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THE FINAL INJUSTICE

Variation in end of life care in England

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CANCER SUPPORT

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Foreword



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It is often said that dying is the great equaliser. It is one of life's only milestones that happens to every single person, regardless of wealth or status or situation. But at Macmillan, we have seen that the way we die can be far from equal.

How we treat people in their dying months shows the value that we, as a society, place on life – and at Macmillan we believe that there is such a thing as a 'good' death. At a time when you are at the mercy of medicine, and of your own body, you can feel extremely disempowered and out of control. And, as a family member, you can feel that everything is happening *to* you and *around* you. I know from personal experience how disorienting this can be. But having genuine choice about how you are cared for and where you spend the last days and hours of your life can help address this. It can also have a lasting and meaningful impact on friends and family left behind.

Macmillan wants everyone approaching the end of their lives to receive the care they need, be comfortable, and have their pain controlled no matter where they are being looked after.

We know that too many people don't have a 'good' experience at the end of their lives. There are still thousands of cancer patients dying in hospital in England when they wanted to die at home or in a hospice. What's more, over 12,000 patients a year in England aren't getting the pain relief they need in their final days. Too many families have their final months with a relative blighted by disruptive visits to A&E – as the people who have bravely shared their experiences for this report can testify.

The fact that people are suffering in their precious final weeks is heartbreaking. But the real injustice – and we have a growing body of evidence for this – is that your experience when you die can depend on where you live and who you are.

Over the last few years, the Government has committed to improving the situation in England, so that everyone gets the right care when they die, and has real choices. But, so far, Macmillan and the coalition of charities we work with has been disappointed with the lack of progress to deliver these changes.

In this report, we are calling for national and local action to ensure that everyone has access to the right care at the right time regardless of where they live.

Something as fundamental as dying with your basic human needs met should not differ. It should be something we can all count on, for ourselves and the people we care about, regardless of who we are.

Executive Summary

In July 2016, the Government made a 'National Commitment' to improve end of life care across England. This included making sure everyone has access to the right end of life care, regardless of geography, age, diagnosis, background or means. While this ambition at a national level is encouraging, more than a year later, we are disappointed with the lack of progress to bring about real change to people's experiences of care.

The Government's Commitment came with no extra funding – instead, it is set to be delivered through local sustainability and transformation partnerships (STPs) in England. However, when the End of Life Care Coalition – comprising of six charities including Macmillan – analysed the draft plans of STPs in England, we found that 41% of them had no mention or little detail of how end of life care would be improved.

We know that there continues to be unacceptable geographic variation and inequality in the end of life care people with cancer receive in their dying months. While some people have choices around where they die, and the chance to spend time with the people who matter to them, others spend their final year in and out of A&E, and have little opportunity to access the care of their choosing.

Something as fundamental as the care a person receives in their dying months should not depend on where they live or the level of deprivation they experience. However, the studies we cite in this report show that there continues to be inequality

in end of life care. The most deprived people dying due to cancer are 18% more likely to die in hospital, and have on average five emergency admissions in their last year of life. This is compared to four emergency admissions for those who are least deprived.

The human cost of this is difficult to quantify, but bereaved friends and relatives Macmillan has spoken to – some of whom are quoted in this report – describe distressing experiences when the people they cared about had repeat emergency admissions at the end of their lives. As for the financial cost, Macmillan recently carried out research on this with City, University of London and the Economic and Social Research Institute. We found that end of life hospital care for cancer patients in the most deprived areas of England costs the NHS an extra £4.6 million every year, for the four most common cancers alone. Clearly, a more sustainable solution that offers choice and quality care needs to be found.

Macmillan, alongside other charities, and organisations, has developed innovative service models and added resource to the system to provide better, more co-ordinated care for patients. Two examples of good practice – Macmillan Specialist Care at Home and the North Manchester Macmillan Palliative Care Support Service – are included in this report. But, with demand for end of life care set to substantially increase over the next twenty years, we urgently need the national and local health leaders to play their part.

In this report, we make the following recommendations:



The Department of Health must **clearly set out** how it intends to honour and resource its 'National Commitment' to end variation in end of life care.

The Department of Health and NHS England must ensure there is clear accountability for addressing variation in end of life care beginning with the **regular publication of metrics** from all CCGs and sustainability and transformation partnerships.



The **Secretary of State for Health must report annually** on the progress being made towards delivering the Governments 'National Commitment' in full by 2020.



Leaders from all sustainability and transformation partnerships along with local commissioners and providers must plan for, and provide, sufficient resources to deliver **high quality and personalised end of life care** to all patients.



The Department of Health and Health Education England must act now to address resource, staffing, and training requirements **to respond to projected increases in demand** for end of life care.

The Department of Health and National Institute of Health Research should commission research to understand the **disparity of experiences in end of life care** for the most deprived patients.



End of life care in England

What is end of life care?

