

## Briefing:

# Open up hospice care

### Introduction

We are all, in some way, affected by death and dying. With 600,000 deaths per year in the UK, and almost half of adults reporting being bereaved at some point in the last five years,<sup>1</sup> it is likely that we have recently been personally touched by loss, or know someone who has. And yet, despite the inevitability of our lives ending, in the UK 118,000 people every year do not receive the care they need at this vital time.

The reasons for this vary, but as a nation we have to do more to ensure that expert end of life care is available to all who need it, regardless of who they are, where they live, and why they are dying.

Providers of hospice care in particular are committed to reducing inequities in access to expert end of life care and to reaching more people, and their families, as they approach the end of their lives.

### Who needs expert end of life care?

When we consider the need for expert end of life care we need to determine the scale of need for such care. We have drawn on the methodology set out in 'Funding the Right Care and Support for Everyone Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review' (2011) to quantify the level of need.<sup>2</sup>

Taking the formula used in this report, which was limited to England, and extending it to 2015 UK-wide mortality statistics, we find that 75.5 per cent of all deaths, or 455,000 people, will have had a 'predictable death' in that their death was not sudden and their health was known to be poor.<sup>3</sup> These 455,000 people are the ones who might benefit from expert end of life care. Of these, 118,000 people and their families could be missing out on this support. We estimate that 1 in 4 families (more than 25 per cent) are not able to access the expert end of life care, including hospice care, they may need at the end of life. (See Figures 1 and 2 below)

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<sup>1</sup> National Council for Palliative Care (NCPC). Life after death. London: NCPC, 2013. Available from: [www.dyingmatters.org/sites/default/files/Life%20After%20Death%20FINAL\(1\).pdf](http://www.dyingmatters.org/sites/default/files/Life%20After%20Death%20FINAL(1).pdf)

<sup>2</sup> Hughes-Hallett T et al. Funding the right care and support for everyone – Creating a fair and transparent funding system: the final report of the Palliative Care Funding Review' An independent review for the Secretary of State for Health. London: Department of Health, 2011.

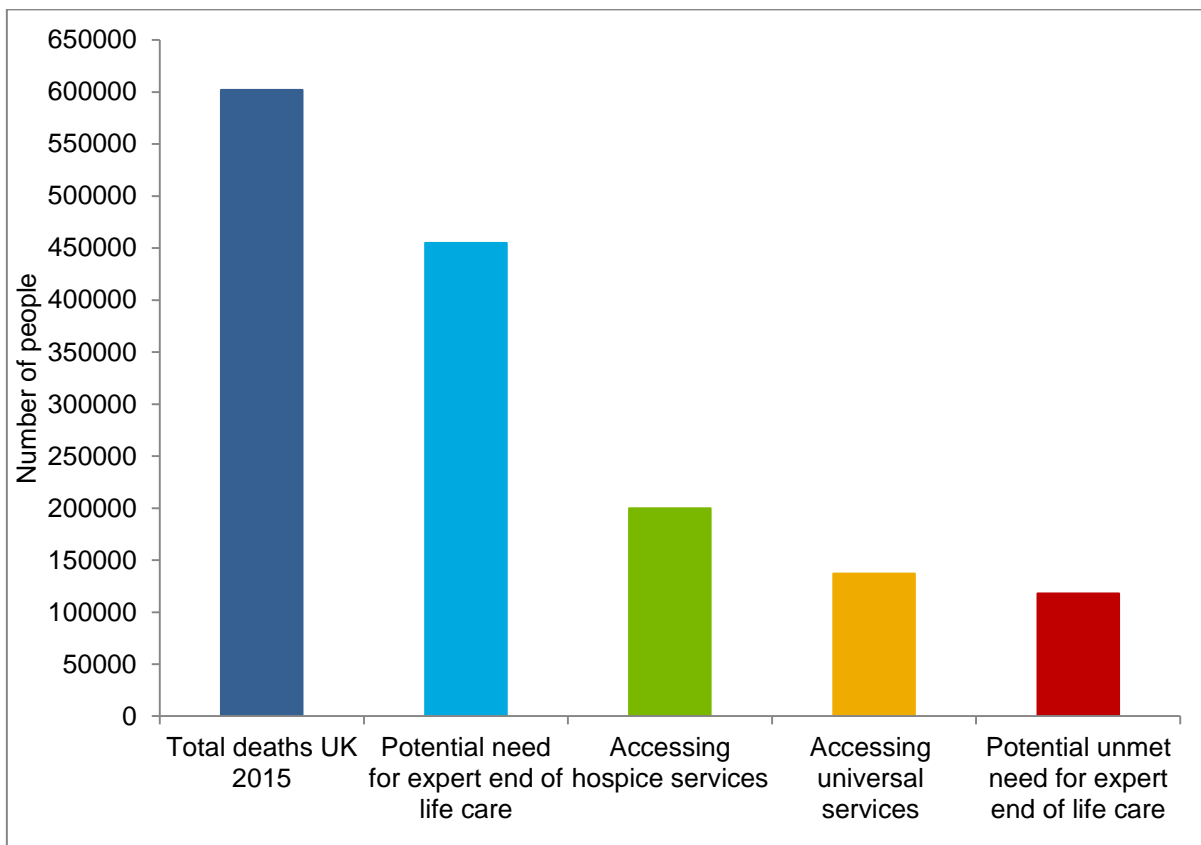
<sup>3</sup> Murtagh F et al. How many people need palliative care? A study developing and comparing methods for population-based estimates. Palliative Medicine 2014; Vol 28(1) 49–58.

