



**Equality in hospice  
and end of life care:  
challenges and change**

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# About Hospice UK

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Hospice UK is the national charity working for those experiencing dying, death and bereavement. We work for the benefit of people affected by death and dying, collaborating with our hospice members and other partners who work in end of life care. Our hospice members influence and guide our work to put people at the centre of all we do. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

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# Foreword

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Everyone has the right to high quality care and support at the end of life. But many people are still not enabled to access the help they need in their final days and months. Inequalities of access and standards of care are particularly felt by those who have already encountered unfairness and discrimination throughout their lives. This is not acceptable. We – palliative and end of life care services, commissioners and partners – must do more and do so quickly.

The hospice sector rightly prides itself on leading the way in designing and delivering quality and innovative care. However high quality does not equate to universal reach, which is why many hospices, like Hospice UK, are putting acknowledging and addressing inequalities at the heart of their strategies. This drive within our sector reflects a wider movement in society, in the UK and at a global level.

Hospices and other end of life care providers equally have a responsibility to ensure that everyone who needs it can access the care they want and need in a way that reflects who they are. The onus must be on the sector to listen, reflect, innovate and advance so that people from all communities are included, along with their families and carers. People are not 'hard to reach', and no-one should be made to expect or assume a reduced level or quality of service because of who they are. A service that is 'open to all' is not enough if the service continues to be structured on an outdated and unsuitable demographic model.

As part of our successful negotiations with governments across the UK for hospice funding support during the COVID-19 pandemic, we asked hospices about their ongoing work to open up services to all parts of their community. We are very grateful to more than 100 hospices who responded – many of their developments are included in this report and many more will be used in the future. A change in emphasis is underway and progress to reach further into communities to meet unmet and under-met need can be found throughout the UK. However, it is clear, from looking at population level data, research and from listening to people's stories, that there is still an incredibly long way to go. Individual projects or recruiting to new roles in pursuit of equality are to be welcomed, but the ambition must be for a fully embedded culture of inclusivity across everything we do as a sector.

This will require renewed energy, resource and dedication from all involved to keep evolving and developing services. Staff will need to be adequately supported, particularly after tireless work to combat COVID-19, in order to have the capacity and capabilities to take on this challenge. Action shaped by lived experience must lead the way. Equally, national and local policy priorities including resourcing, efforts to drive integration of services and implementation of models of population-based commissioning will need to build an environment that facilitates the required change in provision of services.

Through this report we aim to provide a snapshot for ourselves, and for the sector, of practice, academic research, progress and ways forward. Hospice UK will act in response to the findings of this report, listening to and sharing people's stories, exploring reasons why services are still not engaging fully with some parts of our communities, and put forward recommendations for change. The first in a series of deep-dive reports, focused on imprisoned people, has just been published on our website.

We look forward to working with all partners, both within and beyond hospice and end of life care, as we seek to address existing inequalities and ensure we achieve our vision 'that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life'.



Tracey Bleakley


A handwritten signature in black ink, appearing to read 'Tracey Bleakley', written in a cursive style.

# Context

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The United Kingdom ranked top of 40 countries in a 'quality of death' index based on palliative service provision and national strategic approach.<sup>1</sup> Yet it is estimated that as many as one in four people are not able to access the palliative and end of life care services and support needed.

National policy priorities for palliative care in the UK have consistently highlighted the urgent need to address inequalities. As far back as 2004, the Department of Health and Social Care in England 'acknowledged as a major concern' the level of inequality in provision of palliative care. The Select Committee on Health at the time reported:

*Health inequalities are compounded in that services are disproportionately needed in areas of social deprivation and disproportionately present in areas of social affluence; services deal predominantly with cancer patients and seem not to be geared to the palliative needs of other disease groups; services are underused by those in black and minority ethnic communities; services favour some age groups over others; and they seem hard to access by those with complex needs.  <sup>2</sup>*

The 2008 End of Life Care Strategy from the Department aimed to be a 'step change' in access to all people approaching end of life 'irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status'.<sup>3</sup> The national Ambitions Framework that built on the 2008 Strategy, both for 2015-2020 and the recent refresh to 2026, equally place driving down health inequalities 'which remain unacceptably high' as a key focus for the 34 partnership organisations and government bodies.<sup>4</sup>

The Scottish Government's 2015 Strategic Framework for Action on Palliative and End of Life Care made a commitment that, by 2021, "access to palliative and end of life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location".<sup>5</sup>

In May 2016 the Care Quality Commission (CQC) published a review into inequalities in end of life care in England. The review and resulting frameworks identified similar challenges on both a local and national level. Some of the main barriers included recognition of end of life, poor communication from staff, inequalities in accessing good care, staff awareness and non-collaborative working. Soon followed 'Our commitment to you for end of life care' from the Department of Health in England, which again promised to work with partners to address inequalities.<sup>6</sup>

In the same year, the first UK wide hospice sector five year strategy was launched to 'Open Up' hospice care with the first of four pillars being to 'tackle inequality and widen access to hospice care.' It identified as key priorities timely access to care for non-malignant conditions, support appropriate to individual needs, improved understanding of unmet need in local populations and better collaboration and joined up working across health and care systems.

In response to a range of oral and written evidence received that highlighted there remains significant unmet need and under-met need in Wales, the Cross Party Group on Hospices and Palliative Care made a range of recommendations in 2018 to Welsh Government, commissioners and service providers aimed at improving equality of access to care.<sup>7</sup>

However, despite a consistent approach to national policy spanning decades and changes in the academic grounding and application of services as demonstrated in this report, a recent extensive literature search demonstrated persistent inequalities in hospice care provision. This has been found to be particularly prevalent for people without cancer, the oldest old, racialised communities and those living in rural or deprived areas, who all remain under-represented among those receiving hospice care. Equally, while a substantial body of evidence now exists on inequalities linked to general health in the late stages of life, there are still huge gaps in the evidence base, including appropriate end of life care for the LGBTQ+ community, people experiencing homelessness and those living with specific conditions.<sup>8</sup>



# Introduction

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This report is intended as a springboard for us, as Hospice UK, to work with the palliative and end of life care sector to tackle inequality. In the chapters that follow, we examine a number of thematic areas, in each case looking at some excellent examples of good practice, while also considering what more needs to be done at a sector level. Some common observations emerge.