End of life care is care that helps all those people with advanced, progressive illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life, especially the last 12 months, into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual, and practical support. The National Institute for Health and Care Excellence (NICE) quality standards for end of life care for adults [QS13] sets out markers of high-quality care including early identification, coordinated care, effective care planning and holistic support.¹

While the specific duration of any one person's end of life care will vary depending on their circumstances, numerous clinical trials have demonstrated that early access to this type of care can lead to fewer emergency hospital admissions, improved quality of life and more choice over how and where individual care is provided.² Early identification of patients who will benefit from end of life care is vital as it helps to improve the quality of life and experiences a person has during this time.

We know that for people approaching the end of life, being cared for and dying at home surrounded by loved ones is often the preferred choice. However, we also know that currently too many people's preferences are not being met. For example, 64% of people with cancer would prefer to die at home with the right support,³ yet less than a third (30%) do.⁴ Macmillan estimates that every year in the UK 62,000 people die of cancer in hospital, despite the majority of people with cancer stating that they would like to die at home.⁵

'My father was diagnosed with lung cancer and just four weeks later passed away at home ... However, it wasn't easy to make happen and was extremely challenging to manage as a family. The care he required often left us feeling overwhelmed and bereft ... There is not enough support to make end of life at home feasible for everyone and for those that do make this happen the experience could be so much more improved.'

Hayley

Each year in England, an estimated 48,000 people experience poor care in the final three months of their lives.⁶ And more than 12,500 cancer patients (10% of those who die in England each year) spend the last two days of their lives without adequate pain relief, according to a survey of bereaved relatives and carers.⁷ Enabling choice and improving people's experiences go hand in hand. **Real choice for people approaching end of life depends on the confidence they have that they will receive the right care at the right time in the place they choose to die.**⁸

Resources for end of life care

In 2017, there is predicted to be around 490,000 deaths in England. Looking ahead to 2035/36, this figure is predicted to rise by nearly 20% to over 580,000.⁹ With each year that passes we expect people to die at an older age, with more complex conditions. In addition, we know from published studies that demand for end of life care will see a considerable increase over the coming decades placing further pressure on currently stretched health and care services (See Figure 1).¹⁰

Current spending on end of life care in England is estimated to be £3.9 billion per annum¹¹ with previous estimates suggesting £1.8 billion spent caring for people with cancer alone in their last year of life.¹² It is therefore essential that the care people receive is not only of the best quality but is also financially sustainable.

Previous research by Macmillan and Public Health England shows that this may not always be the case. On average, around 22,000 (35%) of those who die each year from one of eight common types of cancer have five or more emergency visits in the

last year of their life. More than 3,000 (5%) of these patients have more than 10 emergency visits in their final 12 months.¹³ Not only is this distressing for patients and their carers but, in some cases, it can also drive up costs unnecessarily for the NHS.

Community end of life care – such as community nursing, palliative care, pharmacy, and occupational therapy to support people to stay at home – is one of the few interventions shown to be effective in reducing reliance on emergency and acute care. Access to community-based end of life care could feasibly save £104 million per year for cancer patients alone as a result of fewer emergency admissions and reduced length of stay.¹⁴ However, the limited availability of community and home care services means that hospitals are too often the only places where people can access care.

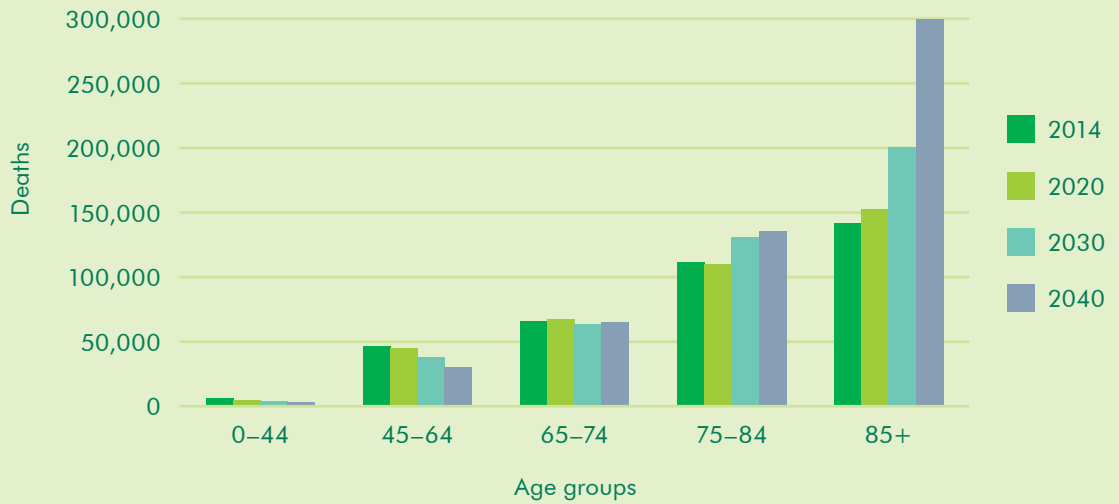
More must be done if people approaching the end of life are to have access to high quality and personalised care and support, particularly in community settings. This is not only in line with people's preferences, but has also been recognised as crucial by the Government.

