriorated, he required stronger pain relief, which healthcare at Usk couldn't provide.

In November, staff wrote to Mr E's oncology consultant, asking for information on his treatment and prognosis in order to arrange his transfer to another prison. The report wasn't received until almost two months later. During this period, he remained at Usk as his condition deteriorated. Nursing staff and prison managers contacted a number of prisons multiple times, but could not secure a transfer. Records show that prison managers rejected the transfer for operational reasons including Mr E's vulnerable prisoner status and lack of family connections.

He was admitted to hospital twice in February 2016 with severe pain but, on both occasions, when he was discharged, Mr E was not provided with appropriate pain relief due to the prison's restrictions and healthcare regime.

Mr E continued suffering significant pain and was re-admitted to hospital at the end of February. He remained there for end of life care and died in May 2016 of metastatic renal cell carcinoma.

Earlier transfer to a prison with 24-hour medical care would have enabled Mr E to receive appropriate pain management in the later stages of his illness. The PPO were concerned that the failure to arrange a transfer prevented Mr E from accessing healthcare services, equivalent to that he could have expected to receive in the community.

Staff at Usk had tried many times to arrange a transfer but the PPO said it was apparent from reviewing the records and speaking to the staff involved that the focus was not on his pain management as a requirement for 24-hour healthcare, which should have been the case.

The Prisons and Probations Ombudsman (PPO) investigates death of prisoners in England and Wales, of which 180 were from natural causes in 2018/19. Deaths from natural causes account for the majority (54%) of the fatal incident investigations and the majority of those are men over 60 , largely explained by the increase in older prisoners and associated age-related conditions. The Prisons and Probation Ombudsman natural cause investigations focus in particular on the need for prisons to provide appropriate healthcare at a level equivalent to that which could be expected in the community.

Expected deaths in prisons are often treated the same as those that are unexpected, to ensure no wrong-doing, and all deaths occurring in prisons ultimately lead to a Prisons and Probation Ombudsman investigation. Through these investigations the Ombudsman has repeatedly raised concerns about the way in which very ill and dying prisoners are sometimes treated and in particular has highlighted the inappropriate use of restraints. It is not always easy to achieve a good balance between security and humanity, however, and staff can often find themselves in a very difficult position when dealing with dying prisoners.[61]

In general, prisoners may not necessarily be owners of their own healthcare, and delivering healthcare for this population can be challenging. It's thought that as many as 90% of prisoners[62] have a diagnosable mental illness, and symptoms of other malign diseases may be overshadowed by this.The ageing prison population means that the prison service now has to accommodate prisoners with terminal and incurable illnesses. This has brought new challenges for both prison regime and facilities. To overcome these challenges, a number of prisons have built palliative care cells or units for prisoners requiring specialist end-of-life care. Many prisons employ more able-bodied prisoners as 'buddies' to help those who are not physically or mentally able to carry out everyday tasks. For some dying prisoners, particularly those who perhaps because of the nature of their offense no longer have links with family and friends outside prison these buddies also provide much needed emotional support.[63] Other prisons have developed links with local hospices to enable prisoners to receive treatment outside the prison.[64]

Prisoners may be released from custody before their sentence has expired on compassionate grounds for medical reasons, this is usually when they are suffering from a terminal illness and have a life expectancy of less than three months. But for many prisoners, as in Edinburgh above, there are those who despite being eligible for compassionate release, don't actually wish to be released from prison to die. They feel that the prison is where their home and their family is and therefore where they want to be. For some prisoners, it may be more appropriate to use the term Permitted Place of Death, as for most, compassionate release to their place of choice is not an option.

There are significant challenges that exist for delivering good, personalised, end of life care in prisons, not least because of the security risks and ability for prisoners to choose where they wish to die, but also due to funding for end of life care in the UK, both in and outside of the prison setting. As one recent study noted, the lack of government funding and strategy to focus action around the escalating numbers of older prisoners, and particularly those living with dementia, appears to contribute to a context where interventions targeted at this highly vulnerable group can be deprioritised.[65]

4.3 People from ethnically diverse backgrounds

All categories: ethnic group	63,182,178	% UK Pop
White	55,010,359	87.1
Black / African / Caribbean / Black British	1,904,684	3.0
Asian / Asian British: Indian	1,451,862	2.3
Mixed / Multiple ethnic group	1,250,229	2.0
Asian / Asian British: Pakistani	1,174,983	1.9
Asian / Asian British: Other Asian	861,815	1.4
Other Ethnic Group	580,374	0.9
Asian / Asian British: Bangladeshi	451,529	0.7
Asian / Asian British: Chinese	433,150	0.7
Gypsy / Traveller / Irish Traveller	63,193	0.1

In the 2011 Census, the figures above were provided for the UK population by ethnic group,[67] demonstrating the diversity of ethnicities in the UK. This diversity amplifies the importance of understanding and responding to the cultural differences that exist, both between and within different groups.

Recognising that people from different ethnic and cultural backgrounds have distinct needs and health risks is critical to improving services, as is understanding how these differences impact the choices people make with respect to where they prefer to die, the end of life care services they need and access, and why perhaps people from different ethnic groups may not access existing community services.

At an individual level, awareness of a person's cultural values, behaviours and beliefs can certainly influence end of life care and its outcomes. Differences between cultures such as who is involved in decision making, and what meaning is ascribed to pain and suffering can affect the quality of end of life care provision.[68] When we talk about different ethnicities, religions, cultures and belief systems we must remember that people within groups are not homogenous,[69] and while groups may largely share certain characteristics there will be fundamental differences too. Caring for people, particularly at end of life, should be personalised and stereotyping individuals based on expected cultural beliefs and behaviours damages the end of life experience for everyone.

There are numerous potential barriers to accessing palliative care services for people from ethnically and culturally diverse backgrounds identified in research. For example, these include a lack of cultural and religious sensitivity in how services are delivered, discrimination (and/or the fear of it), absence of translation resources, different cultural views regarding the acceptability of openly discussing death, shortages of female doctors for Muslim women and assumptions that family members from ethnically diverse backgrounds will be able and willing to care for relatives at home.[70]

In a review conducted by the LSE in 2015, it was found that people from Black, Asian and minority ethnic backgrounds were no more or less likely to die in hospital than at home when compared to people of white ethnicity. However, they did find these people, compared to people of white ethnicity, were less likely (at the 99 per cent significance level) to die in a care home rather than hospital, which may be due to people from Black, Asian and minority ethnic groups reporting poorer quality of care in care homes and therefore choosing not to access the service, as seen in the VOICES survey.[71]

A literature review into end of life care for minority ethnic groups in the UK[72], conducted in 2011, identified six key themes exacerbating the low uptake of end of life care services by members of minority ethnic groups including, structural inequality, inequality by disease group, referrals, place of care and death, awareness and communication issues, and cultural competency.[73] On place of death, the review noted specifically that while there have been a number of studies highlighting the perceived preference among minority ethnic groups for home care, this isn't always the case. The authors noted one 2005 study which found that the preferred place of death for people from the Chinese community was dependent on multiple factors, including the quality of housing and the length of time spent in housing, and that services could be acceptable when well-established and understood by members of the Chinese community. Another study, from 2009, emphasised that different ethnic groups may have different perceptions of hospice care by highlighting a study in which 'those of Chinese origin living in the UK' were said to perceive hospice care negatively. Above all, the need for discussion and choice regarding place of death was identified as a priority by members of minority ethnic groups.[74]

In another recent study, it was noted that planning ahead for end of life needs to pay attention to the emerging evidence in that cultural values and ethnicity of a person may play an integral role in end of life decision-making.[75] The researchers found that almost 80% of respondents in the study agreed or strongly agreed that being comfortable and out of pain was more important than prolonging life if they had a disease that could not be cured. This was more so for respondents from Anglo-Celtic and Asia/Pacific backgrounds than Mediterranean and Eastern Europeans.

Researchers went on to note that almost 60% of respondents, regardless of their background, answered that being at home would be more important than being in the hospital if they had a disease that could not be cured. However, the same percentage of people also answered that they would still want to go to the hospital if they found that they had a terminal illness. In particular, the people with an Asia/Pacific background indicated strong preference for being in the hospital (60% disagreed or strongly disagreed with being at home) and for going to the hospital or the emergency room (87%) if they had a disease that could not be cured and if they could be taken care of at home.

Understanding access to palliative care by ethnic minority groups in the UK with a focus on people from South Asian communities

In 2020, Marie Curie researchers from the Bradford Hospice were awarded a grant to determine whether people from South Asian communities are able to have equitable access to palliative care. The study will also look at the factors that affect access to palliative care and will deliver policy-level recommendations for the UK hospices sector.

The study will involve two stages:

(1) To investigate patterns in referral by GP surgeries to palliative care by ethnicity.

(2) Interviews and focus groups with patients and healthcare professionals, investigating how to improve access.

The study will run until January 2022.