First, our work at Hospice UK and as a sector more widely must be grounded in the experience and wishes of the people who we hope will benefit from what we do, in all their diversity. At every opportunity, we must engage with and listen to individuals, communities and organisations with expertise and lived experience in the areas outlined in this report. Initiatives to drive change that are evaluated and evidenced through research involving people using services are essential.

When tackling inequalities, our existing reliance on committed individuals within some regions, communities or services is neither adequate nor sustainable, and must be replaced. Good practice, attention to language, 'reasonable adjustments' as outlined in legislation, and instances of proactive engagement by palliative care services must be applied to all health and social care settings, across specialist and mainstream services.<sup>9</sup>

Third, we must take an intersectional approach, considering how people are discriminated against and disadvantaged based on a multitude of characteristics, such as race, gender and socioeconomic status. Consideration of intersectionality helps to provide a much needed holistic view of people's experiences, in turn giving greater opportunity for approaches that recognise the needs of an increasingly diverse population.<sup>10</sup>

These experiences are often shaped by the multiple barriers people face in accessing health and social care services due to fear, stigmatisation, discrimination, past experiences of being turned away, and punitive social policies.<sup>11</sup> The impact of intersectionality of the experiences that combine and overlap for different population groups throughout their lives will therefore need to be central to reducing inequalities in palliative and end of life care.

The absence of national datasets and resulting analysis on access to end of life care for different population groups means we are unable to accurately assess how widely people are being reached. For now, this document seeks to use a range of recent academic research, submitted examples of good practice and wider sources of data to shed light on the current position. A common dataset on access and outcomes across specialist and generalist palliative and end of life care services, reported regularly and accessible to all, would be an important step to understand how well needs are being recognised and responded to.



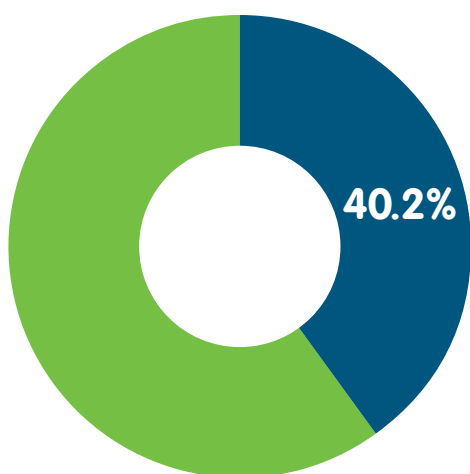


# Equality of hospice and end of life care with and for...

## Racialised communities

The call to action is resoundingly clear; whilst there is work under way, greater and more sustained energy is essential to address unmet need and unequal access to end of life care for people from racialised communities in the UK.<sup>12, 13, 14</sup>

Data from the 2011 Census tell us that 13% of people in the UK belong to a Black, Asian, Mixed or Other ethnic group.<sup>15</sup> Referring to Census data, Calanzani et al (2013) also note that figures from the 1991, 2001 and 2011 UK Censuses indicate that the UK has become more ethnically diverse in the past 20 years.<sup>16</sup> However, distribution is not equally spread – according to the 2011 Census, the most ethnically diverse region in England and Wales was London, where 40.2% of residents identified with either the Asian, Black, Mixed or Other ethnic group.<sup>17</sup> Nevertheless, it's vital to acknowledge the importance of action no matter the size of any population group.



**London residents identified with 'Asian, Black, Mixed or Other ethnic groups' (2011 census)**

Health inequalities exist between ethnic minority and white groups, and between different ethnic minority groups, presenting a complex picture affected by deprivation, environmental, physiological, behavioural and cultural factors.<sup>18</sup> The different and unique needs in providing culturally sensitive and person-centred care to different community groups, means that one chapter cannot give adequate consideration of this variety of need. Here we feature mainly examples of work to support the palliative care needs of people from South Asian communities. However, we are aware of work under way to support people from other communities, such as refugees, Gypsy, Roma and Traveller people – for whom racialised issues often intersect. As we take forward our work on addressing inequitable access to end of life care, we are sharing these examples to inspire and energise others.<sup>19</sup>

### A note on terminology

The evolving conversation around terminology is one we all need to engage with and reflect upon to ensure that appropriate and respectful terms are used. It's important to note too that senses of identity are hugely personal, meaning that everyone has their own preference on how they wish to describe themselves. Here we have included the words racialised communities and ethnic minorities to reflect some of the different perspectives on terminology. The former term intends to acknowledge that people are categorised by race like this, because of the white-led systems they live within. 'Racialised' doesn't define people's community or identity, but the phenomenon that is happening to them, drawing attention to the racialisation of people of colour.

## What is the impact on people?

People from racialised communities access end of life care less and later than some other population groups, and clinicians may lack confidence in supporting them.

This delayed and unmet palliative and end of life care need amongst racialised communities can be due to 'lower access to services, lack of cultural sensitivity among healthcare providers, language barriers, previous negative experiences, and conflicting values between family / religion and the notion of palliative care'.<sup>20</sup>

Furthermore, there is 'growing evidence that ethnic and cultural differences can influence patterns of advanced disease, illness experiences, healthcare seeking behaviour, and the use of healthcare services'.<sup>21</sup>

## How are services responding to meet palliative care need?

### Building knowledge to improve care

Research priorities at LOROS hospice acknowledge that it can be more difficult for people from culturally and linguistically diverse communities to access or obtain information, support and services that will meet their needs.

LOROS hospice is leading a National Institute of Health Research funded study into how health professionals can improve the care for people from ethnically diverse communities at the end of life and the needs of those patients and their families when they are very ill.<sup>22</sup> The Thinking Ahead study began in 2018 and has interviewed 102 patients, family members, health professionals and bereaved family caregivers to gain a more in-depth understanding of how people approach living with serious illness, thinking about the future, planning for dying and what they want from health professionals in care and decision-making.