Providing palliative care in the community: Macmillan Specialist Care at Home¹⁵

We have been working with six centres to pilot our Macmillan Specialist Care At Home service in different contexts across the country. This multidisciplinary team is consultant led and provides community-based care to people with cancer and other life-limiting conditions towards the end of their life. People are referred to the team early, allowing them enough time to build strong relationships, plan and provide practical and emotional support when needed. With Macmillan Specialist Care

at Home, we anticipate to avoid unplanned admissions, with people spending fewer days in hospital and being more likely to die in their preferred place of care. In the 102 VOICES questionnaires returned by bereaved carers from across the pilot sites, it was reported that where a preference for place of death was known, 79.4% of patients had died in that preferred place. A high percentage (88.3%) of respondents also felt that the person they cared for had died in the right place.

Figure 1 Demand for end of life care in England and Wales will increase in the next decades – number of people estimated to require palliative care by age, 2014–2040



Etkind et al. BMC Medicine (2017) (Reproduced under Creative Commons Attribution 4.0 International License <http://creativecommons.org/licenses/by/4.0/>) See reference 10.



The 'National Commitment'

In 2015 the Choice in End of Life Care Programme Board published its independent Review of Choice in End of Life Care (the Choice Review). This identified the issues people approaching the end of life were currently facing and sought to offer a national blueprint for how greater choice in end of life care could be achieved. The review emphasised that for most people approaching the end of life, being cared for and dying at home is the preferred choice.

'Hospitals are busy sterile places, with set routines and often understaffed, not a place anyone would choose to die. If there is time and a choice, it should be made available. It would also free up much needed bed space for the next patient in need.'

Sacha (whose Mum died from cancer)

However, we know that currently too many people's preferences are not being met. Just 1% of people with cancer want to die in hospital.¹⁶ Yet 38% of people – more than 62,000 – who die from cancer, die in hospital each year in the UK.¹⁷

Nationally there has been much recognition from Government and policy makers of the need to provide choice and good quality care at end of life. In July 2016, the Government published its response to the Choice Review **setting out a new national commitment that everyone at the end of life should receive high quality care tailored to their needs and wishes by 2020.**

Furthermore, the Government committed to:

- exploring and implementing new ways of delivering effective end of life care in community settings,
- working with partners to address inequality and variation of access to end of life care services, and
- ensuring Health Education England (HEE) plan for and develop the GP and community nursing workforces.

While these commitments are encouraging, the Government's response did not allocate any additional resource to implement any of the recommendations. This is despite the fact that the Choice Review recommended that an additional £130 million be identified in the next spending review and invested in social care and NHS commissioned services to deliver a national choice offer in end of life care. Instead, the Government indicated that the emerging sustainability and transformation partnerships (STPs) across England would be the key vehicle to ensure patient choice at the end of life is delivered. **However, analysis of these plans carried out by the End of Life Care Coalition in March 2017, revealed that 18 out of the 44 STPs had either no mention of end of life care or no details on how they plan to improve it.**¹⁸

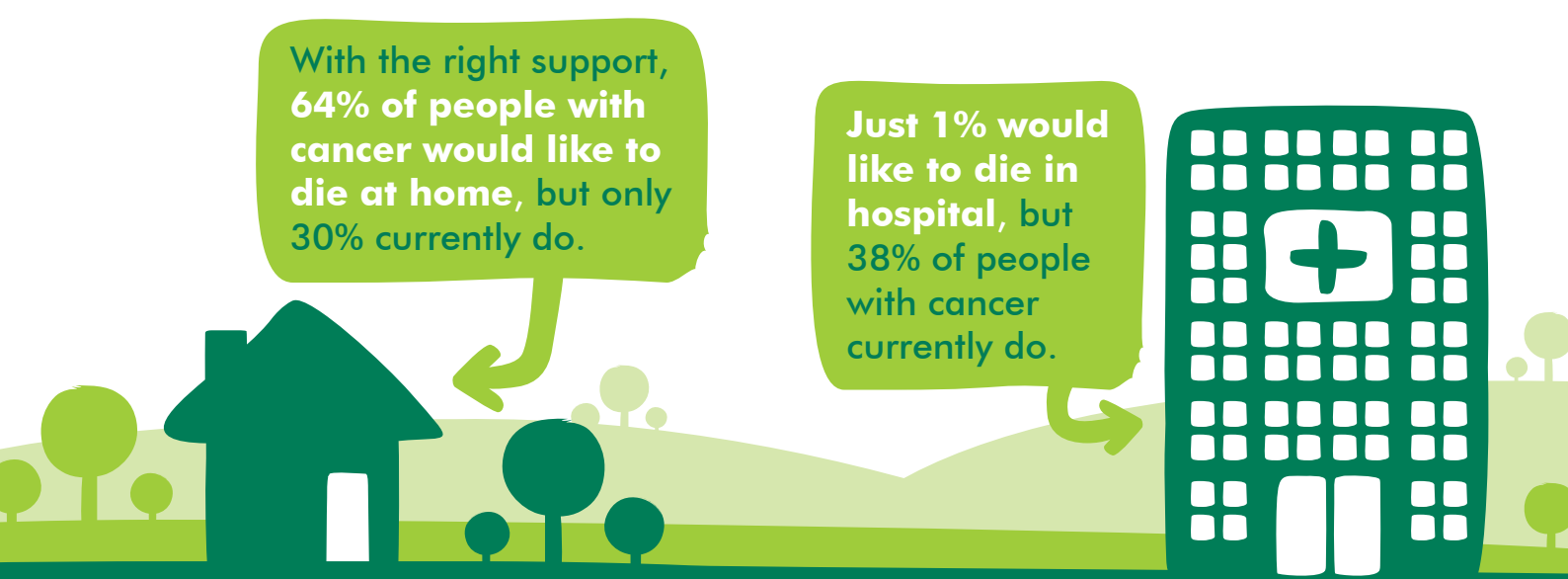
The Government's *One Year On* report highlighted that some progress is being made to deliver the National Commitment, including plans to support STPs to consider ways improved end of life care can progress their emerging priorities. There was also reference to the ongoing development of a metric on end of life care, for inclusion in the CCG Improvement and Assessment Framework for 2018/19.