In 2012, Marie Curie launched a three-year project, funded by the Big Lottery, titled *Improving access to palliative care services for people from Black, Asian and Minority Ethnic backgrounds in South East Cardiff*.[76] The project explored through discussion groups why, despite the Marie Curie Hospice in Cardiff and the Vale being located in an area with high percentage of residents from ethnically diverse backgrounds, it had a very low take up of services among these groups. Researchers found the following perceived barriers to accessing hospice services for these communities:

- a lack of awareness of the hospice, its services, and the range of conditions it supported
- terminology around words like hospice, palliative care and symptoms were not easily understood by participants
- anxieties and a general lack of trust and faith in healthcare services
- concerns about diet, as appropriate food and food preparation was important to participants and would play a role in their decision to use a service
- language was seen as a barrier especially for older community members
- culture and religion – some felt that palliative care services were not set up for people from ethnically diverse backgrounds and had concerns over whether the hospice was culturally and religiously appropriate
- the need for single gender wards and bays, and wellbeing groups
- lack of own transport, difficulties with public transport and the distance between the hospice and local communities
- lack of staff diversity, including volunteers
- GPs not referring people from ethnically diverse communities to Marie Curie services, or even explaining what services were available, including respite care
- attitudes – participants discussed a stigma attached to sending a relative to a hospice, rather than caring for their loved one personally.

Community engagement in Solihull

Solihull is in the midst of dynamic and rapid socio-demographic change. The population of people from ethnically diverse communities has more than doubled since the 2001 Census and now represents nearly 11% of the total population. On this basis, the borough is less diverse than England as a whole (and significantly less so than neighbouring Birmingham), but with people from Black, Asian and minority ethnic groups representing a relatively higher proportion of young people in Solihull, ethnic diversity is set to increase.

The Marie Curie Hospice, West Midlands is very aware that this community is under-represented in the people that use our services and we recognise this is a community with whom we need to build stronger relationships. Not only do we need to raise awareness of the services we provide, but also learn how we can develop them to be more inclusive.

In February 2020, the hospice ran a community engagement event with a group of sixteen Muslim women (aged 25 years plus). We wanted to explore what was important to them when it came to achieving good end of life care and their perceptions of how the hospice could help them achieve this.

Discussions very much focused on cultural requirements and there was an assumption from the women that the hospice would be unable to meet such needs. Together, we explored ways we could ensure that cultural needs were met. The women were very enthusiastic and creative in ways they could support the hospice to be more accessible and were extremely motivated to work with us to develop our services.

At the end of the event everyone was given a postcard to complete, sharing the thing that will matter the most to them when they reach the end of their life. Key themes included:

- being with their family
- having the Qur’an read
- having a quick and decent burial
- being pain free.

We’re now working together with representatives of the group to improve access to the hospice for this community.The women have invited other teams from the hospice to attend their monthly group to share more about services we offer and volunteering opportunities.

Important aspects of hospice care that came out of the session include the option to have ritual bathing straight after death done at the hospice. Currently this is done at the central mosque which is in the city centre (45 minutes drive away). Also, having the Qur’an read when entering the dying phase (either in person or recorded). And attention to dignity around personal care, for example asking if someone’s happy to be seen naked in a shower, or if they wish to be covered.

Following the discussions, a number of interventions were identified to help remove the barriers to accessing services. These included improving outreach, particularly through word of mouth, to local communities to increase awareness of the range of services offered. Also, offering visits to the hospice to experience the positive environment, break down barriers and dispel myths.[77]

Another Marie Curie study exploring the state of palliative and end of life care provision for people from ethnically diverse groups in 2013 found that overall, palliative and end of life care provision for ethnically diverse groups is often inadequate. Demographic data tell us that the number of people from Black, Asian and minority ethnic groups will increase, and a substantial number of them will be older people who might need care. This raises questions on how care, which was reported as inadequate, will meet the needs of even larger numbers of people, including those usually not represented in research, for example the White Irish community (with one-third of their population already over the age of 65) and the Gypsy and Irish Traveller communities, as discussed below.

4.3.1. People who are Gypsies and Travellers

Understanding Gypsy and Traveller communities' cultures is critical to delivering personalised end of life care in a place of choice for this vastly heterogenous group (see below). As with people who are homeless, accurate population data for this group is lacking, and this adds to the challenge of providing best possible end of life care.

For example, the 2011 Census included the ethnic category 'Gypsy, Traveller and Irish Traveller' for the first time, and in total around 63,000 people in the UK identified themselves as members of these groups, of which 58,000 were living in England and Wales, 4,000 were living in Scotland, and 1,000 were living in Northern Ireland.[78] However, other sources estimate the population in the UK is closer to 300,000,[79] and this may be due to there being several distinct ethnic groups within this cohort including, but not limited to, Romany Gypsies, Sinti, Roma, Irish Travellers, Scottish Travellers, Welsh Gypsies, New Age Travellers, Bargees, and Circus and Showground people.

The Census also provided the following statistics relating to accommodation and care for Gypsy, Traveller and Irish Travellers, which have implications for end of life care and place of death options:

- Whole house or bungalow was the most common type of accommodation for respondents who identified as Gypsy or Irish Traveller, at 61 per cent (84 per cent for England and Wales as a whole), followed by caravan or other mobile or temporary structure at 24 per cent (0.3 per cent for England and Wales as a whole)
- Gypsy or Irish Travellers were more than twice as likely to live in social housing than the overall population of England and Wales (41 per cent compared to 16 per cent) and less likely to own their accommodation outright (21 per cent compared to 26 per cent)
- Gypsy or Irish Traveller ethnic group was among the highest providers of unpaid care in England and Wales at 11 per cent (10 per cent for England and Wales as a whole) and provided the highest proportion of people providing 50 hours or more of unpaid care at four per cent (compared to two per cent for England and Wales as a whole).[80]

In one small qualitative study conducted with the Gypsy and Traveller Community in Oxfordshire in 2018, interviews with participants considered, amongst other things, the practical factors and beliefs influencing decisions around place of care and death.

Although there were only a small number of participants, they described loved ones dying in a wide variety of settings including in their own home, the hospital, a care home and the hospice. Despite this breadth of experience, the participants echoed the well-recognised settled population's preference for home death and a dislike of the institutional death, and this was further supported by the description of a strongly held and expressed community preference for caring for loved ones at home. However it was also challenged by the realities of caring for unwell and dying people in home environments particularly in the absence of supportive care with participants recognising that sometimes more care was needed than was available at home.

Conversely, and more novel was that, participants spoke about the implications of the impurity of a death in the home environment. This impurity resulted in two traditional practices; that of burning caravans after a community member had died within and the subsequent avoidance of locations where people had died by the rest of the community for at least a year.

Gypsies and Travellers experience some of the worst outcomes of any group, across a wide range of social indicators. Yet research into the experiences and understanding of death and dying for members of this community is extremely limited. Contributory factors are complex and often interrelated[81]; strong ethnic identity, and coherent cultural beliefs and attitudes underpin health-related behaviour and health experiences need to be understood in this context, alongside the specific effect of the social and economic hardship, and social exclusion.[82]

Many Gypsies and Travellers now live in settled accommodation and do not travel, or do not travel all of the time, but nonetheless consider travelling to be part of their identity. A number of studies have identified the poor health experiences of Gypsy and Traveller groups compared with the general population, including higher rates of mortality, morbidity and long-term health conditions, low child immunisation levels, and a higher prevalence of anxiety and depression.[83]

Common issues that have been identified when discussing end of life care with people from Gypsy and Traveller communities include the following issues around accessing palliative care services.[84]

- A lack of trust in public bodies and services
- Significant difficulties registering for and accessing services – such as GPs, and enforced mobility with no permanent address makes the situation worse (ie having to move around because local authorities move them on)
- Many people have had bad experiences of health and social care in the past – ie discrimination and prejudice
- Stigma around health problems, especially mental ill-health, in the Traveller community can mean it's undesirable to seek medical help


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- Healthcare staff don't understand or try to accommodate aspects of Traveller culture and there have been conflicts over visitor numbers, no provision for extensive family and loved ones, and examples of staff removing religious items (relics/medals) left by family
- Literacy issues can make it difficult to understand medication and prescriptions, medical jargon, appointment notifications and filling out medical forms
- Cultural concerns around talking openly about serious illness, diagnosis, prognosis and death for fear of bad luck, causing the person to give up hope and hasten death and the challenges this brings for advance care planning
- The suitability of places of care, for a community who potentially see hospitals as places of hope and cure, versus hospices as places of death, and death in the home as bad luck
- Concerns regarding funeral debt, as burials for members of the community can be expensive, with the suggestion that the money spent on the occasion demonstrates respect to the individual.

There is a need for palliative care services to take steps to ensure that people from Gypsy and Traveller communities are accepted and feel able to access services. This should include cultural competency training for all staff, the provision of accessible language materials and adequate time spent to ensure understanding.

4.4. People who are LGBTQ+

LGBTQ+ people[a] have all the palliative care needs experienced by others, including symptom management such as pain, spiritual needs and emotional needs. But they may face additional challenges and barriers to getting the care they need – including facing discrimination in their own homes at a time of extreme vulnerability.