The findings will be used to provide resources for the training of doctors and nurses in how to support people more effectively in person-centred care and improve patient-related outcomes at the end of life.

Meanwhile, in the West Midlands Wolverhampton has one of the largest populations from Black, Asian and Minority Ethnic groups outside London (35.5%, of which 17.5% are South Asian), but just 3% of Compton Care's patients fall into that demographic.<sup>23</sup>

In acknowledgement of this low uptake of its services, Compton Care in Wolverhampton worked with the South Asian community to try and identify the challenges faced when accessing its services. The study, which engaged more than 500 members of the South Asian community, was commissioned to break down barriers and help more people benefit from its care.

Through a series of one-on-one conversations, focus groups, roadshows and events, Compton uncovered some core challenges. These include deep-rooted stigma and shame associated with gaining external support, while others face inter-generational differences in opinion on what level of support is acceptable from outside the family. Language barriers and limited understanding of the types of services available, were also found to prevent the community from exploring palliative care options for themselves or a loved one.



In response, Compton Care developed a series of recommendations for the palliative care sector, highlighting changes to practice designed to give greater access to services in a wider range of care settings. These span increased investment in community engagement activities; ensuring literature is culturally appropriate and disseminated correctly; appointing dedicated employees to boost engagement with the South Asian community; nurturing and empowering champions and ambassadors responsible for providing support; delivering more personalised care and leading more targeted events for specific communities.

Since completing the study, Compton has begun implementing these changes in its services. This includes the production of a short video on advance care planning which features actors speaking in four South Asian languages with subtitles in English. More recently the hospice launched a virtual bereavement hub for people from the South Asian community in response to increased pressures due to COVID-19.

### **Cultural liaison**

A recent review of inequalities in access to hospice care acknowledges differing levels of public awareness about what hospice care offers and for whom, which may in turn be affected by differing degrees of knowledge about health services and levels of health literacy (Tobin et al, 2021). The long-standing and multi-stranded approach at the Prince and Princess of Wales Hospice provides one example of work to raise awareness and service uptake among their catchment's diverse ethnic communities.

Scotland's population is projected to become increasingly ethnically diverse, and it's suggested that 'by 2031, around 20% of Glasgow's total population (and 25% of children) will belong to a non-white minority group' (Walsh et al, 2019).<sup>24</sup>

In Glasgow, the Prince and Princess of Wales Hospice was the first in Scotland to introduce a dedicated Cultural Liaison Officer.<sup>25</sup> This award-winning programme cultivates and fosters links with ethnic minority communities in an effort to raise awareness and uptake of the hospice's services.

With insights from initial scoping work, post-holders work with groups and organisations in the community, including Awaz FM, Scotland's Asian radio station. In the community and visiting the gurdwara and mosques, the Cultural Liaison Officer speaks about hospice and end-of-life care, helping to build knowledge. Information resources in languages such as Urdu, Punjabi, Polish and Arabic also help to address low awareness of the hospice's services. As a result, the hospice now has 60 volunteers from different ethnic backgrounds and there has been an increase in the number of referrals.

In South Yorkshire, St Luke's Hospice employs an Engagement & Quality Officer, from the South Asian Muslim community of Sheffield. This is a unique role in the city, and one in which community engagement is nurturing change in the delivery of services. Reflecting on this role, the post-holder highlights how important it is to recognise that people from ethnic minority communities need reassurance in order to accept help from mainstream services and health professionals.

*“ It is something to look forward to ”*

*Gupshup Club participant*

The Engagement & Quality Officer provides active engagement with the South Asian population of Sheffield including the 'Gupshup (chit-chat) Club' which is hosted by St Luke's; this is immensely popular and provides cultural and holistic support and information to engage the community with palliative care.

The Engagement & Quality Officer also supports the hospice's Muslim communities at the Inpatient Centre and in the community with regards specialised spiritual and cultural requirements for end of life including facilitating communication with clinical teams, access to bereavement services and support for families and mosques. This has continued throughout the pandemic and provided a vital means of connection and communication as an integral part of the hospice's service offering.

St Luke's Hospice reports that this initiative is succeeding in supporting people who may previously not have accessed palliative care to do so, particularly amongst the Muslim community of Sheffield; the hospice has seen a doubling of patient numbers over recent years, now representing 7% of its patient cohort (the Asian community in Sheffield represents 8% of the population).

The Engagement & Quality Officer also works with GP practices in areas of high ethnic population, supporting their connection with their communities and helping to break barriers in accessing services.

### **Diversity in the workplace**

A diverse workforce supported by an inclusive workplace is vital in terms of supporting the care of increasingly diverse populations and enabling people to reach their potential. A number of hospices have got in touch to tell us about their work in this area. For example, the Hospice of St Francis has radically reviewed its approach to inclusion and inclusive recruitment, notably changing the job profile requirements for all posts. This included changes to its essential requirements for the recruitment of trustees to include lived experience and proactively seeking to recruit new trustees (as existing trustees came to the end of their term) who identify as being from a Black, Asian or Ethnic Minority background.

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### **Addressing racism in palliative care**

A recent editorial makes clear that in order to create environments where diversity is valued, then the issue of racism must be acknowledged (Hussain, Koffman & Bajwah, 2021).<sup>26</sup> Pointing to the growing body of research which indicates that there are racial and ethnic disparities in access, quality and outcomes of care, the authors outline a number of vital steps, including how to encourage action, in order to create an environment where diversity is valued'.<sup>27</sup>

### **Looking forward**

Extending good person-centred care at the end of life depends upon principles which include:

#### **Data informed action**

Tools such as Hospice UK's PopNAT<sup>28</sup> (Population-based needs assessment tool) help service providers and local decision makers across the UK to identify unmet need, innovate and commission services based upon intelligence about the end of life and palliative care needs of the local populations.