However, Macmillan remains concerned that the gap in resources for community-based health and social care services has yet to be addressed and we feel there is a long way to go to translate the commitment into tangibly better care for patients. For example, there is still little detail on how local areas can establish 24/7 end of life care for people being cared for outside hospital or how the limited capacity of social care can be addressed.

Continued failure to fulfil this National Commitment will have a substantial impact on the ability to deliver better care and choice for all patients at the end of life.

Recommendations

- The Department of Health must clearly set out how it intends to honour and resource its 'National Commitment' to end variation in end of life care.
- Leaders from all sustainability and transformation partnerships, along with local commissioners and providers must plan for, and provide, sufficient resources to deliver high quality and personalised end of life care to all patients.



With the right support, **64% of people with cancer would like to die at home, but only 30% currently do.**

Just **1% would like to die in hospital, but 38% of people with cancer currently do.**

Exploring variation in end of life care

We have just outlined the importance of choice at end of life as well as the need to ensure that community services are strengthened to enable people to have access to the high quality and personalised care of their choosing. We have also highlighted that unless urgent action is taken at both a national and local level we risk jeopardising the opportunity for people approaching the end of life to be cared for and die at home or in a familiar environment surrounded by their loved ones.

The case for change is further exacerbated by the fact that there continues to be considerable geographic variation and inequality of access to personalised and high quality end of life care.

Variation in place of death

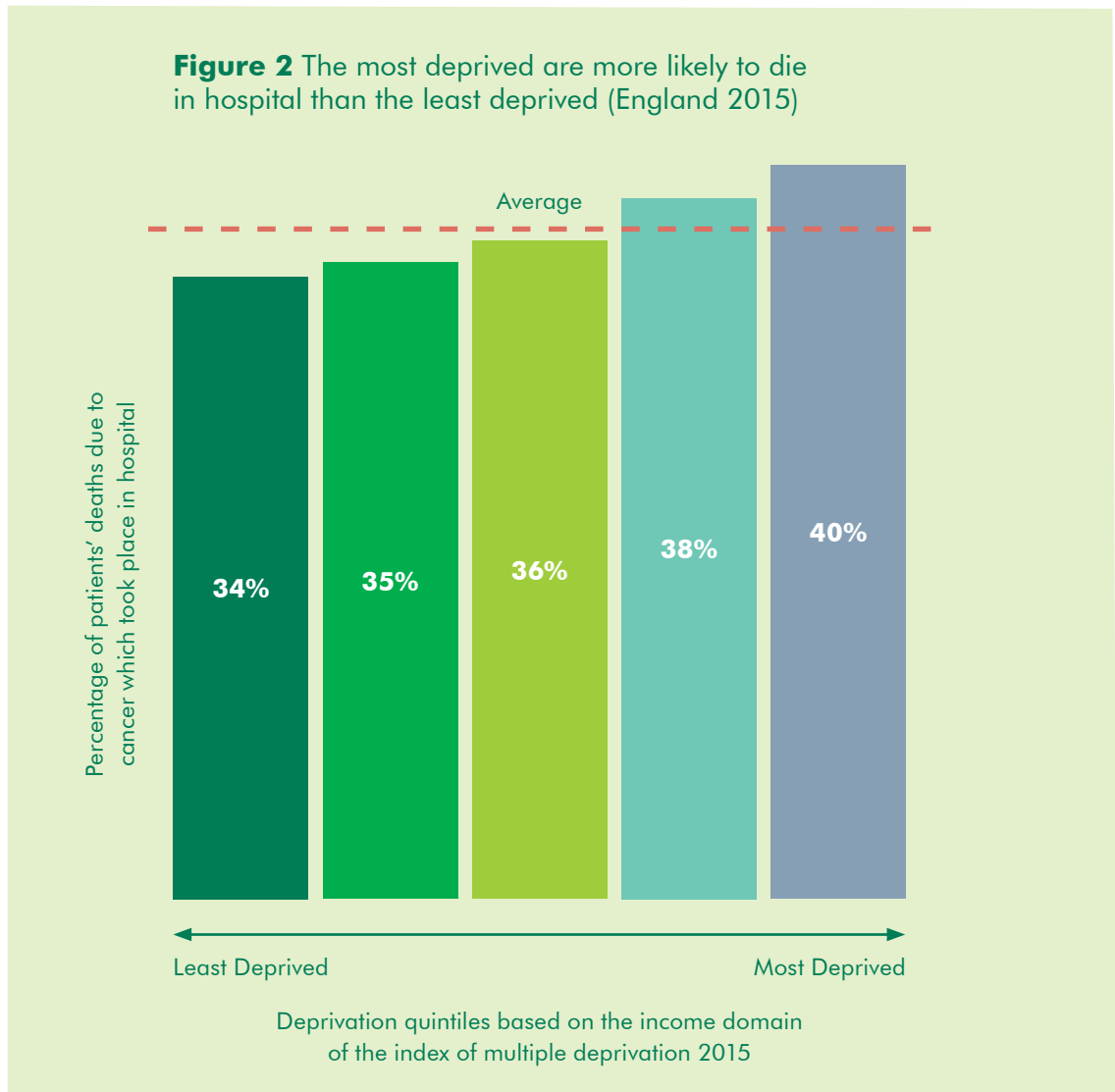
We have set out that most dying people do not choose to spend their last weeks and months in hospital. We also know that experiences of end of life hospital care tend to be poorer. Key results from the most recent National Survey of Bereaved People (VOICES), published in 2016,¹⁹ support this and the Care Quality Commission (CQC) has also found that while 90% of hospices inspected are rated as outstanding, 42% of end of life care services in acute hospitals are inadequate and require improvements.²⁰