In 2017, there were an estimated 1.1 million people aged 16 years and over identifying as LGB[b] in the UK (out of a population aged 16 years and over of 52.8 million) and 69.4% of people who identified themselves as LGB had a marital status of single (never married or in a civil partnership).[85] There are particular end of life care needs and concerns that need to be addressed for the ageing LGB population in the UK[86], not least because LGB elders who are now reaching old age represent a generation who lived through times when the community faced legal persecution and widespread intolerance[87] which may make people more wary about entering care homes, hospices and other places of care at end of life.

These past experiences, and continued discrimination still affects LGBTQ+ people today, despite equality legislation and changing social attitudes. They have an impact on how and where people would like to receive end of life care. Older LGBTQ+ people may still be reluctant to disclose aspects of their identify and therefore access formal services. They are also more likely to live alone and to age without partners and children[88] (see chapter on Older people, living alone).

In 2016, Marie Curie published the *Hiding Who I Am* report, which looked at the real barriers that LGBTQ+ people have experienced in trying to access high-quality palliative and end of life care in the UK.[89] They found the barriers ranged from outright discrimination, such as a doctor who wouldn't treat a lesbian woman without a chaperone, to more commonplace, but no less damaging issues, such as the experience of having to come out to each new healthcare professional encountered. Lack of continuity of care is a massive obstacle for dying at home and for trans people it can be even more acute, particularly if they're at an early stage in transition and the name on their medical records doesn't match their lived gender identity.

The Hiding Who I Am report found that LGBTQ+ people, particularly if they're older, are often concerned that healthcare professionals will not accept their sexuality and gender identity, or worse, will be actively hostile. They worry that palliative and end of life care services are simply 'not for them', or that they will receive worse treatment than their straight peers.

Despite it being against the law in the UK to discriminate against anyone who is LGBTQ+, in any circumstances, many LGBTQ+ people have experience of being discriminated against or targeted with abuse. *The Hiding Who I Am* report found that some LGBTQ+ people had experienced discrimination in palliative care settings with staff not being accepting of them. Some LGBTQ+ people said that they don't access palliative care services because they think they will be discriminated against.

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[a] The abbreviation LGBTQ+ covers a diverse group, with very different experiences and needs, and understanding the distinctions between people who identify as LGBTQ+ is vital to understanding their end of life experiences .

[b] The term LGB is used by the ONS Sexual Orientation Data 2017

This has an impact on a person's ability to choose where they'd like to die.

Health and social care staff often make assumptions about people's sexuality or gender identity. For example, they might assume that a man will have a wife or that a female partner of a lesbian patient is her sister or friend. This can make LGBTQ+ people and their partners feel excluded, especially because carers and partners of LGBTQ+ people are less likely to be offered support while they're carers, and also with bereavement.

This has a significant impact on a person's ability to really choose their place of death, depending on the care and support they expect to receive, and the questions they may prefer not to answer. While some people express a preference to die at home, this can mean having a range of health and social care professionals coming into one's home which can be daunting for LGBTQ+ people in a number of ways:

- Having care workers coming into their homes may lead LGBT people to alter their home, for example putting away items or photographs that might be associated with their sexual orientation or gender identity.
- Some people may live in households with more than one partner or have a number of people close to them with whom health and care professionals need to interact[90]
- The potential for health and social care professionals bring personal prejudices into their professional lives remains something that has the potential to impact on the care LGBTQ+ people have in all care settings.

Phil Hardman/Marie Curie

Previous Marie Curie commissioned research findings [91]

In May 2014, Marie Curie funded a joint project led by King's College London, with the University of Nottingham and the Gay Men's Health Charity (GMFA), to improve demand for and supply of palliative care for LGBT people who are in the later stages of a life-limiting illness.

Interviews for the ACCESSCare project revealed evidence of anxiety about care delivered in the home. In particular, individuals faced constant fear associated with disclosure of their identity, and the response they'd get.

For LGBTQ+ people this situation, as well as every contact with a new health and social care professional, represents another coming out, which brings with it anxiety about the reaction of the health and social care professional and whether this will impact on the care they receive. This kind of anxiety in itself has a negative impact on the experience of care at the end of life insofar as it diminishes the wellbeing of the dying person and their family and friends.

We know this kind of anxiety is not limited to care at home. Some respondents to The Last Outing survey, commissioned by Marie Curie and run by the University of Nottingham and published in 2015, also said that health and social care settings like hospices, care homes, and hospitals do not represent safe spaces to disclose important aspects of their identity, or to demonstrate affection towards their partner at a time when they may feel more vulnerable. The research suggests that these factors are leading LGBTQ+ people to delay access to services.

The benefits of early access to palliative care are well-established, particularly for people with terminal cancer, where earlier involvement of palliative care services can:

- improve quality and length of life
- result in fewer hospital admissions and reduce the likelihood of dying in hospital
- help family carers to have lower levels of anxiety and depression.

If LGBTQ+ people are delaying or refusing access to health and social care support at home at the end of life, it may also mean that they are relying heavily on family and friends to provide informal care, which in turn places significant strain on people without adequate support from health and social care professionals.

Further, anecdotal evidence from the studies suggests that palliative and end of life care services may not always ensure LBGTQ+ patients and their families have the same spiritual and emotional needs addressed at the end of their life as any other patient. Gay men in particular may be concerned they'll be treated with hostility by church-affiliated providers of hospice care with the chaplaincy often (at least in NI) being populated by people who are unwelcoming to LGBTQ+ people, leaving them with nowhere to turn for emotional support.

Service providers must consider the role of recognised and unrecognised religious affiliations in delivering a holistic approach to end of life care which considers the whole person and what is important to them.

4.5. People with learning disabilities

The Learning Disabilities Mortality (LeDeR) Programme showed that, in England in 2016, the proportion of people with learning disabilities who died in hospital (64%) was considerably greater than that of the general population (47%). Of those people with learning disabilities who didn't die in hospital, 30% died in their usual place of residence (which included their own or family home, and residential or nursing home), and just 2% died in a hospice or palliative care unit. Younger people with learning disabilities were more likely to die in hospital than older people were, with 76% of those aged 24 and under dying in hospital compared to 63% of those aged 65 and older.

LeDeR also found that of the 828 people (out of 1,244) for whom the severity of their learning disability was recorded at notification, those with profound or multiple learning disabilities were more likely to die in hospital (71%) than other people with learning disabilities (59%). They were less likely to die at their usual place of residence (23%) compared to other people with learning disabilities (35%).

The health inequalities faced by people with learning disabilities are well documented. What demonstrates this most clearly is that on average people with learning disabilities die 15-20 years earlier than people in the general population.[92]

According to Mencap and figures taken from the Office for National Statistics, there are approximately 1.5 million people with a learning disability in the UK.[93] It's thought that up to 1 in 4 people with a learning disability have a severe disability.[94] There are however no official statistics available for how many people with learning disabilities die annually or where they die.

While someone with a mild learning disability may be able to do most everyday activities but might need some additional support for tasks, such as managing finances or filling out forms, people with a severe learning disability will need more care and support with areas such as mobility, personal care and communication.

Everyone who has a learning disability is unique, with their own experiences, needs and preferences. People with learning disabilities face the same challenges as other people at the end of life, they have all the same palliative care needs, but they may have additional needs due to their disability. In particular, around understanding complex health information and making decisions about their wishes, including about where they would like to be cared for and where they would like to die.

It's often been assumed that for almost every person with learning disabilities, the best place to die is at home[95], but as found in the Veronica project (see box) dying at home is not always the best option.

There are lots of issues that can be challenging for people with learning disabilities towards the end of their life because people with learning disabilities[96]:

- may have more physical and mental health problems and these can be complex

- are more likely to be vulnerable and socially isolated
- may have difficulty accessing healthcare systems and understanding complex, sometimes euphemistic, language used by clinicians
- are more likely to be diagnosed with cancer later which means they have a poorer prognosis
- have a higher risk of dementia – people with Down's syndrome may also have dementia at a much younger age than average
- may have communication difficulties which make it harder to express their symptoms
- are more likely to be impacted by "diagnostic overshadowing" where clinicians assume that symptoms are because of a person has learning disabilities, rather than being a symptom of something acute
- may find it harder to express their wishes about their care
- may conversely find it easy to express their wishes, but clinicians may be unwilling or unable to understand their wishes because the clinician has made assumptions about their capacity to do so.

Providing the best person-centred care involves identifying and addressing these additional needs and challenges, and this involves addressing assumptions about the preferred place of care and death.

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The Veronica Project [97]

The Veronica Project was an in-depth study of 13 people with learning disabilities who had cancer, conducted over three years in the late 2000s by Professor Irene Tuffrey-Wijne. The study found that despite repeated assumptions that 'home' was the best place for people with a learning disability to die, this was not always the case.

The Veronica Project found that the important factors of a good place of care included being in safe surroundings with familiar people, being free from pain and anxiety, and having carers who were well supported. While an individual's preference was a factor in influencing place of care, illness trajectory and the availability of social and outside support also played a significant role in deciding where a person could be cared for.