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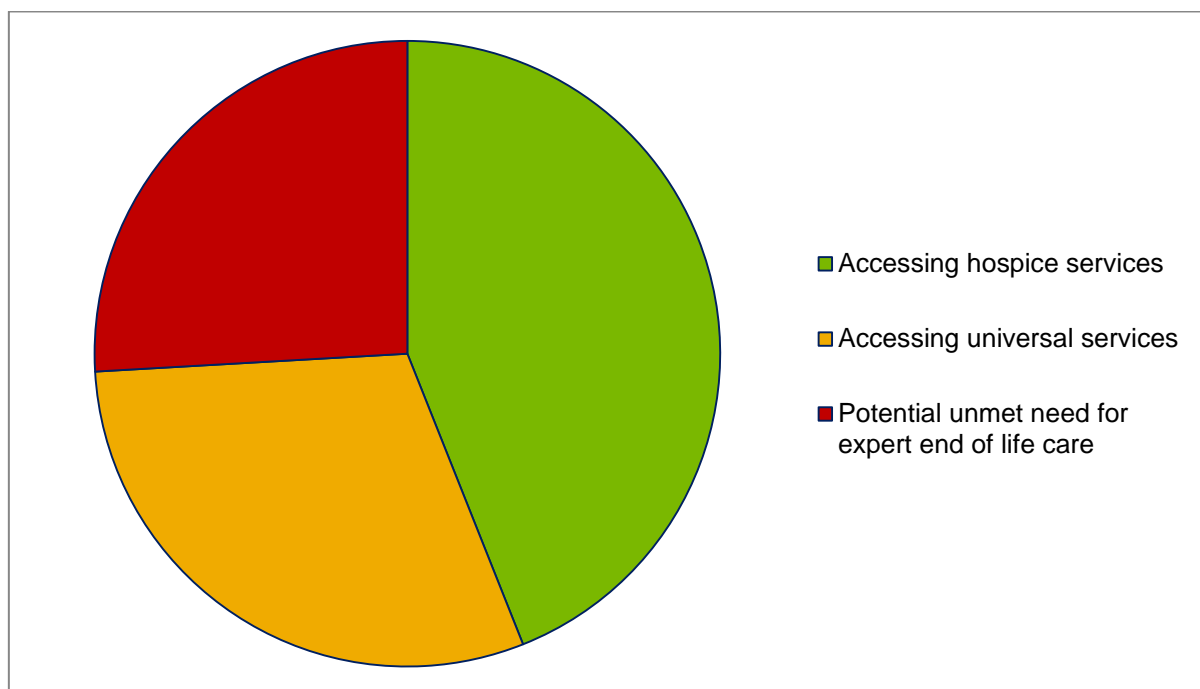
## What is expert end of life care and hospice care?

There is great variation in people's needs and wants at end of life, and thus there is no one setting or model of care that is right for everyone. Great end of life care can happen in many different settings – in hospices, hospitals, care homes and at home – and by a wide range of specialist and generalist medical and social care practitioners. At Hospice UK, we use the term “hospice care” to mean a type of expert end of life and palliative care, which aims to affirm life and death. It means working with and within local communities to tailor palliative care around the needs of each adult and child with a terminal or life shortening condition, whatever that may be, and extends to supporting their carers, friends and family before and after bereavement. Hospice care is provided by multi-disciplinary teams of staff and volunteers who offer expert support that places equal emphasis on a person's clinical, physical, emotional, social and spiritual needs, with the understanding that everyone will be different.