‘In some cases, when a person is extremely unwell and has a lot of complications, hospital can be the best place for a dying person, as there is all the support you need in one place. But, when a person is in hospital at the end of their life, surrounded by all this medical support, it’s very easy for them to be over-treated and for extending their life to be prioritised over maintaining their quality of life.

‘People often don’t get choices about their care and where they die, especially if they don’t have family around them who can advocate on their behalf, or if they aren’t known to their local services – and even if they are, things can go wrong. There genuinely is a postcode lottery when it comes to what end of life services are on offer, and this inequality is not good enough and likely to disadvantage the most vulnerable.’

**Dr Ollie Minton,
Macmillan Palliative Care Consultant**



Recent studies and new analysis by Macmillan Cancer Support therefore raise some worrying concerns about the impact that income deprivation and geographic location has on choice at end of life.^{21,22,23} For example, a recent study in open access journal *BMC Medicine* found that patients with respiratory disease who lived in deprived areas were more likely to die in hospital than those who did not.²⁴ Macmillan too has examined the impact of income deprivation on place of death for people dying of cancer and found that the most deprived are more likely than the least deprived to die in hospital in England (see Figure 2).²⁵

Although most people wish to die at home, we do also acknowledge that there are reasons why this option is not possible in all cases. For example, the Choice Review highlighted that dying at home may not be as important for some people as other factors such as management of pain, the presence of family and friends or not being a burden to loved ones.



Dave with his first grandson, Ollie

Dying in hospital: Dave's story

Dave, 69, was diagnosed with advanced lung cancer in July 2009 after suffering a stroke. He was offered palliative chemotherapy and radiotherapy treatment but had a heart attack three days after diagnosis. His daughter, Caroline, and wife, Sue, were offered no support from the oncology team, Dave's GP or palliative care team, and end of life care was never discussed.

In September, Dave's condition dramatically worsened and he was taken to hospital. He required an emergency chest drain and remained in a coma for three days before passing away with his wife and daughter by his side.

'There was no joined-up care between the cancer team, heart team, the GP and palliative care. My mum was left to take care of him on her own, 24 hours a day for over six weeks and he ended up dying in hospital, with no dignity.

'As strange as it sounds, no one told us he was dying. It was only the morning he died did the nurse say we only had a few hours left with him. We felt angry and guilty for a long time that we couldn't give Dad the death he wanted.'

Caroline, Dave's daughter

Income deprivation and emergency admissions

High quality and personalised end of life care should mean access to the right care at the right time in the right setting. It should mean end of life care is planned for. However, Macmillan knows that beyond place of death, the level of deprivation also impacts on the number of emergency hospital admissions that cancer patients experienced during the last 12 months of life. Our research found that in 2015 in England the average number of

emergency admissions for cancer patients in their last year of life is 4.5. Of most concern, we found that the most deprived had notably more emergency admissions in their last year of life compared with the least deprived (see Figure 3).²⁶

New research funded by Macmillan on 533,000 people in England who died from cancer between 2011 and 2015 within 10 years of being diagnosed found a worrying picture of emergency hospital visits in the period between diagnosis and death (up to a maximum of three years).