#### **Collaborative service development**

In setting out its vision to improve end of life care, the refreshed 'Ambitions for Palliative and End of Life Care' framework (2021)<sup>29</sup> is clear that the success of its vision is founded in part upon principles of co-design. Recent research also highlights the essential need for sensitive involvement of communities in the co-design of services (Tobin et al, 2021).<sup>30</sup>

#### **Listen, and listen again**

Asking for, and listening to people from racialised communities about their experiences and needs, discovering and mapping community assets; working to understand cultures, and supporting community members to take a place at decision-making tables are all essential steps in developing and improving care across all settings, which in turn starts to deliver on choice options for people facing the end of life.

The Senedd Cross Party Group on Hospices and Palliative Care's report into the role of the Compassionate Cymru programme notes that "engagement between formal services and diverse communities must be accompanied by a commitment to listen and implement change if connections between communities and services are to be meaningful and sustainable."<sup>31</sup>

### Raising public awareness

Sustained effort to raise public awareness of what hospice care has to offer, in ways that acknowledge differing levels of health literacy and familiarity with health services remains critical. This in turn requires excellent links with local community groups.

### Learn from action

At a panel event hosted by Hospice UK to mark Dying Matters Awareness Week 2021, participants were urged to take action to address inequalities in end of life care – and importantly, to evaluate those actions. We learn together.

## People experiencing homelessness

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A calamitous and complex mix of personal and structural circumstances make people vulnerable to homelessness. The national charity Homeless Link explains that these circumstances may include 'poor physical health, mental health problems, alcohol and drugs issues, bereavement, experience of care, and experience of the criminal justice system'.<sup>32</sup> Homeless Link goes on to identify the impact of other issues such as 'poverty, inequality, housing supply and affordability, unemployment, welfare and income policies'.<sup>33</sup>

It is difficult to count accurately the number of people who are experiencing homelessness. This is because homelessness not only covers people who are sleeping rough (and maybe bedding down at different times, or sleeping in derelict buildings), but also those living in temporary accommodation, or less visible because they are sleeping at friends' houses or living in unfit or insecure residences. However, 4,266 people were deemed to be sleeping rough in England on a single 'typical' night in autumn 2019.<sup>34</sup>



4,266

**People sleeping rough in England on a 'typical' night (2019)**

Furthermore, statutory homelessness figures indicate how many households have contacted councils for help with homelessness. In England alone, 288,470 households were owed a prevention or relief duty in the first instance from local authorities in 2019/2020.<sup>35</sup>

Sadly, despite concerted efforts to get people into safe accommodation, the COVID-19 pandemic has exacerbated vulnerabilities. Indeed, a report from Crisis (2020) found that across Great Britain 'there has been a continued new flow of people experiencing homelessness since the start of the pandemic.' This began in part with the additional visibility of those already experiencing homelessness in vulnerable or transient housing situations where living conditions forced people to seek help, through to acknowledgement that 'the economic impact of coronavirus is exerting sudden pressure on people already pushed to the brink by low wages and high rents'.<sup>36</sup> Furthermore, the work by Crisis found that homelessness 'among people with No Recourse to Public Funds has been a continued issue throughout the whole of the pandemic'.<sup>37</sup>

## What does evidence and research tell us?

A recent scoping review highlighted 64 articles (11 from the UK) involving 2117 homeless and vulnerably housed people that tell us what support people experiencing homelessness may require.<sup>38</sup>

### Understanding the views of people experiencing homelessness

People who are homeless are more likely to be exposed to death, especially premature, violent, and traumatic deaths. This can lead to strong acceptance or aversion of mortality, and a heightened importance of religion, spirituality, and an afterlife. Perception of a good or bad death is also shaped by previous experience. A good death may be quick, involve resolution of relationships and spiritual issues, peace, and access to substances of addiction. A bad death may involve violence, dependence, loneliness, and uncertainty over what will happen to the body.

Autonomy, respect, and dignity are held in high regard. However, experiences of “discrimination, disrespect and disempowerment” create actual and perceived conflict between accessing services and integrity to personal values.<sup>39</sup> Such treatment discourages engagement, increases felt stigmas, and prevents open and honest discussion of substance use, necessary for safe prescribing. Small but strong social networks may spread news of negative experience quickly. This makes institutional trust slow to re-build, but quick to break.

### Understanding the needs of people experiencing homelessness

Homelessness alters the ability to access services. This may be through direct barriers (for example, requirement of an address), or indirect barriers (for example, rigid models of care not adapting to the uncertainty homelessness creates).

Competing issues may result in the de-prioritisation of engagement with services. Often these involve basic needs, however, needs around relationships and personal values should also be considered. Addiction,

disproportionately common among people who are homeless, represents one of the greatest challenges.

The underlying pathologies of people experiencing homelessness are often complex. Disproportionately prevalent diseases such as AIDS and liver failure follow unpredictable trajectories with frequent admissions and high symptomatic burden. Late presentation, care-avoidance, and physical or mental co-morbidity add further clinical challenges. The practicalities of homelessness may then alter the feasibility of conventional management plans.

### Understanding how the needs of people experiencing homelessness can be met

Where dedicated interventions have been successful, mostly around improving the uptake of advance care planning, these have aimed to build around the needs of people experiencing homelessness. This requires understanding of the experiences, beliefs, and complexities any one individual may have.

Holistic care requires multi-sector expertise. Hostel, social, and addiction or harm-reduction workers may have built up relationships with people who are homeless and vulnerably housed. These groups have insight into the needs of those they serve, can aid in the provision of holistic palliative care, and crucially can act as trusted gateways into services. However, staff may be over-burdened and under-equipped, and require practical and emotional support in helping facilitate care at the end of life.



## Gaps and limitations in the research

Firstly, the body of research focusses on those living on the streets and in emergency accommodation. However, the needs of other homeless and vulnerably housed groups such as those “sofa-surfing”, living in temporary accommodation, or mobile homes, are less well understood.



Secondly, to translate theoretical understanding into action, thorough evaluations of what successful models of provision may look like are still required. This is especially true for UK models of partnership working and harm-reduction approaches to addiction.

Finally, it should be noted that the specific experiences, beliefs, and needs of local people experiencing homelessness are far from homogenous. What is universal, is the need to understand these factors in providing accessible, acceptable, and effective care.