It was previously considered that people with learning disabilities should be cared for in familiar surroundings and be supported to die at home, but Tuffrey-Wijne has advocated for a change in this assumption since the Veronica Project's research, instead suggesting that the question of preferred place of care and death is complex and it would therefore be a mistake to assume that dying at home is best for this group of individuals.

Of the 11 people interviewed who were terminally ill and died in the course of the project, four lived in their own flats and seven in staffed residential care, where they had been for several decades, at the time of diagnosis. At time of death, only three died in their usual place of residence (one died in his own flat and two in their residential care home) while two died in a hospice, two in a nursing home and two in hospital. Tuffrey-Wijne noted that if any of the people in the Veronica project had been asked in the months before their deaths where they would like to be cared for and where they would like to die, most would have said 'here, where I am living now', but it's also noted that of the two who did expressly say this, they both changed their minds when their health deteriorated further.

The Project found that there were a number of factors influencing choices about place of care, with several people realising that 'home' was not a realistic option because their needs changed in ways they couldn't have foreseen. It is noted that project participants became aware that their families, friends and carers were unable to cope with the additional care and didn't want to burden them and tried to protect their carers and changed their minds about their preferred place of care and of death.

Ultimately the project demonstrated that there are serious challenges to providing people with learning disabilities with a meaningful choice about their place of death, not least because many didn't view their normal place of residence (ie a residential care home) as 'home' to begin with, but also because the staffing and other financial resources to support a person with a learning disability, with increased care needs, to die in a place of their choice were most commonly unavailable.

4.6. People from low socioeconomic groups


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Socioeconomic factors have been shown to affect palliative care provision, including access to preferred place of death. A number of UK-based studies show links between place of death and social class[98], with people from higher socioeconomic groups more likely to die in community settings and less likely to die in hospital, than people from lower socioeconomic groups.[99] Surveys have repeatedly shown that, when asked, two-thirds of the population say they would prefer to die at home, and this remains the case regardless of whether one is a homeowner, a private renter or a social renter.[100]

A recent study reviewed existing qualitative evidence on the effects of socioeconomic status and preferred place of death. It found that, regardless of socioeconomic status, the size and composition of an individual's support network had a significant effect on preferred place of death and the ability to die there, with a number of papers suggesting that living alone meant that it was not realistically possible to die at home[101] (see next chapter). However, the study also found that there was limited evidence that socioeconomic status was a barrier to accessing a person's preferred place of death at an individual level, with the only evidence of social class having an impact being that a person from a higher socioeconomic group was more likely to be more vocal in requesting the care and support they needed.[102,103]

The interaction of socioeconomic status with place of death

In 2018 one study, published in *BMC Palliative Care,* [103] explored the interaction of socioeconomic status with place of death through interviews with palliative care doctors who provided home-based care.

The study participants identified three key factors that impacted a patient's ability to have a home death. These were:

- a preference for home death
- a strong support network to supplement professional care
- suitable, stable and safe housing for meeting their needs and those of their caregivers.

For example, in point three above, a home environment was considered suitable if it was able to accommodate medical equipment, if care providers had access to basic amenities and if it was free of hazards.

"Sometimes a place is so small or cluttered that you can't put a hospital bed in there, or sometimes there's vermin in the dwelling, so [also] physical factors of them not being able to get from one place to the other, not having access to the washroom or a shower." (Participant 1)

Participants felt that patients living without access to reliable or subsidised housing were more likely to die in an institutional setting.

"It's not a widespread problem but for the people who don't have access to housing, it is a big problem" (Participant 9)

The safety of the home environment also influenced the ability to provide care for patients at home. The safety concerns described were typically associated with lower-income situations, and included living in neighbourhoods with run down buildings, a higher prevalence of mental health issues, and substance abuse issues.

"The other piece is safety. In a lot of these places, can we have things like opioids and controlled substances in a place where if they're alone they need to keep the door unlocked and so who is going to go in and potentially affect them… a lot of these places unfortunately are deemed unsafe." (Participant 3)

"One of the barriers, especially in my area is a lot of those areas are what we call 'no go' zones at night. So, if someone calls after hours or when it's dark, a doctor isn't going to go out to see them because it's unsafe." (Participant 5)

While a higher socioeconomic status was not identified as a primary determinant of a home death, it was consistently noted that it improved the other contributing factors because people had better health and health care understanding, a higher capacity for advocacy, a more stable home environment, and more caregiver support.

Figure 1. Overall quality of care by deprivation quintile in the last three months of life, England, 2015

Source: ONS. Significantly more people with the most deprived status have care rated as fair or poor (29%) compared with the least deprived group (22%).

The 2015 VOICES survey found that there was a pattern of overall quality of care which existed when considering the level of deprivation of a person's usual area of residence. The survey found that while there was no difference in the proportion of people rated as receiving outstanding care by deprivation level, there was an association between greater deprivation and ratings of poor care (see above).[104]

Another key finding from the VOICES survey included that significantly more respondents of patients who lived in the least deprived quintile felt the patient had enough choice about where they died (54%) compared with those who lived in the most deprived quintile (44%).[105]

In 2015 a review of evidence by LSE, commissioned by Marie Curie, found that people in more deprived areas were less likely than those in the least deprived areas to feel they had sufficient support to care for someone dying at home. They were also more likely to die in hospital than at home. The analyses controlled for age, sex, diagnosis, whether the decedent had a spouse or partner and ethnic background. The review stated that the reasons for these differences between areas were unclear, but suggested that it could be due to housing in more deprived areas providing a less suitable environment for end of life care, or that people from more affluent areas could pay for additional support.[106]

In 2014, Marie Curie published a report on the role of social housing providers in supporting terminally ill people in Wales.[107] The report looked at the experiences of social housing providers in supporting their tenants in achieving a high-quality end of life and built upon the recognition that more needed to be done to support people dying in the community and that social housing providers can be key partners in achieving this. At the time in Wales, the social rented sector constituted approximately 17% of all households (over 225,0000), 0.7% of which were considered 'extra care'.

The housing providers involved in the project identified a number of challenges for delivering end of life care consistently for their tenants. These included, a failure to recognise death and dying as a relevant issue for their involvement (ie not seeing a tenant's illness as being their responsibility), staff not having support to engage with tenants about their wishes, misunderstanding about what housing could deliver, lack of coordination and communication with other providers, and funding (ie Continuation NHS Healthcare packages not being agreed).

> *Regardless of socioeconomic status, the size and composition of an individual's support network had a significant effect on preferred place of death and the ability to die there, with a number of papers suggesting that living alone meant that it was not realistically possible to die at home*

Dying in the margins: uncovering the reasons for unequal access to home dying for people living in poverty

In 2019, The Economic and Social Research Council awarded researchers at the University of Glasgow and at Marie Curie a grant to explore the barriers to, and experiences of, dying at home for people living in poverty in the UK in both urban and rural locations.

The new research aims to understand the home environment and the lived experience at end of life for people who are socio-economically deprived and will explore:

a) how the home environment is perceived, modified, and made use of over the course of the illness trajectory

b) the influence of type of housing and material resources on end of life experiences and ability to die at home

c) similarities and differences within and between the urban and rural context.

The study will pioneer ethically sensitive and inclusive methods to engage those with the lived experience of socio-economic deprivation in urban Glasgow and rural Dumfries. To do this, the researchers will use digital storytelling, professional photography, interviews, focus groups and observation. The study is due to run until September 2022.

4.7. Older people who are living alone

The ageing population in the UK presents a number of challenges for health and social care delivery and will have a significant impact on palliative care services as older people suffer from an increasingly complex range of comorbidities.

Most policy discussions about the importance of a person being able to have a choice in place of death, assume that people will have family members or close friends around to provide informal care for them, to supplement the formal care, at home. Increasingly however, this can't be assumed, with the number of older people living alone expected to rise to more than 4.5 million by 2041[108] and the growth in adult children living further away from their parents.[109] For an increasing number of older people in the coming decades, living at home will mean living alone – and dying at home could mean dying alone. This is especially acute for elderly women who may have cared for their (male) partner at home and now not have a home death option available to them due to lack of available care.

There's a significant body of evidence that suggests that people living alone with terminal illness have more hospital admissions and are less likely to die at home than people who have family carers.[110] There's also evidence that many older people – especially people who have been widowed or are separated – see the fact that they live alone without access to close relatives as precluding them from considering a home death.[111] More and more people are living alone into old age, and dying at home is still perceived to be the ideal, from a policy perspective at least.

It's especially difficult for those living with chronic degenerative conditions (see next chapter), increasing frailty and mental incapacity[112] – all hallmarks of conditions which affect predominantly older people – to be cared for at home, especially when an increasing number will be living alone in the coming years.