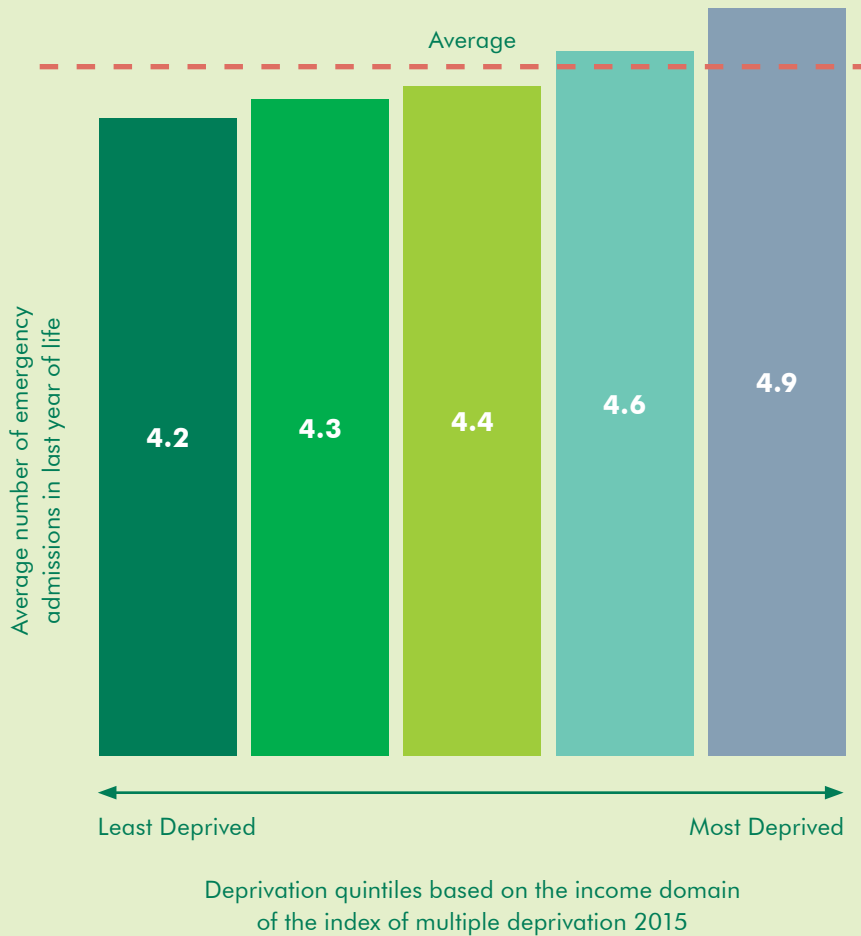
It found that **people from the most deprived areas who die from cancer each year have 15,000 more emergency hospital visits in the final year of life compared with those from the least deprived areas.**²⁷

Previous Macmillan-funded research has also shown that cancer patients with the four most common types of cancer from

the most deprived areas in the last six months of their lives also spend longer in hospital on average following an emergency admission.²⁸

Together the findings of the research cited here presents a startling picture of the experiences of those from deprived backgrounds in their dying months.

Figure 3 The most deprived experience more emergency admissions than the least deprived (England 2015)





Valerie with her daughter, Charity

Emergency admissions: Valerie's story

Valerie, 65, was diagnosed with pancreatic cancer in October 2014 and it soon became apparent she was terminal. Her local hospital's support worker promised the family they would coordinate care between the local hospice and hospital.

In December 2014 Valerie's condition rapidly deteriorated and she was rushed to A&E. The family were told that her bowel had perforated and nothing could be done. With Valerie in the last hours of her life, her daughter Charity, 30, felt she had to fight for pain relief. Valerie passed away the next afternoon.

'I spent the last hours of my mum's life running around the hospital trying to get her some pain relief. When my mum died, she didn't look peaceful... Those final hours are the lasting memories I have of my mum.

'Three years on and I'm still really angry with the way she died. The thing that will always haunt me is that I had promised her that no matter what happened, she wasn't going to die in pain. I wasn't able to keep that promise.'

Charity, Valerie's daughter

Quality of end of life care

We know more people have poorer experiences of dying in hospital compared to dying at home, in a hospice or in a care home. Results from the most recent VOICES survey show that respondents from the most deprived populations rated more poorly the quality of end of life care for their loved ones compared to ratings from those in least deprived areas (see Figure 4).