Figure 1: Estimated need for expert end of life care, access to services and unmet need



**Figure 2: Where care is accessed by people who could benefit from expert end of life care**



Research by Hospice UK in 2016 found that approximately 200,000 people a year receive some form of direct support from a hospice service, be that through home-based care, outpatient clinics, day hospice or inpatient hospice.<sup>4</sup> Many of those who are not receiving hospice care will be supported through other generalist or universal services, such as community hospitals, district nursing, general practitioners and care homes.

Yet there are potentially 118,000 people per year who die without receiving the support of expert care that could reduce their pain, provide comfort through psychological or spiritual care, address social needs, and ensure they have the best day possible given the limitations of their situations.

## What is unmet need?

'Unmet need' for expert end of life care is not one experience, it manifests in many different ways. It can mean that a person has complex pain issues which might benefit from the specialist skills of a consultant, but no referral is made and thus their pain is never managed. It can mean that without being supported to understand the processes of end of life a family calls an ambulance for a person experiencing breathlessness, leading to them then dying in a busy accident and emergency department instead of peacefully at home. It could mean a person dies sooner than they might because a need like mobility was not given the priority required. It can mean a person has repeated acute hospital admissions in which their needs are never fully addressed.

<sup>4</sup> Hospice UK. Hospice care in the UK 2016. London: Hospice UK, 2016. Available from: [www.hospiceuk.org/docs/default-source/What-We-Offer/publications-documents-and-files/hospice-care-in-the-uk-2016.pdf?sfvrsn=0](http://www.hospiceuk.org/docs/default-source/What-We-Offer/publications-documents-and-files/hospice-care-in-the-uk-2016.pdf?sfvrsn=0)

All these types of experiences have knock on effects for families, friends and communities. For families and friends there is the emotional and psychological impact of experiencing a loved one's fraught death. Communities are negatively impacted by the resources used across services which do not meet people's needs, but which are more expensive to deliver than the care that is really required.

## Why do 1 in 4 families miss out on expert support at the end of life?

Just as the needs of people and their families at the end of life vary, so too, do the reasons that people miss out on the right support. Studies have shown that people from economically deprived areas, BAME (black and minority ethnic) and LGBT (lesbian, gay, bisexual and transgender) people are not seen in palliative and expert end of life care services as often as expected. People with terminal conditions other than cancer access hospice care in fewer numbers and later in their illness than others. People who live alone at end of life also tend to have barrier to accessing expert end of life care.<sup>5</sup>

### Black and minority ethnic communities

For the BAME community, research<sup>6</sup> suggests that there are numerous potential barriers to accessing palliative care services. These include "lack of cultural and religious sensitivity in how services are delivered, discrimination (and/or 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 BAME backgrounds will be able and willing to care for relatives at home.

People of BAME backgrounds are also more likely to die in hospital than non-BAME people,<sup>7</sup> which may indicate difficulties with both referrals to appropriate end of life services, and of uptake of referrals.

### Lesbian, gay, bisexual and transgender people

Recent research by Marie Curie noted that LGBT people may experience barriers to palliative care because of several related social determinants known to correlate with poor access to appropriate care, such as being single, not having children or estrangement from one's birth family. This is in addition to real and perceived pressure to hide one's true self. These challenges, in accessing care for themselves and their loved ones, are also experienced by partners and spouses before and after bereavement.<sup>8</sup>

### Diagnosis

Research has shown that a cancer diagnosis significantly influences the likelihood of being referred to expert palliative and end of life care services. Even though cancer

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<sup>5</sup> Dixon J et al. Equity in the provision of palliative care in the UK: review of evidence. London: Marie Curie, PSSRU, London School of Economics, 2015. Available from:

[www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf](http://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf)

<sup>6</sup> Ibid.

<sup>7</sup> Murtagh F et al. Understanding place of death for patients with non-malignant conditions: a systematic review. National Institute for Health Research, 2012.