In the 2015 review conducted by LSE, it was 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.[113]

The review also demonstrated that there was a gender imbalance in being able to die in a place of choice because, despite a narrowing of difference in life expectancy between men and women, women still tend to outlive male spouses and are more commonly carers for men than men are for women, and therefore more likely to be living alone following the death of their male partner.[114]

The LSE review also found that people with spouses or partners were those most able to die at home and were found, through analysis of the VOICES survey, to be most likely to access community-based services such as hospice at home. The benefits of having a spouse or partner didn't stop at being able to die at home, it was also found that people with spouses or partners also experienced better pain control and were also more likely to experience better quality overall care, and more likely to experience 'excellent' care from GPs, care homes and out-of-hours services. It was suggested that this may be because spouses and partners act as advocates, informal care coordinators and direct care providers.[115]

Other research has shown that older people perceive factors they associate with 'home' as crucial to a good death, most notably presence of friends and family, but some anticipate that they would prefer to be cared

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for elsewhere when dying. This runs counter to assumptions that the medicalised, institutional death cannot be a 'good death'. It's important that dying in hospital is not demonised, but rather efforts made to examine how institutional deaths can take on a more meaningful quality.[116]

In February 2020, Professor Chris Whitty, England's new Chief Medical Officer, warned that drastic action was needed to cope with the number of patients aged over 65, noting that rural districts and coastal towns with older populations often lack essential medical services such as GPs, hospital clinics, ambulances and out-of-hours providers.[117]

Professor Whitty was quoted as saying "The ageing of the population of rural areas will occur much faster and there will be a much higher concentration of people who are older who therefore have more health needs in the rural areas. We have to think about this both for now and also accordingly for the future, this is a future issue. If we did nothing on this, we'll get to a situation where the burden of disease for the country – the number of people who are actually suffering from lots of long-term medical conditions – will go up and service delivery will stay where it is.

"The gap between what people need and what people get will widen. We have under-appreciated how much in the future this is going to be an issue. This is predictable and it's solvable, provided we take a long run at it."

The issue Professor Whitty raised is particularly applicable when considering where elderly, rural, patients will die in the future and how they can be supported to die in a place of choice.

Older people living alone at the end of life in the UK: research and policy challenges [118]

In a discussion paper published in *Palliative Medicine* in 2010, researchers noted that older people who live alone face particular challenges if they are to age and die well in the place and manner of their choosing.

The paper examined the experiences and needs of older people living alone towards the end of life particularly focusing on the fact that end of life care policy and service development initiatives post-2008 prioritised home as a place of support and care. But, the authors noted, the policy initiatives failed to acknowledge diversity in the older population and make little provision to meet the specific needs that older people living alone may have as they approach the end of life.

They identified three broader social factors that influence whether older people who live alone can remain at home until the end of their lives:

1. their physical environment, ie the nature of housing available and the accessibility of neighbourhood amenities
2. their material environment, ie on average older people spend a higher proportion of their household income on housing, fuel and food, and although many older people own assets such as their home, their incomes tend to be comparatively low and this is especially the case for women and those living alone
3. their social environment and supports ie their formal and informal care networks.

The increasing demands placed upon services by older people living alone at the end of life was identified, with people requiring considerably more assistance with hygiene, more home help and other liaisons with health and social services than people who had informal carers present to assist. The authors questioned how realistic it was for patients to be supported to die at home, if they chose, given the need for guaranteed 24-hour care and support and back up from appropriate specialists.

4.8. People with dementia

One third of people aged over 65 will die with dementia. It's the most common cause of death in the UK and the incidence is increasing. According to the ONS, in 2018 deaths due to dementia and Alzheimer's disease in England and Wales, accounted for 12.8% of all registered deaths, remaining the leading cause of death and continues to rise.[119]

It's estimated that by 2040, 220,000 people with dementia will die each year. Yet despite being the most common cause of death in the UK, we currently don't know the best way to provide care for people with dementia and their families in the last months and years of life.[120,121]

In 2015 Marie Curie published a series of reports looking at living and dying with dementia in England[122], Scotland[123] and Wales[124]. The reports identified several barriers to accessing end of life care services for people with dementia, including the lack of recognition of dementia as a terminal condition, advance care planning not being done early enough and a failure to refer people with dementia to palliative care services.[125] The reports also demonstrated that there were inconsistent care standards for people with dementia accessing palliative care services, with services often only being accessed when a person has reached crisis point.

The failure to engage with people about advance care planning early enough in their dementia journey significantly impairs the ability to understand what's important to someone and the choices they wish to make. Not just personally significant lifestyle decisions about what someone wants to eat, or what calms them, but more familiar decisions about where someone wants to be treated and important medical decisions such as whether to refuse CPR or other invasive treatments. Where someone has not been able to express wishes and preferences about their own end of life care, the decisions fall to the healthcare professionals and the family and carers, which may result in distressing hospital visits and unwanted aggressive treatments being delivered.[126]

The end of life care trajectory for people with dementia can be much more prolonged and uncertain than for acute illnesses such as cancer and people with dementia also often struggle with daily living and taking care of themselves at an earlier stage than those with some other conditions due to the nature of the symptoms. As a result, many people with dementia will find themselves living and dying in care homes.

According to a report published by Public Health England, and the National End of Life care Intelligence Network in 2016, the place of death for people that die with dementia in England is significantly different from all other deaths. Nearly two-thirds of deaths with a mention of dementia for people aged 65 and over occur in care homes compared to a quarter of all deaths for people aged 65 and over. While people with dementia are less likely to die at home (8%) compared to all deaths for people aged 65 and over (21%).[127]

As with many conditions, most people with dementia would like to die at home or in their usual place of residence (ie a care home), but a significant proportion of people with dementia are likely to die in hospital[128] and it's still unusual for people with dementia to die in a hospice. Recently published data from the ONS reveals the scale of the problem, with only 10% of people with dementia dying at home, and 64% dying in a care home, compared to

Figure 2. Place of death for people with underlying cause of death listed as dementia and Alzheimer's disease (ICD-10 F01, F03 and G30) in England and Wales, compared to the five-year average of all-cause deaths (2015-2019)

Place of death	Total dementia and Alzheimer's disease deaths England and Wales 2018	Percentage of dementia and Alzheimer's disease deaths 2018 %	Percentage of all-cause deaths, five-year average 2015-2019 %
Hospital	17,020	25	47
Home	6,696	10	24
Care home	44,737	64	22
Other	1,001	1	8

Source: ONS – Number of deaths caused by dementia or Alzheimer's disease by place of death, England and Wales: 2018[129] compared to five-year average deaths by place of death, England and Wales, that occurred between 2015 and 2019[130]

24% and 22% respectively of all-cause deaths based on the five-year average.

In Scotland, in 2018, there were 6,484 deaths where dementia or Alzheimer's disease was the underlying cause, with most occurring in care homes (61% of males and 72% of females). Men were more likely to die in hospital than women (31% and 19% respectively), and only a relatively small proportion of deaths occurring at home or in another non-institutional setting (8% for both sexes)[131], compared to 11% (home and other) in England and Wales. While in Northern Ireland in 2017, 62% of deaths registered with an underlying cause of Alzheimer's disease or dementia occurred in a nursing home.[132]

The likelihood, however, is that the number of deaths from dementia is currently being significantly under-reported, due to difficulties in diagnosis, particularly during the early stages of dementia, and because it is difficult to identify the number of people dying as a result of dementia as many are not directly attributed to dementia, but rather to the immediate cause of death, such as an infection or another coexisting condition.[133]

Enabling people with dementia to remain in their usual place of residence is considered an essential component of good care.[134] For people with dementia the move to a hospice (or any other unfamiliar care setting such as a hospital) can cause unnecessary confusion and distress at a stage in the condition when the person may be less able to cope with change.

Becoming a dementia friendly hospice

In 2017 the Marie Curie Hospice, Cardiff and the Vale pledged to work towards becoming a dementia friendly hospice, in line with Alzheimer's Society's Dementia Friendly Communities initiative. A group of people with dementia and their carers visited the hospice to provide feedback on how the hospice's physical environment could be improved to be made more accessible for people with dementia, and their feedback helped shape the delivery plan.

The hospice has subsequently made the following changes, amongst others:

- Improved bilingual (Welsh/English) and pictorial signage in the hospice to identify key rooms such as toilets and lounges.
- Installed 'calendar clocks' which clearly show the date and time and are colour contrasted for easy identification, to support patient orientation when on the wards.
- Developed a dementia resource kit for each ward which contains various items to support patients with dementia, including items to support sensory stimulation and reminiscence.

Some of these changes will improve the accessibility of the hospice more widely, such as the pictorial signage which can also be helpful for people with learning disabilities and those for whom Welsh or English is not their first language.

They may therefore not be considered an appropriate environment for care without adjustments being made to make the setting more accessible for people with dementia.

We must therefore consider how well social care and palliative care services are designed to be accessible for people with dementia so that an individual can routinely access palliative care, regardless of where they live.

The progressive and degenerative nature of dementia, coupled with current and projected levels of dementia diagnosis, mean that it's essential we explore how we can make all relevant health and social care services more dementia friendly and appropriate, particularly for those approaching the end of life.[135]

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The cost of social care for people living with dementia will nearly treble by 2040 [136,137]

In 2019, a report by the Care Policy and Evaluation Centre (CPEC) found that the cost of social care for people living with dementia will nearly treble by 2040.