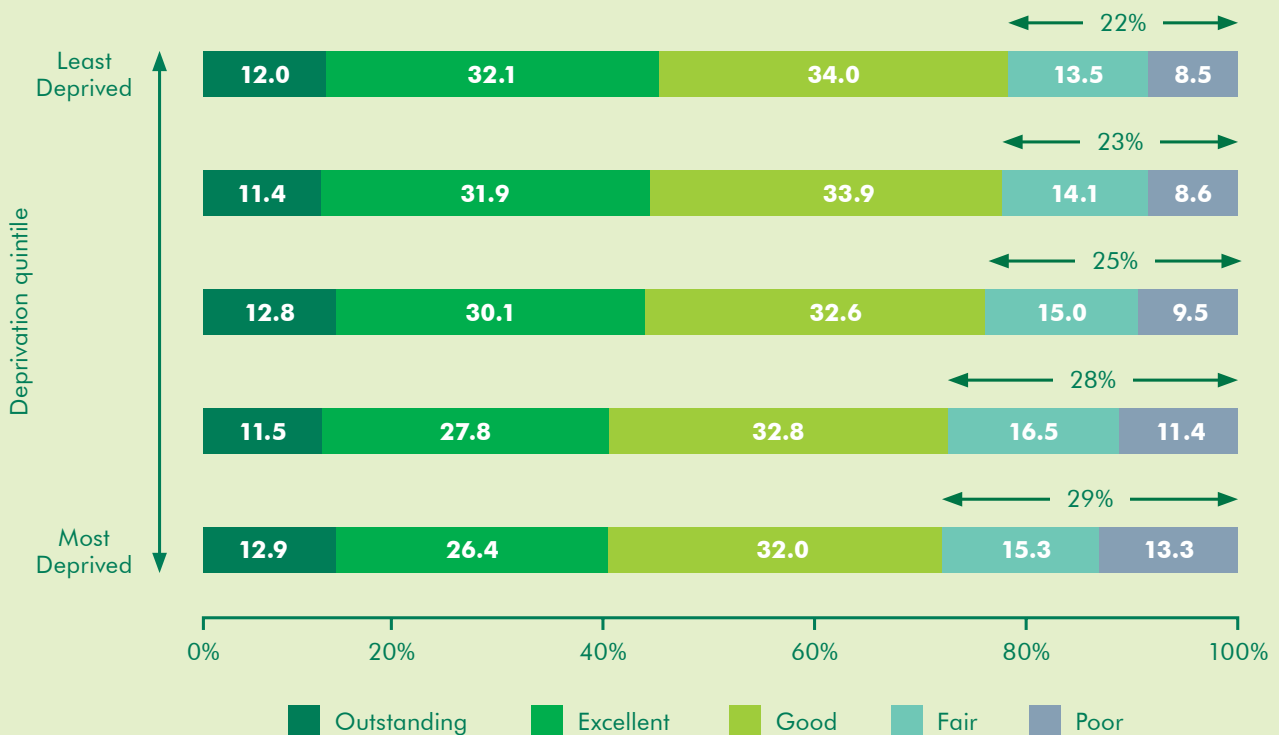
Together, this evidence on place of death and emergency admissions paints a very worrying picture that a person's background and where they live can have a substantial impact on their experience at the end of their lives.

This not only represents a poor – and often distressing – situation for patients, but it also places a costly and unnecessary strain on already stretched accident and emergency departments. In fact, in Macmillan’s recent study **with City University, we estimated that improving end of life care for the most deprived cancer patients, for the four most common cancers alone, could save the NHS £4.6 million a year.**³⁰

‘I suffer from an incurable condition and it worries me greatly what will happen to me at the end of my life. I have been advised to make a living will to cover this exact issue. We are all human beings who deserve dignity and respect regardless of our circumstances.’

Anonymous

Figure 4 The most deprived experience the poorest quality end of life care – overall quality of care by deprivation quintile in the last three months of life (England, 2015)



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With the Government's 'National Commitment' we have the right blueprint to achieve choice at end of life for all. However, meaningful progress will not be achieved unless urgent action is taken to address variation in end of life care and resources are shifted into community care settings in line with people's preferences.

This not only makes economic sense but it will also ensure that a person's experience at the end of their lives does not differ based on where they live or who they are. The benefits of taking a multidisciplinary approach to providing community based end of life care are evidenced in the example below.

The North Manchester Macmillan Palliative Care Support Service (NMPCSS)³¹

Prior to the service launch in North Manchester, there was a higher than national average number of deaths in hospital for patients with life-limiting conditions – of these 40% were found to have no medical needs. There is no hospice in the local area and research finds that 70% of people would prefer to die at home. This service was launched in April 2015, delivered by The Pennine Acute Hospitals NHS Trust, to ensure that patients with life-limiting illnesses in North Manchester can access the care and support they need.

The team brings together professionals and trained volunteers, working together to deliver the full package of support to patients, based in the heart of the community. Improved communication and information-sharing are central to improving patient care and meeting their needs. The NMPCSS team provides a seven-day service from 8am to 8pm and responds to an open referral system for patients, carers, and professionals. As well as offering a telephone advice service from 8am to 8pm and continued support overnight from the District Nursing service

and St Anne hospice advice line, the team also provides patients with end of life care in their homes. This is a multidisciplinary approach led by a Macmillan consultant in palliative care who supports dedicated professionals working together with patients and carers.

The service works collaboratively with the local hospitals and primary care. The palliative care consultants care in the community while also in reaching into the local hospital for patients from the north Manchester community to ensure continuity of care and reduced hospital stays.

Deaths are now reviewed to assess whether patients achieved their preferred place of care, and if not then why not. The consultant and team also regularly review patients' case notes when admitted to hospital to determine whether this could have been prevented. 82% of patients on the caseload died in their recorded preferred place of care in 2015/16 compared with 59% in 2014/15. For patients on the caseload, average deaths in hospital reduced from 21% in 2014/15 to 13% in 2015/16.