### How are services responding to meet palliative care need?

There is clear and encouraging evidence of burgeoning activity across the sector in support of end of life care for people experiencing homelessness and their support networks. This engagement embraces a wide range of approaches from hospices and we have heard of examples including facilitating cross-sectoral working, delivering tailored training, efforts to support practice and co-workers, and to disseminate knowledge and support research activity.

St Luke's Cheshire Hospice is a trailblazer in transforming the palliative and end of life care experiences of people experiencing homelessness. The hospice works with people and their support networks which may include family, friends, homelessness support workers, voluntary groups, GPs, hospital teams and drug and alcohol services, amongst others.

Acknowledging that many of their service users have complex needs and require assistance to navigate similarly complex health and social care systems, the hospice offers support through advocacy, case coordination and planning for the future.

St Luke's Cheshire Hospice also offers training at hostels, hospitals and universities, and in 2019 the hospice hosted the 'Dying for a home' conference which brought together hospices, social workers, GPs, nurses and care agencies from across the country. This work to improve choice and access to care is explored in more detail elsewhere.<sup>40</sup>

A three-year independent evaluation of the service at St Luke's Cheshire Hospice during its project phase (2016-19) found that the project had already met its targets by the end of the second year. Whilst delivering beyond its targets, the project also 'worked to disseminate learning, share good practice and develop resources to ensure the long-term viability of its work'. The external evaluation noted that it was evident that 'the project has had a meaningful impact on the delivery and accessibility of end of life care for homeless people. Effective collaboration, communication and networks of professionals who understand, and can work with, complexity and uncertainty are key to successfully supporting end of life care for homeless people.'

## **Dedicated counselling and other support for clients and staff**

The Homeless Palliative Care Service at St Ann's Hospice (Manchester)<sup>41</sup> offers support to clients, keyworkers and health and social care staff when someone's health is getting worse. The service aims to reach people earlier on in their illness and improve the quality of care for those with advanced ill health. This support for people experiencing homeless, staff and teams is augmented by a homelessness and loss counselling service.

Support for clients includes giving information to aid informed decisions, case management, advocacy and social support, helping people to reconnect with loved-ones and the provision of specialist end of life care. The free use of iPads encourages engagement with health services.

The hospice also offers free counselling to people who are homeless themselves, or for staff working in the homelessness sector who have experienced a loss of any kind. With an accent on access, the hospice's counsellor can go to the client and there are flexible appointment times, drop-in clinics and one-off sessions. Access to interpreting services offers support for those whose first language is not English.

The Homeless Palliative Care Service is committed to supporting anyone who works with someone experiencing homelessness who has advanced ill health. The hospice also offers training tailored to the needs of a particular team and topics might include: how to identify clients of concern; an understanding of palliative and end of life care and how it can help; care planning in temporary accommodation, along with bereavement support, self-care and resilience.

### **Joint working**

A project in Kent is amongst the examples Hospice UK heard about where hospices are working together with local homelessness support organisations to deliver person-centred care. In this example, Pilgrims Hospices and a local homelessness charity are planning the roll out of a sustainable multi-disciplinary model of person-centred care and support for people

experiencing homelessness with advanced ill health. This work is under-pinned by research and scoping activity to identify challenges faced by people experiencing homelessness, and by staff supporting them.

In aiming to twin community palliative care services with hostels, the approach will see palliative care specialists trained and facilitated to visit the hostel once or twice a month to deliver training and provide support for both staff and residents, with a focus on developing a multi-disciplinary approach to supporting residents with advanced or deteriorating health.

The value of champions in helping to build connections between palliative and homelessness services is recognised in the research literature,<sup>42, 43</sup> and it's an approach which features here.

### **Pledge to care**

Dr Kershaw's Hospice have provided care for people experiencing homelessness during the pandemic and in 2019 Dr Kershaw's Hospice became the first hospice in the UK to take the homeless friendly pledge and are now a 'Homeless Friendly' service. This is a commitment which is reflected throughout the organisation with staff at all levels – from volunteers to board members – accessing awareness training on homelessness.

Training in end of life care and how people can access support from the hospice's services is also on offer to staff working in hostels, foodbanks, homeless charities and housing associations.

### **Looking forward**

Encouragingly, a report from the Care Quality Commission and Faculty for Homeless and Inclusion Health (2017) notes that 'hospices are ideally placed to champion an equality-led approach to end of life care for homeless people, and engage and support staff and others in the community to do the same'.<sup>44</sup>

Undoubtedly, there are a growing number of initiatives to support people who are homeless and living with advanced ill health in the UK. But there is more we can do to nurture and sustain this momentum.



It is clear from analysis of the evidence base<sup>45</sup> that further research is required to understand the particular needs of those living with advanced illness who are vulnerably or precariously housed, living for example, in temporary accommodation or in mobile homes.

### Learn from what works

As emerging models of care are established, it's vital that formal evaluations are conducted and published. For example, there are early promising results from a first project to evaluate a model providing in-reach support from palliative care professionals into homeless hostels.<sup>46</sup>

Alongside this, and in light of responses to the COVID-19 pandemic, the role and potential of remote learning, training and support needs also to be considered.

**Continue to invest in partnership working and multi-agency, multi-disciplinary approaches to deliver person-centred care.** Mutual recognition of the expertise within different sectors and knowledge sharing are amongst the hallmarks of effective care delivery. Connections and coordination are key enablers.<sup>48, 49</sup>

**Lived experience informing service development.** An exploration of the end-of-life concerns, preferences and priorities of a number of people experiencing homelessness in the UK highlights the need for new models of care (Webb et al, 2020).<sup>50</sup> This in turn underlines the importance of enabling the voices of people with lived experience to shape and inform service delivery.

An intersectional lens brings value in acknowledging that the inequalities experienced by people who are homeless are further exacerbated by inequalities based on gender, sexuality, immigration status and more.