The research, which was commissioned by Alzheimer's Society, showed that by 2040 the number of people living with dementia in the UK is expected to nearly double (to 1.6 million), but that the cost of social care is expected to almost triple, increasing from £15.7 to £45.4 billion.

The analysis found that the number of people living with more advanced dementia will rise more rapidly than the number of people living with mild and moderate dementia. And, as the likelihood of living in a care home increases with severity of dementia, this means that in future a higher proportion of people living with dementia will live in care homes rather than receive care in the community. As such, people will have higher associated care needs and more people will need social care for longer, increasing average social care costs.

The research showed that all four countries of the UK face very substantial costs of dementia. Northern Ireland is projected to have the largest increase, with the number of people living with dementia rising by 95%, while in Wales it is an increase of 70%, the smallest increase among the four countries.

The study also estimated that families are already providing £13.9 billion a year in unpaid care for people living with dementia, which is projected to increase to £35.7 billion by 2040.

The total cost of dementia to the UK economy has risen to £34.7 billion and will continue to rise to £94.1 billion by 2040. This includes costs to the NHS, paid social care and unpaid care.

5. The disproportionate impact of the covid-19 pandemic

From very early on in the coronavirus pandemic it became clear that covid-19 didn't affect all people equally. Several analyses have shown that older age, sex, occupation, and geographical area amongst others are associated with increased risk of becoming infected, severity of symptoms and death, with the impact on ethnically diverse groups being especially profound.[138]

Evidence suggests that people of Bangladeshi ethnicity have experienced twice the risk of death when compared to people of white British ethnicity. People of Chinese, Indian, Pakistani, other Asian, Caribbean and other Black ethnicity had between 10 and 50% higher risk of death when compared to White British people. The inequality in covid-19 mortality between ethnic groups is the opposite of that seen for all causes of death in previous years.[139]

Studies of covid-19 to date have suggested that there are other factors that compound the risk of catching covid-19 for people from ethnically diverse groups. These include occupation, because many key worker occupations have a high proportion of ethnically diverse workers, and where a person lives, because ethnically diverse people may be more likely to live in urban areas, in overcrowded, multi-generational households, often in deprived areas.[140,141]

Ethnically diverse communities were also more likely to be at increased risk of poorer outcomes once they acquired the infection because there are some co-morbidities which increase the risk of poorer outcomes from covid-19 that are more common among certain ethnic groups. For example, people of Bangladeshi and Pakistani background have higher rates of cardiovascular disease than people from white British ethnicity, and people of Black Caribbean and Black African ethnicity have higher rates of hypertension compared with other ethnic groups.[142]

But it isn't just the immediately apparent health and socioeconomic inequalities that increased the impact of covid-19 on ethnically diverse communities. Historical racism plays a role too. In particular a lack of trust in health services due to persistent discrimination leads to many people delaying going to hospitals and other healthcare providers. This issue was discussed in a report for the Welsh government that explored the impact of covid-19 on ethnically diverse groups:

> *The overall theme… is the impact of longstanding racism and disadvantage and lack of BAME (Black, Asian and Minority Ethnic) representation within decision making to effect better socio-economic outcomes. Although many of the issues highlighted have been identified and discussed previously, they have not been addressed in any systematic and sustained way. The coronavirus pandemic is, in some respects, revealing the consequences of such inaction on race equality.*[143]

While Public Health England also said:

> *Stakeholders pointed to racism and discrimination experienced by communities and more specifically by BAME key workers as a root cause affecting health, and exposure risk and disease progression risk. Racial discrimination affects people's life chances and the stress associated with being discriminated against based on race/ethnicity affects mental and physical health. Issues of stigma with COVID-19 were identified as negatively impacting health seeking behaviours. Fear of diagnosis and death from COVID-19 was identified as negatively impacting how BAME groups took up opportunities to get tested and their likelihood of presenting early for treatment and care. For many BAME groups lack of trust of NHS services and health care treatment resulted in their reluctance to seek care on a timely basis, and late presentation with disease.*[144]

The mortality rates from covid-19 in the most deprived areas were more than double the least deprived areas, for both males and females, while survival among confirmed cases, after adjusting for sex, age group, ethnicity and region was lower in the most deprived areas, particularly among those of working age where the risk of death was almost double the least deprived areas.[145]

Public Health England found that up to 21 May 2020 a larger proportion of patients critically ill in intensive care units with covid-19 were from the most deprived quintile of areas (25.0%) than the least deprived (14.7%).[146] While a report for the Northern Ireland Department of Health in June showed that the infection rate in the 10% most deprived areas was a fifth higher than the rate in the 10% least deprived areas and two-fifths higher than the NI average. While the rate in urban areas was 90% higher than the rate seen in rural areas, the rate was highest in mixed urban/rural areas.[147]

Almost as soon as cases of coronavirus began being reported globally it was found that people over 70 were particularly at risk of catching, and dying from, covid-19. According to Public Health England, the largest disparity their research found was by age, where among people already diagnosed with covid-19, people who were 80 or older were seventy times more likely to die than those under 40.

As dementia is a disease that predominantly affects people later in life, and who are frequently living in care as a result, this combination of factors made the virus even more dangerous for this group of people. Coupled with the loss of routine, the lack of familiar faces as personal protective equipment became necessary and the social distancing measures introduced, this group of highly vulnerable individuals have been significantly impacted. Since the start of the pandemic, 49.5% of care home resident deaths have involved covid-19.[148,149] Dementia is mentioned in 25.7% of death certificates where covid-19 was also mentioned. Prior to the pandemic, dementia deaths accounted for just 35% of all deaths in care homes, with circulatory diseases (22%), cancer (18%) and respiratory diseases (10%).[150]

The Vivaldi study, a large-scale survey commissioned by the Department of Health and Social Care, looked specifically at infections in care homes which provide care for people with dementia and older people across England. It estimated that over half of the 9,081 care homes in the study have had at least one confirmed case of covid-19 among their staff and residents.[151]

Similarly, the impact on people who are homeless has also been significant. For example, in one study there were 54 men and 13 women diagnosed with covid-19 with no fixed abode, likely to be rough sleepers. This represents 2% and 1.5% of the known population of women and men who experienced rough sleeping in 2019.[152] People who are homeless may be disadvantaged by an inability to self-isolate, as may be the case for Gypsies and Travellers, seasonal migrants in communal accommodation and asylum seekers and refugees.[153]

The beginning of the coronavirus pandemic saw the emergency building of field-style hospitals across the UK. At the same time, critical care capacity was increased significantly through cancelling non-urgent surgeries, 'nationalising' private hospitals, asking existing hospitals to add makeshift covid-19 wards and re-purposing non-essential wards in order to increase in critical care bed numbers.

As infection rates and death rates increased across the UK in late March, the scale of the pandemic, its impact on hospitals and concerns about the lack of personal protective equipment for NHS staff becoming apparent, the challenge for care homes was only just emerging. Up to 10 April 2020, deaths in care homes accounted for just 10% of all deaths from covid-19 in England, however, this percentage increased dramatically with time and in the week ending 8 May, care homes accounted for a much greater proportion (43%).

One study found that deaths in care homes in England and Wales increased by 220%, while home and hospital deaths increased by 77% and 90%, respectively, during the first 10 weeks of the pandemic.

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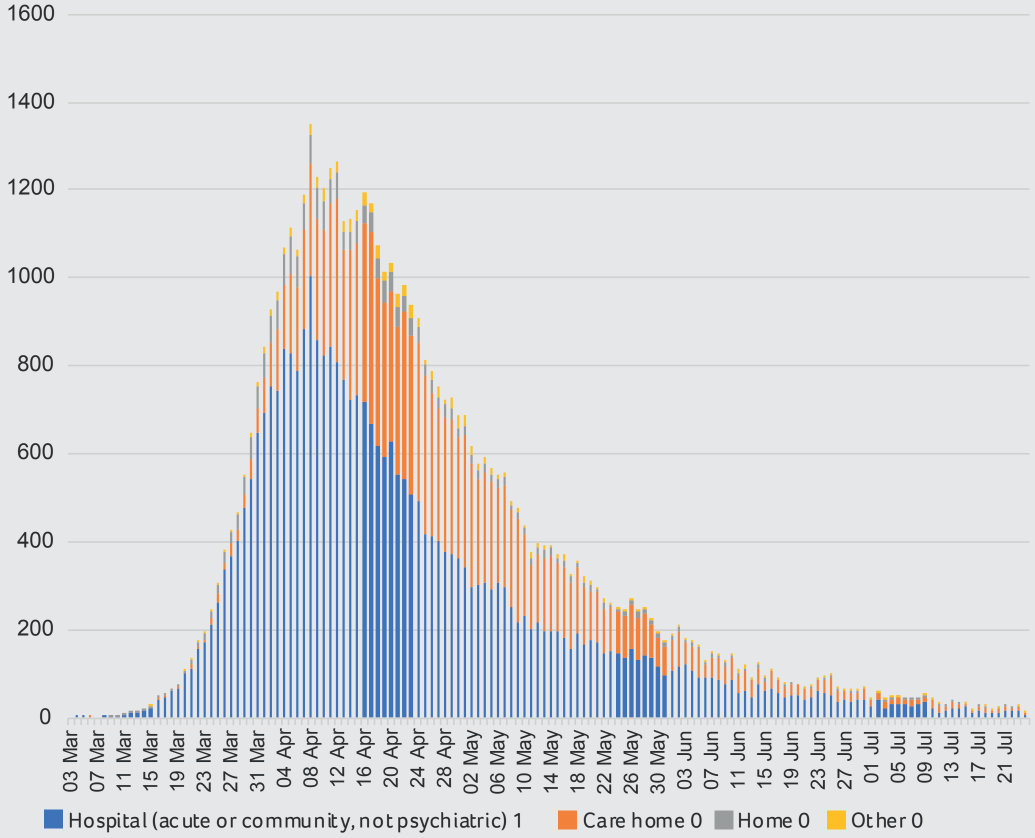
Figure 3. Number of deaths involving covid-19 by place of occurrence, England and Wales, occurring up to 4 September 2020, and registered up to 12 September 2020