<sup>8</sup> Marie Curie. Hiding who I am: the reality of end of life care for LGBT people. London: Marie Curie, 2016. Available from: [www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf](http://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf)

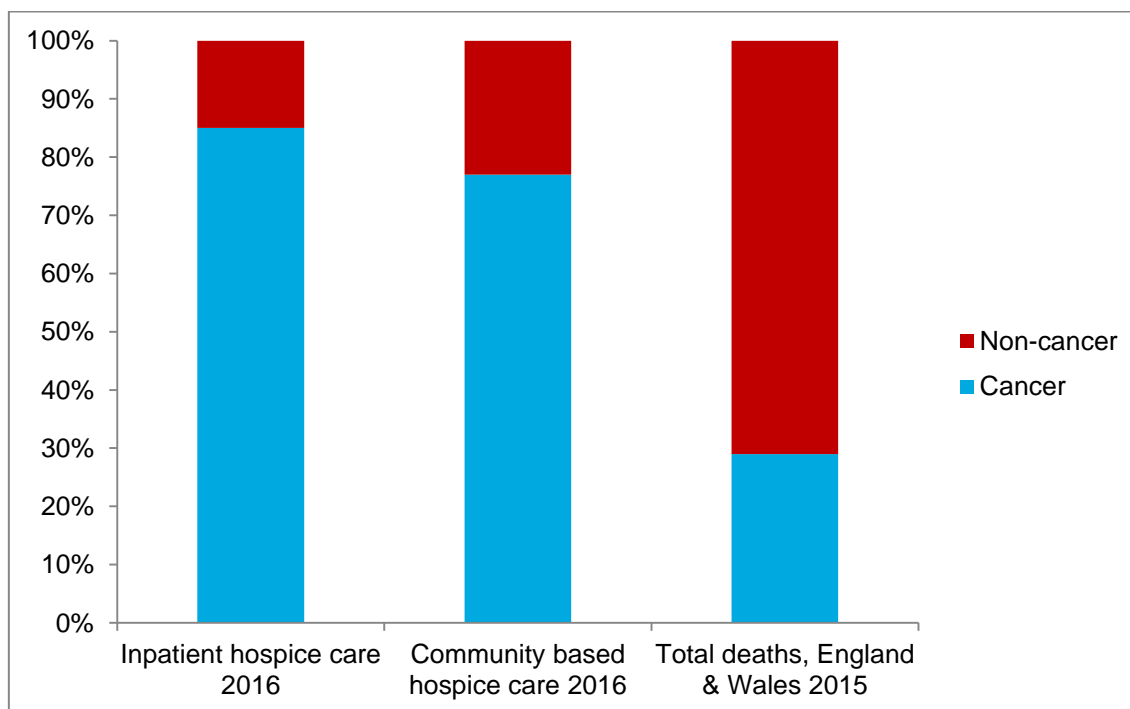
accounts for 29 per cent of deaths, in 2012-13 in England, Wales and Northern Ireland, 88 per cent of palliative care inpatients and 75 per cent of new referrals to hospital support and outpatient services were for people diagnosed with cancer.<sup>9</sup>

This same pattern is seen in hospice services. People with a cancer diagnosis are currently overrepresented in hospice care referrals. Charitable hospices estimated that the vast majority of the referrals they received in 2015-16 were for people with cancer. Hospices report that referrals for people with a non-cancer diagnosis are slowly increasing, but cancer remains the primary diagnosis in most people they see. This tells us a lot about what doctors, from GPs to specialists, know about hospice care and how they understand end of life.

### Having a carer

The presence of a carer, be that a spouse, partner or other relative or friend, is also implicated in access to services and achieving preferred place of death. Living alone and not having a caregiver in one's latter years means that a person is more likely to die in hospital. As women tend to outlive men, it is not uncommon that men are cared for by a female spouse, who then has no carer herself and thus has a different experience of end of life care than her partner did. Single or widowed people are less likely to die at home, and are more likely to die in a care home. Those who are married are more likely to have a home death.<sup>10</sup> Whilst good end of life care can be provided in any setting, these findings suggest that the having carer means that a person has someone to ensure their wishes are met, and thus access expert care on their behalf.

**Figure 3 Proportions of people seen in hospice care settings by cancer/non cancer diagnosis and proportion of deaths caused by cancer**



<sup>9</sup> Dixon (2015) op cit.

<sup>10</sup> Murtagh F et al (2012) op cit.

It is interesting to note that more people with a non-cancer diagnosis are seen in community based hospice care settings (such as hospice at home, outpatient and day hospice clinics). This is worth exploring to understand what different service models mean for people with different diagnoses.

Because expert end of life care services generally require a referral from a medical professional, it is important that we further explore reasons why referrals are so biased towards people with a cancer diagnosis and provide support and systems to encourage referrals of people at end of life with a non-cancer condition or needs.