## Imprisoned people

The prison population is growing older and sicker. The number of imprisoned people aged over 60 has more than tripled in the past twenty years.<sup>51</sup> 90% of the older prison population have at least one moderate or severe health condition<sup>52</sup> and troublingly, their health outcomes are worse than those of the same age outside prison,<sup>53</sup> despite being entitled to the same healthcare and treatment.<sup>54</sup>



### Older prisoners with at least one moderate or severe health condition

In the past decade, deaths in prison in England and Wales due to natural causes have increased by 77%, with older people accounting for over 50% of all deaths in custody.<sup>55</sup>

With growing numbers entering prison later in life with long sentences and severe health conditions, come growing numbers of people dying with palliative care needs while incarcerated. The need for end of life care, therefore, is and will continue to grow more acute.

It is especially important that this growing need for end of life care is met as imprisoned people are considered an inclusion health group i.e. a group that faces the sharpest edge of exclusion and marginalisation, and as a result, particularly poor health outcomes.<sup>56</sup> Certain lived experiences tend to present across inclusion health groups, such as trauma, poverty, and domestic violence.

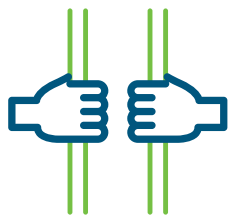
## What is the impact on people?

Hospice UK analysis of deaths in prisons in the year up to December 2019 demonstrated that 153 incarcerated people died in England. Of these, 136 were categorised as due to natural causes. Further analysis revealed that 95 of these deaths (62%) were described as foreseeable and as requiring palliative care.<sup>57</sup>

Hospice UK research demonstrated significant shortcomings regarding imprisoned people's end of life care:

### In 8 out of 95 cases

the care the imprisoned people received at the end of life was considered inequivalent to that which would have been received in the community.



### In 20 out of 95 cases

the imprisoned people were inappropriately restrained (e.g. handcuffed) at the end of life.



### In 15 out of 95 cases

there was delayed or no consideration at all of early release on compassionate grounds despite imminently facing the end of life.



## How are services responding to meet palliative care need?

We found that 25 hospices in England are providing this care, working with a total of 34 prisons across the country. This demonstrates that at least 15% of hospices in England are engaged in this important work. The support they provide ranges from providing on-demand specialist palliative care advice to prison clinicians, to directly caring for imprisoned people within the prison estate and hospice in-patient units. Some services have been working with prisons for over 15 years, while others are at the beginning stages of establishing relationships with their local prisons.



## Hospices in England working with prisons

Of the respondents to a survey we issued working with prisons:

- 65% are providing on-demand end of life care advice to prisons.
- 62% are providing direct clinical care to people in prisons.
- 54% are providing end of life care teaching and training to prison staff.

A nurse working in HMP Durham contacted St Cuthbert's Hospice following a request from an imprisoned patient to die in a hospice. At the time, the hospice held a position of not accepting patients from prison, most likely originating from reputational risk concerns. Working together with the prison's clinical team and Governor, the Chief Executive put a successful case to the hospice's board of trustees in order to overturn this position, and the hospice started to accept imprisoned people into its inpatient unit. The discussion was solution-focused, transparent, and established the relationship between the prison and the hospice.

At the start of the COVID-19 pandemic in April 2020, St Peter's Hospice's Education Team held a virtual training session for healthcare staff working in all five prisons in the Bristol area with no experience of delivering end of life care. Prison staff were anxious at the prospect of having to deliver end of life care within the prison setting in a climate exacerbated by COVID-19. This session was very well received: "anxieties were so high prior to it, but afterwards they were much more comfortable about the prospect of delivering end of life care." (Abi Bartlett, Head of Nursing and Allied Health Professionals at Hanham Secure Health).

### Looking forward

#### Assessing local need and working in partnership

Hospice services should assess the need for palliative and end of life care support for imprisoned people in their community and proactively engage and work closely with local specialist organisations supporting prison health and care services to ensure that need is met.

#### Building relationships with prison governors

It is vital that there is a better shared understanding of the support that is available from hospice services, and the unique needs that imprisoned people will have at the end of life. National organisations and local services should commit to dispelling myths and misconceptions.

#### Sharing good practice

National organisations and local organisations should support and facilitate the sharing of good practice across the palliative and end of life care system for those providing care for imprisoned people.

## LGBT people

### What is the impact on people?

The vulnerability of LGBT people to health inequities is well documented within and beyond palliative care.<sup>58</sup> Sadly, as Rosa et al (2020) reflect, 'LGBTQ+ persons have a significant history of dehumanizing and marginalizing experiences when interacting with health care systems and professionals who often lack the training and infrastructure needed to equitably and inclusively respond to these populations'.<sup>59</sup>

Despite a legal duty under the Equality Act 2010 for healthcare services to treat LGBT people fairly and without discrimination, the evidence is clear that LGBT people have disproportionately worse health outcomes and experiences of healthcare. Such experiences are voiced in a national survey of LGBT people launched by the Government in 2017. With more than 108,000 responses, it was reported that at least 16% of survey respondents who accessed or tried to access public health services had a negative experience because of their sexual orientation, and at least 38% had a negative experience because of their gender identity.<sup>60</sup>



With more than 108,000 responses, it was reported that at least

**16%**

of survey respondents who accessed or tried to access public health services had a negative experience because of their sexual orientation, and at least

**38%**

had a negative experience because of their gender identity.

Good end of life care is founded upon good communication; something which is not possible when fears (both experienced and expected) of negativity and discrimination, and a presumption of heteronormativity shroud such interactions.