Causes of variation in end of life care

Despite the increasing evidence that place of death, quality of care and emergency admissions at the end of life in England can be linked to deprivation status, we still do not fully understand the reasons why this would be the case.

Newly commissioned health research will be required to understand how deprivation affects poor experiences in – and the quality of – end of life care.

‘This inequality reflects a lack of consistency in the support for dying people in the community, particularly the availability of coordinated out-of-hospital care for pain control and other forms of symptom management 24 hours a day, seven days a week.



Other factors could also be affecting the most deprived people when they die, for example:

- less appropriate housing for end of life care at home,
- a greater reliance on emergency care over elective care,
- limited or overstretched social support,
- lower rates of health literacy, general literacy and education resulting in less choice and planning in end of life care,
- differences in lifestyle resulting in a higher rate of cancer types with poor survival rates, such as lung cancer, and
- inability to bear the costs of caring for someone at home.’

Dr Pete Nightingale, Macmillan GP Advisor

Recommendation

- The Department of Health and National Institute of Health Research should commission research to understand the reasons for disparity of experiences in end of life care for the most deprived patients.

Tackling variation and improving care

Equal access to end of life care is a shared responsibility. We already know that all commissioners and providers are required to abide by the Equality Act 2010 when planning for and delivering their services. Furthermore, the NHS Constitution and Mandate clearly indicates that inequalities must be addressed across the NHS.

Specifically, in relation to end of life care, *Ambitions for Palliative, and End of Life Care: A national framework for local action 2015–2020* has set out six ambitions for end of life and palliative care. One of the founding principles is equal access to end of life care. NHS England is a member of the partnership and the Government has expressed its support for the ambitions.

Furthermore, in its response to the Choice Review, the Government stated:

‘In making this Commitment, we are sending out the message that high quality personalised care has to be universal. We are determined to end variation in care due to geography, age, diagnosis, background or means. This is a National Commitment to high quality care for all.’

However, until improving the commissioning and delivery of services that support people at the end of life is viewed as a priority at both a national and local level, ending variation in this type of care will be challenging. As previously mentioned, sustainability and transformation partnerships (STPs) have been tasked with leading improvements in services in their local area, yet analysis of plans has shown that initiatives to deliver changes to end of life care services risk being forgotten among competing priorities.

As things stand, the disparity between local health economies’ plans to improve end of life care in STPs risks exacerbating pre-existing variation across England. If we are to achieve universal high-quality end of life care, there needs to be transparency on progress and greater accountability for delivery, particularly at a STP level. We know that an indicator for end of life care is being established by NHS England for inclusion in the CCG Improvement and Assessment Framework for 2018/2019 as a means of developing an atlas on variation in end of life care.³² However, there needs to be clarity on how this and future end of life care metrics will align with and be included in the STP dashboard.

Furthermore, while metrics may shine a light on inequality, they alone will not address the enduring variation in the end of life care that exists. They will need to be backed up by strong national and local leadership to act on variation and to implement improvements. To enable this, we will need the right workforce and community resources to support the increasing and diverse needs of people as they approach their end of life.

Recommendations

- The Department of Health and NHS England must ensure there is clear accountability for addressing variation in end of life care beginning with the regular publication of metrics from all CCGs and sustainability and transformation partnerships.
- The Secretary of State for Health must report annually on the progress being made towards delivering the Government's 'National Commitment' in full by 2020.
- The Department of Health and Health Education England should now address resource, staffing, and training requirements to respond to projected increases in demand in future decades for end of life care.



Conclusion

Providing care for those for whom a cure is no longer possible should always be focused on one goal: ensuring the dying person has a 'good' death.

In the Government's 'National Commitment' we have the right blueprint to achieve good quality and personalised end of life care for all.

However, as this report has highlighted not enough progress is being made to translate the commitment into tangible improvements for patients. Progress at a national level has been slow and lacking clarity, while locally far too many sustainability and transformation partnerships (STPs) have failed to set out how they will address the end of life care needs of their populations.

Central to the Government's commitment is ending variation in end of life care. However, as this report shows the most deprived in society continue to experience more chaotic care in their dying months with less choice over their place of death. We need to do more to fully understand the reasons behind this variation but it is a situation that cannot continue.

With demand for end of life care projected to increase, a failure to take urgent action on the Government's commitment risks exacerbating the inequalities that this report has sought to highlight. By implementing the recommendations in this report, we believe that substantial progress can be made towards the ambition that everyone, regardless of background, receives quality end of life care now and in the future.

'Making someone's last wishes happen is the most dignified and compassionate thing you can do. I am an oncology/ chemotherapy nurse and have seen patients plan their last days and the calmness and peace they achieve cannot be ignored. Each person is unique, each death is unique.'

Diane, an oncology nurse

Recommendations

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- The Secretary of State for Health must report annually on the progress being made towards delivering the Government's 'National Commitment' in full by 2020.
- The Department of Health and Health Education England must act now to address resource, staffing, and training requirements to respond to projected increases in demand in future decades for end of life care.
- The Department of Health and National Institute of Health Research should commission research to understand the disparity of experiences in end of life care for the most deprived patients.

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