## Changing patterns of death and dying

One of the great triumphs of modern medicine is that most of us can expect to live well into old age. In fact once people in the UK reach 65 years, they are likely to have, on average, another twenty years of life. But with the increase in longevity it becomes more likely that up to half of those twenty years after 65 will be affected by illness and disability.<sup>11</sup>

This is different to how we have come to understand approaching death – the pattern of a short illness with a terminal diagnosis is decreasing, while a longer period of decline – the ten years of illness and disability in latter life is increasing. We see this pattern in frailty, heart failure, neurological conditions or respiratory illness.

The number of people with a need for expert end of life care is also likely to increase as the number of people dying each year is projected to rise over the next 25 years. This is due to the large ‘baby boomer’ generation reaching end of life. This changing demographic means that there will be more people living and dying with multiple conditions, at the same time as having less family support locally. All this will change the end of life journey for large numbers of people, and presents a clinical challenge too, as it becomes increasingly difficult to identify the ‘dying phase’.

To meet these changing patterns of end of life we must find new ways of planning for, thinking about and designing services for end of life, or we risk many more people not receiving the care they need.

## How can we open up hospice care?

Hospice UK’s vision is hospice care for every person and family in need. We are committed to extending the reach of hospice care to all people, regardless of their location, diagnosis, sexual orientation, ethnicity or disability,, as outlined in our five-year strategy for transforming hospice care.<sup>12</sup>

To achieve this, we need to understand more about who does and does not access expert end of life care and why, encourage medical professionals to refer more people to hospice care, design services which meet the needs of people who are currently missing

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<sup>11</sup> See Office for National Statistics:  
[www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthstatelifeexpectanciesuk/2013to2015](http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthstatelifeexpectanciesuk/2013to2015)

<sup>12</sup> Hospice UK. Transforming hospice care: A five-year strategy for the hospice movement. London: Hospice UK, 2017. Available from: [www.hospiceuk.org/about-us/our-strategy](http://www.hospiceuk.org/about-us/our-strategy)

out, raise awareness of the benefits of hospice care and how to access it and support people in the community with a degenerative or terminal condition to access to hospice care. In sum, we need to improve demand for and supply of hospice care.

**We need to improve both the demand for, and supply of, hospice care.**

## What actions are needed?

The responsibility to meet the needs of all people at end of life does not fall to one set of shoulders. Rather, a multiplicity of actions are needed, by providers of hospice and expert end of life care, health professionals, health and social care decision makers, national governments and other health care funding bodies, and the public.

Here we list a small selection of actions for a range of stakeholders that could drive reductions in the inequities in access to expert end of life care that we see today.

### For providers of hospice and expert end of life care:

- **We need better intelligence**

We need to know a lot more about people's needs at end of life, who accesses expert end of life care, and their experience of care. Filling those gaps in our knowledge is critical to reducing the inequalities in care that we know exist.

- **We need creative service design**

Innovative service design that reflects changing experiences and trajectories of death and dying in the UK so that people know there will be care that meets their specific needs.

### For health professionals

- **Refer early, refer often**

Understand more about hospice/expert end of life care and refer people and their families as early as possible. Expert end of life care can work alongside other medical interventions to support pain relief, mobility and nutrition, as well as social, psychological and spiritual needs, ensuring a holistic approach to care.

### For local health and social care decision makers:

- **Death and dying must be a central feature of public health**

Death and dying are public health issues, but are not priorities in most strategies. Public health bodies at national and local levels have a vital role to play in encouraging more open and honest conversations about dying, death and bereavement. This is particularly important in the context of an ageing society where more of us will live and die with increasingly complex needs and frailty.

## For national governments and other health care funding bodies across the UK:

- **Reliable funding is needed so that providers can plan and deliver sustainable, long term services that meet the needs of local communities**

Hospice care is a mixed economy of charitable and NHS funded services, and in hospice care this means around 30 per cent of expenditure is met by statutory sources and the rest from charitable fundraising. Statutory funding must be provided in terms of levels of local need, and with an understanding of increasing demand in the future.

## For the public:

- **Find out more and help spread the word**

Visit our website ([www.hospiceuk.org](http://www.hospiceuk.org)) to understand more about hospice care and how it might help you, your family and community. Join our campaign to open up hospice care so that everyone who needs hospice care, gets hospice care:

[www.hospiceuk.org/openup](http://www.hospiceuk.org/openup)

## What is Hospice UK doing to open up hospice care?

As the national charity for hospice care, we work with over 220 local hospices to deliver and grow outstanding hospice care for adults and children across the UK. We champion the expert compassionate and free care that hospices provide. We invest in training, resources and activities across health and social care services, and work with local and national decision makers to widen access to hospice care.

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