The pain of bereavement can also be exacerbated by disenfranchised grief which has been described as 'a mourning process marked by stigma and a lack of social recognition and validation that the bereaved person has suffered a significant loss, and subsequent lack of support' (Cloyes et al, 2018).<sup>61</sup> Alongside additional legal and financial issues and other stressors, there is also risk of heightened or prolonged grief, as Bristowe et al (2016) point out. Thus Bristowe et al conclude that by 'integrating careful questioning about who is important to an individual into routine practice, avoiding assumptions of heterosexuality, and not being afraid to ask sensitively about identity, clinicians can be enabled to deliver holistic individually centred care'.<sup>62</sup> It is noted too, that further research in particular into the bereavement experiences of trans and bisexual people is required.<sup>63</sup>

This is not to suggest that health and social care organisations do not wish to provide the best possible services for LGBT people but the evidence is clear that barriers impede these aims. In essence, failures in communication, providers' lack of awareness, education, and competency training, conscious and unconscious biases, and reliance on assumptions rather than knowledge and experience with LGBT patients create additional unnecessary barriers to effective communication and, therefore, care.<sup>64</sup>

### **How are services responding to meet palliative care need?**

Whilst we heard from hospice and palliative care services which routinely care for LGBT people, we focus here on examples which illustrate how service providers are engaging in outreach, working on visible messages of support and seeking to embed cultures which enable LGBT patients, carers and staff to feel comfortable and safe in their care and working environments.

## **Organisational culture and networking**

Royal Trinity Hospice in London is a pioneering force within the sector in addressing LGBT inequality in end of life care and working to enable people to be themselves – as patients, carers and staff. The hospice established an LGBT Friends group to help shape service provision and has forged links with other local LGBT groups. Notably, Royal Trinity Hospice was the first hospice in the UK to be included in the 'Investors in Diversity Top 100 Index', and has introduced 'FREDIE' (fairness, respect, equality, diversity, inclusion, engagement) as part of the hospice's culture so that the workforce are more aware of legally protected characteristics in their patients and colleagues and more aware of their own unconscious biases.<sup>65</sup> Within five months of its launch in February 2019, a staff survey found that 26% thought FREDIE had already made a difference.<sup>66</sup>

In 2017 along with nine other hospices, Royal Trinity Hospice established the London Hospices LGBT Network. The Network is focused on promoting equality, diversity and inclusion of LGBT people across London hospices; providing leadership, support and education; and raising awareness of hospice care in LGBT communities.<sup>67</sup>

The work of Royal Trinity Hospice in creating an inclusive care environment, investing in staff engagement and support and community engagement commitments is further explored in the publication, 'Care committed to me' (2018).<sup>68</sup>

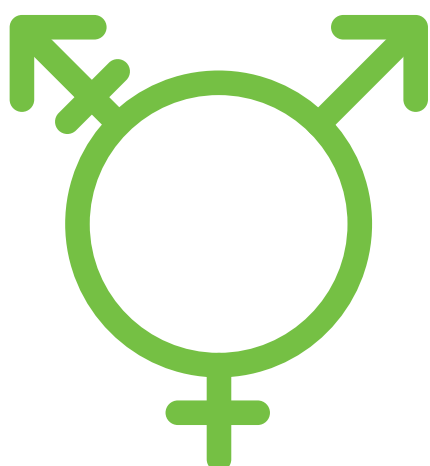
## **Supporting carers**

Meanwhile, in Devon Hospiscare has led work focussing on the needs of LGBTQ+ people, and the specific needs of their carers. This work is multi-dimensional in exploring the needs of LGBT people and their carers, encouraging advance care planning and paying heed to the organisation's workplace culture.

The project was designed to strengthen Hospiscare's staff and volunteers' knowledge and understanding of the specific issues facing the LGBTQ+ community, including what LGBTQ+ carers need from the hospice in order to feel safe and supported at a time of vulnerability. The project aims to take the hospice's knowledge and skills in advance care planning to the LGBTQ+ community in order to reduce the distressing situations LGBTQ+ carers face when they are not recognised as the primary carer of their loved one.

Hospiscare has found that the project has changed fundamentally how the hospice considers all carers, not just those from the LGBTQ+ community, whilst the hospice's Carers' strategy now includes new processes and procedures meaning that carers have their own individual care pathway. In addition, new training around issues of gender and equality and diversity is embedded into the organisation enabling frontline staff and volunteers to have the confidence to open up conversations with LGBTQ+ people and so address their individual needs and concerns, with the ultimate aim of giving the best end of life care that is respectful of gender identity, sexual orientation and relationships. Hospiscare is a Stonewall Diversity Champion organisation and an external review of the hospice's policies, teaching and environment is planned.

Furthermore, LGBTQ+ champions and allies have stepped forward and formed a group; this group feels that the project has had a big impact on staff confidence and knowledge to improve access and work with LGBTQ+ people.



## Supporting trans people

The size of the UK's LGBT population is hard to determine; for reasons such as fear of disclosure, under-reporting means that official statistics may not present the full picture. Furthermore, in considering service planning and commissioning, it's important to note that the visibility of the trans population and knowledge of its size is further hampered by the absence of any robust data. However, the Government Equalities Office (2018) estimate that there are 'approximately 200,000-500,000 trans people in the UK'.<sup>69</sup>

It is to be noted that along with bisexual people, trans people 'face different kinds of prejudice and discrimination from gay men and lesbian women, and this may sometimes come from within the LGBT community itself'.<sup>70</sup> Worryingly, the results of a survey commissioned by Stonewall (2018) found that two in five trans people have experienced a hate crime or incident because of their gender identity in the last 12 months. Whilst two in five trans people 'said that healthcare staff lacked understanding of specific trans health needs when accessing general healthcare services in the last year'. The survey report also notes that trans people often lack support from their families and a significant number experience homelessness at some point.<sup>71</sup>

In Manchester, St Ann's Hospice have adopted a multi-faceted approach in reaching out to trans people. This model includes building links with trans communities and partnering with local advocacy groups to provide support and education, thus enabling a voice for the trans community in terms of what's important to them with regards to palliative and end of life care.



## Looking forward

### Develop evidence base, especially for trans people

Further research is needed into the experiences, wishes and needs of palliative, end of life and bereavement care for LGBT people,<sup>72</sup> and most especially for trans people where evidence suggests, for example, that trans people are less prepared for end of life than LGB people.<sup>73</sup>

### Active and inclusive commissioning

Think actively and inclusively when planning and commissioning services; as the House of Commons Women and Equalities Committee heard (2019), 'LGBT people need to be treated equally, but not identically to, other groups. Access to the same services as others is ineffective if that service is structured for a heterosexual and cisgender default and has limited flexibility. There is not enough understanding from service-providers of the different needs that LGBT people might have'.<sup>74</sup>

### Robust data collection

Sexual orientation and gender identity monitoring is vital for better care. Effective service planning, from providers and commissioners, depends upon better knowledge and understanding of communities, key issues affecting them, specific needs, use of services and unmet need. This in turn highlights the importance of a commitment to robust data collection at local as well as national levels.