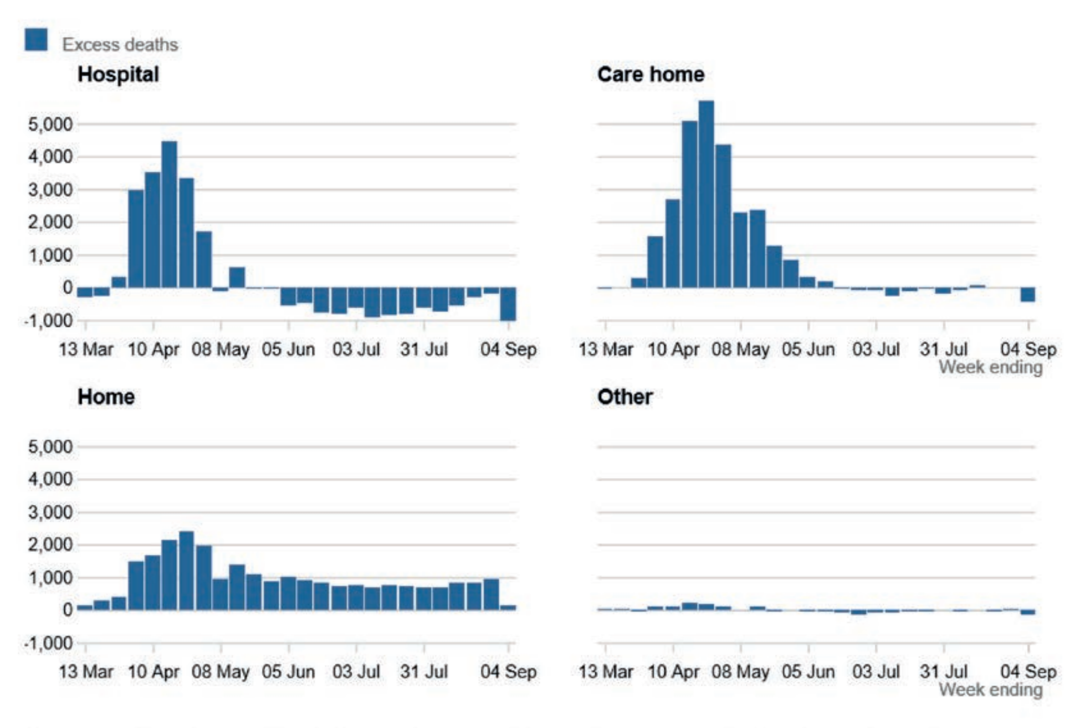


Source: Office for National Statistics, Deaths registered weekly in England and Wales[156]

Hospice deaths fell by 20% during the same period. Marie Curie's experience was that this may have been due both the reduced bed capacity in hospices to prevent outbreaks (ie no multi-bedded bays were available) and families, who had the capacity to care for someone at home, choosing to do so, to reduce the risk of infection and ensure they weren't cut off from visiting. Additional deaths were predominantly among older people (86% aged over 75 years), with most occurring in care homes (56%) and at home (43%). The researchers also estimated that 22% (13%–31%) of covid-19 deaths occurred among people who might have been in their last year of life in the absence of the pandemic.[154]

According to the ONS, in England and Wales, for deaths involving covid-19 up to week 36 (week ending 4 September 2020), 63.4% (33,214 deaths) occurred in hospital, with the remainder occurring in care homes (15,501deaths), private homes (2,485 deaths), hospices (750 deaths), other communal establishments (224 deaths) and elsewhere (202 deaths) as shown in the figure above.[155]

Figure 4. Number of excess deaths by place of occurrence, England and Wales, registered between 7 March 2020 and 4 September 2020



Source: Office for National Statistics – Deaths registered weekly in England and Wales

Source: Office for National Statistics, Deaths registered weekly in England and Wales[157]

By contrast, the Figure 4 above represents the number of excess deaths in each setting compared to the five-year average. While large peaks occurred in both hospitals and care homes (more than 4,000 and 5,000 excess deaths at the height respectively) in the early stages of the pandemic, the deaths in these settings have declined to levels below those seen in the past five years since June. This may be due to a number of factors, including fewer people being admitted to hospital and care homes reporting that new residents aren't moving in, and that in some instances, people who may have been in the end stages of life and would have been expected to die over the summer had already died during the peak of the pandemic. Excess home deaths, however, increased more slowly at the start of the pandemic, and at its peak reached more than 2,000, but has remained consistently higher than average ever since, indicating that people who would otherwise be being admitted to hospital, or moving to a care home, may be choosing to remain at home.

In Scotland, 46% of covid-19 deaths registered to date related to deaths in care homes. 46% of deaths were in hospitals and 7% of deaths were at home or noninstitutional settings. Across the UK there has been a significant increase in 'excess deaths' that don't mention

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covid-19, for example in Scotland where most excess deaths have occurred in care homes, ie between weeks 12 and 31 (16 March to 2 August) there were 2,349 (49%) more deaths in care homes than average. Covid-19 was the underlying cause in 1,875 (80%) of these excess deaths. In the same period, there were 2,925 excess deaths which took place at home or in a non-institutional setting (51% above average). Covid-19 was the underlying cause in 241 (8%) of these excess deaths.[158]

The coronavirus pandemic and the way people have died has brought into focus what matters most to people at the end of life, in particular, the importance of being supported by family and loved ones, regardless of the place of death. Despite all that we know about the pandemic, its disproportionate impact on ethnically diverse communities and others discussed above, the huge death tolls in hospitals and devastation wrought on care homes, we don't yet (and perhaps never will) have the data necessary to give us a detailed picture of where people from all the different groups died during the pandemic.

The coronavirus pandemic has shown us in a very short time what the future of end-of-life care may look like, albeit without a virulent virus and all the complications that brings, with increased numbers of people dying from more complex co-morbidities, and what will happen if we don't rapidly increase palliative care provision in all settings. Increasing the capacity in healthcare infrastructure, workforce planning, and the improved delivery of social care are all important factors that must be addressed if we are to future-proof end-of-life care.

6. Discussion – how do we make end of life care socially inclusive?

6.1. What are the critical services for achieving a ‘good death’ regardless of place?

The use of ‘death in usual place of residence’ as a proxy for a person achieving a ‘good death’, implies a range of associated benefits such as fewer aggressive treatments in the last weeks, days and hours of life, being close to family and friends and being in a familiar environment.[159]

There are countless interpretations of what constitutes a ‘good death’, but it is commonly thought that a variation on the following principles are important.[160]

- To know when death is coming, and to understand what can be expected.
- To be able to retain control of what happens.
- To be afforded dignity and privacy.
- To have control over pain relief and other symptom control.
- To have choice and control over where death occurs (at home or elsewhere).
- To have access to information and expertise of whatever kind is necessary.
- To have access to any spiritual or emotional support required.
- To have access to hospice care in any location, not only in hospital.
- To have control over who is present and who shares the end.
- To be able to issue advance directives which ensure wishes are respected.
- To have time to say goodbye, and control over other aspects of timing.
- To be able to not to have life prolonged pointlessly.

The idea of a good death is an important one in our contemporary death system – it both reflects and creates our beliefs about how end of life should occur, yet it is not without its flaws since a good death requires awareness and agency,[161] which may not be the case for many of the people in the groups discussed in this report. For some people, having the ability to choose where to die is not always possible. For some, home doesn’t exist, it’s unsafe, it’s not permitted, or the level of care is too great and options for where a person may choose to die either are, or become, limited. The oft-cited assumption that the majority of people prefer to die at home, and therefore the tailoring of end of life care services to meet this presumed preference is not appropriate for some people and may be detrimental to their end of life experience.

For example, more older people are living alone in the UK, thereby increasing the prospect of dying alone at home, which therefore tends to be regarded as bad deaths, in that they contravene notions of accompaniment and open awareness espoused in UK end of life care policies.[162]

As we will explore in this series of reports, despite national end of life care policies across the UK prioritising dying at home as a marker of quality, for the majority of people at end of life, this is not where they will be.

So what can be done to both maximise choice and ensure that, regardless of where death occurs, everyone has the best end of life experience possible?

Public policymakers and clinicians should perhaps avoid the assumption that people’s preferred place of death will be at home, or indeed, that where people die will be their only or even their most important consideration. It may instead be more important to focus on ensuring that regardless of place, everyone has the ability to have a 'good death', or rather, the best end of life experience possible. All end of life care settings must deliver high quality palliative care services that meet people's expectations for 'homeliness'. For some, the choice to die at home reflects a rejection of the 'institutionalised death' – dying in the unfamiliar, regimented surroundings of a hospital ward or in a nursing home, but when hospital equipment and staff take over a person's home the sense of familiarity and privacy may already be lost.

Focusing too heavily on where we die risks paying too little attention to the other things that are important to us in our final days and weeks – comfort, familiarity, social engagement and not feeling like we're becoming a burden to our families, and chiefly on making sure our symptoms are managed and we're pain-free. Often, clinicians know that it can be difficult to ensure that these other priorities are properly addressed when we are cared for at home.

With most of us likely not to die in our own homes – whether that's our own choice or because it's inappropriate for our circumstances – it's vital that death outside of the home is not automatically seen as a failure to experience 'a good death.' Rather than viewing this as a failure and resigning ourselves to the idea that people cannot experience 'a good death,' urgent consideration should be given to how deaths in institutional settings – especially hospitals but also hospices and care homes – can take on a homelier quality.

When people express a wish to die at home, they're not necessarily simply preferring one location to another. Our sense of home is provided by feelings of comfort, familiarity, privacy and independence, and by having our loved ones close by in our final days. But crucially, for each individual, different things will play a key role in providing this sense of home. So, by considering what else matters to people and seeking to satisfy all of our priorities and hopes for our death, to the fullest extent possible, we can aim to ensure that everyone is able to experience 'a good death' – wherever that may be.

Governments and private providers must consider how hospitals and other care settings can better incorporate and foster these feelings of 'homeliness' for people who are dying. Relaxing restrictions on visiting hours for the relatives of dying people, for example, and making a special effort to provide people at the end of life with access to a private space into which they can bring some of their personal effects, can help bring some of the familiar comforts of 'home' and ease feelings of being in strange, unfamiliar surroundings at the end of life. It's important to address this, not just for the person who's dying, but also so that we can support families and loved ones in their grief and bereavement by ensuring that their experience is a positive one. We need to be able to provide support for everyone, in all settings, to ensure that where someone dies isn't the defining feature of their death.

Similarly, making an additional effort to have dying patients seen by the same clinician – or small number of clinicians – during their final admission to hospital could help provide a vital sense of continuity for patients and their families, reducing the number of unfamiliar 'new people' they have to deal with, as seen with the LGBTQ+ people, and allowing them to spend as much time together as possible rather than repeatedly explaining their circumstances to different people. Continuity of care means that people only have to tell their story once and should be shared between settings when a person is moved as much as possible.

Whether we wish to or not, there's a good chance that many of us will ultimately end our lives in hospital. It's therefore vital that we take steps to reinvent the hospital as somewhere people can experience as meaningful and 'good' a death as they can elsewhere.

6.2. Is it always realistic to offer choice?

Throughout the discussion regarding choice in place of death and a person's ability to realise that choice, there's an undiscussed reality that it may occur at any time, and to anyone.

For example, a person may be admitted, have their symptoms controlled and be fit for discharge to a nursing home but not their own home, but if they don't want to go to the nursing home, their preference to remain in the hospice may conflict with limited capacity to care for them in that setting.

A second consideration is whether there's a link between disease/condition and a person's ability to exercise choice. Are some diseases just more likely to need care in a hospital when at end of life, regardless of whether or not the person is in receipt of all the home care packages they need? For example, someone with COPD and acute breathing issues may be more likely to need to be in hospital compared to someone with frailty at home. What if, for safety reasons, the person with COPD needs to be in hospital, but wants to stay at home? If there is such a propensity between disease and place of care, do we need to recognise this too and how do we, as palliative care services providers support people to have the best end of life care experience in such circumstances?

6.3. The role of social care in helping achieve choice in place of death and lessons from the pandemic

Social care is an integral part of the palliative and end of life care terminally ill people receive to help them live as well as possible right up until their death. Policies that promote care and death at home and seek to reduce hospital admissions can only be achieved by realising the role that social care has to play in allowing people to remain at home. Without addressing the need to provide adequate support and care at home for everyday tasks for people who are terminally ill, we cannot hope to provide people with the best end of life experience possible, in a place of their choice.

Long-standing, fundamental issues in social care across the UK including lack of sustained financial support, workforce challenges, particularly the lack of palliative and end of life care (PEOLC) training for social care staff. This inevitably impacts experience, and compromised systems have been laid bare as a result of the coronavirus pandemic. Currently, workforces have little/no PEOL social care training yet are expected to deliver it in people's homes. As a result, this has significantly impacted on the care terminally people receive in all settings.

The covid-19 crisis has emphasised that central and devolved governments must urgently review and reform current systems to become more integrated and proactive.[163]

A good example of how social care delivery was improved in England during the

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pandemic was seen through Fast Track NHS Continuing Healthcare (CHC). Fast Track NHS CHC is a funding programme, and if you're eligible, it pays for all your social care, including care home fees or carers if you're living in your own home. Fast-track CHC has been delivered to dying patients in a much shorter timeframe than before the covid-19 outbreak.

Over the last three years, Marie Curie has been highlighting the excessive waits that dying people face when trying to be discharged from hospital into their own home or a care home via fast-track CHC. CHC guidance states the care packages should be put in place within 48 hours. Prior to the covid-19 crisis only 40% of CCGs in England, who provided data, were able to meet this deadline.[164]

While we won't be able to assess CHC data from the crisis period for some time, however, in the areas where we're involved in the delivery of fast-track CHC, we've seen significant reductions in delays to putting care in place. In one area, the average waiting time between referral and a care package being put in place has dropped from one week to an estimated three hours.

Significant additional funding has helped much of this change to happen. But central to it has been a greater sense of urgency to do what's necessary, without delays caused by questioning the appropriateness of a patient being given Fast Track CHC. What this seems to suggest is that there are layers of pre-crisis bureaucracy and process in the NHS and social care that are detrimental to our key mission of getting the right care to people at the right time, in the right place. It should also be noted that improvements have not been universal and some issues remained for hospices. Non-acute trusts were not included in the initial changes and some areas were unable to commission care to facilitate discharges from hospital into hospice settings.

If we're to ensure that everyone is able to have the best end-of-life care experience possible, in a place of their choosing, we must recognise that right now there are significant barriers for a great number of people to achieve this and we must act to do more to ensure the barriers that perpetuate those inequalities are removed.

6.4. Conclusion

Following this report, we'll be embarking on conversations with people from each of these groups to talk about how the barriers they face impact their wishes for end of life care, what 'home' means to them as individuals and to reflect on the things that are most important to this. This will provide insight to help other care settings offer end of life care experiences equivalent to the much sought-after, idealised home death, for those for whom home isn't an option.

Everyone should have the right to express a choice on where they receive their end of life care and where they die, such as a place where they feel safe and secure, with access to pain relief medication and surrounded by friends and loved ones. Health and social care teams should have a duty to ensure that, where possible, this can be achieved and yet, for the many people in the groups explored in this report that is rarely the case, because too often the choice does not exist in the first place.

Healthcare systems need to do everything they can do deliver individual choice. But at the same time we should recognise that there may often be a challenge in the ability to meet a person's stated choice and the potential for that to be compromised by other circumstances as illness progresses. And, as people get older, frailer, with more complex co-morbidities there will undoubtedly be increasing friction between an individual's choice and the system's ability to deliver. Recognising this challenge and acting to improve end of life experiences for everyone means that whatever complications arise, a person's characteristics should not themselves be a barrier to achieving that choice.

In the next reports in the Place for Everyone series, we'll look at the factors that influence personal preferences for place of death, the trends and predictions for where we will dying in 2040, the policies that exist for end of life care and ultimately how they need to evolve to meet our future needs. A key contributor to people being able to be supported to stay at home is having informal carers in place, yet as we've seen in this report, even that may not be enough. We need to look at how health and social care delivery interact for people with palliative care needs and ensure that where heightened social care is necessary, as may be the case for the groups in this report, it's readily available in order to deliver care equitably.

Everyone should have the right to express a choice on where they receive their end of life care and where they die, such as a place where they feel safe and secure, with access to pain relief medication and surrounded by friends and loved ones

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For more information:

Richard Meade
Head of Policy and Public Affairs, Scotland
E: richard.meade@mariecurie.org.uk

Author: Victoria Stone

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Care and support through terminal illness