## Workforce development

Invest in workforce development. Research published by Stonewall in 2015, found that more than half of health and social care staff with direct responsibilities for patient care did not consider sexual orientation to be relevant to an individual's health needs.<sup>75</sup> However, whilst assertions that 'we treat everyone the same' may be well intended, the point remains that not everybody is the same. The danger of this approach is that 'it fails to take account of the person's past experiences and / or anticipation of discrimination; this in itself can be a major barrier to accessing end of life care services and may actually exacerbate inequality'.<sup>76</sup>

### Apply evidence based research recommendations to practice

Act upon the work of the ACCESSCare study which identifies ten evidence-based, low-cost and simple recommendations to improve care for LGBT people.<sup>77</sup>

### A note on terminology

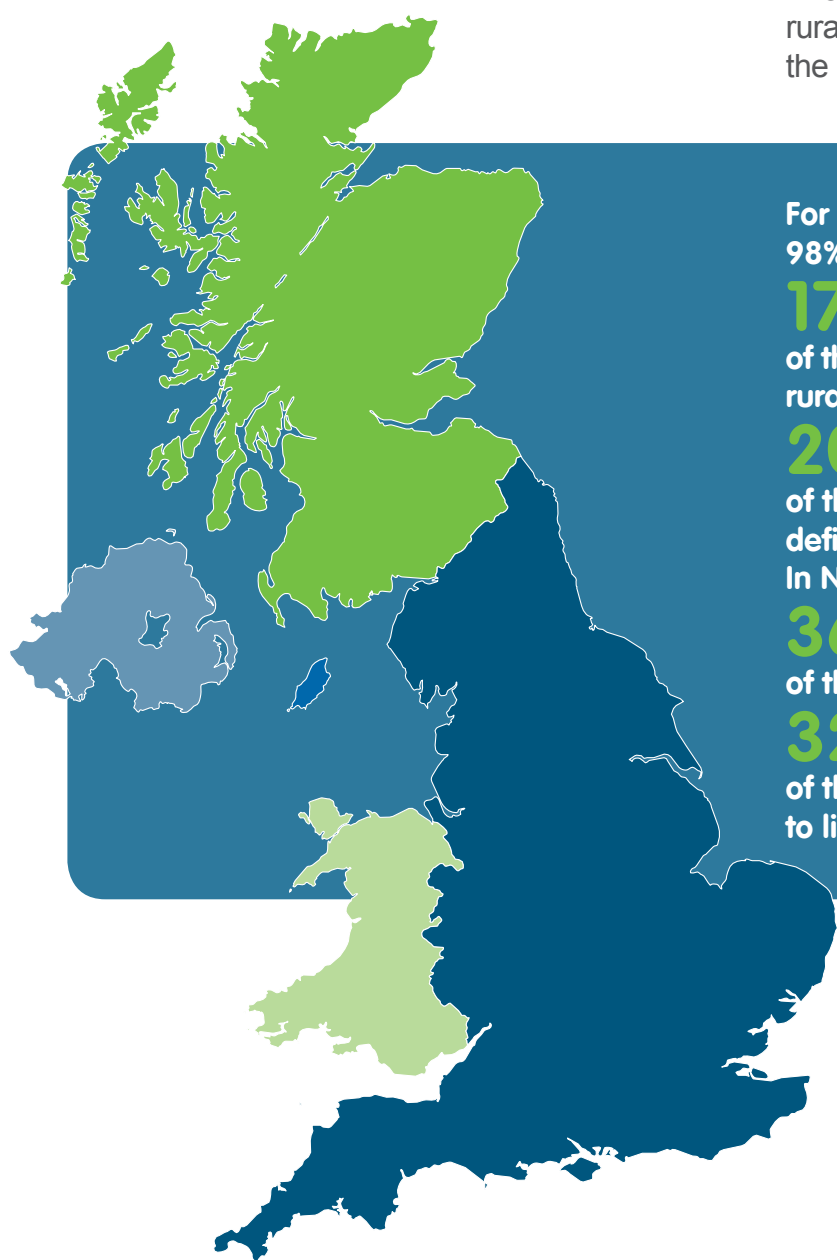
We use the acronym LGBT to refer to lesbian, gay, bisexual and transgender (or trans) people, although it is acknowledged that grouping people under one acronym risks losing sight of a person's individuality and different needs and experiences. Where evidence is cited within this document that describes research participants as LGBTQ people, then this terminology is retained. A number of terms and acronyms are used to describe LGBT people. In essence, lesbian, gay and bisexual are used to describe a person's sexual orientation. Transgender is about gender identity meaning this may include people who are heterosexual, lesbian, gay or bisexual. 'Questioning' may be used to describe someone who is uncertain of their sexuality or gender identity.

## Remote and rural areas

The diversity of environments across rural UK, ranging from coastal communities to remote farmlands and sparsely populated uplands, along with differing pockets of affluence and deprivation, and typically older population profiles means that living and dying in rural areas is by no means a homogenous experience.<sup>78</sup>

Living in remote and rural areas presents challenges which are different to those experienced in urban areas. For example, people living in rural communities may be grappling with issues such as reduced investment in public transport, digital connectivity and greater distances to travel to access health and related services. Such challenges are further exacerbated when someone requires palliative care support. As Goodridge and Marciniuk (2016) point out, vulnerabilities in health status and access to care serve to highlight the need for innovation in service delivery.<sup>79</sup>

The UK's landmass is largely composed of rural areas, although proportions vary across the nations.



For example, rural Scotland accounts for 98% of the land mass of Scotland and

**17%**

of the population are resident there,<sup>80</sup> whilst rural areas make up 90% of England, with

**20.9%**

of the population living in local authorities defined as predominantly rural.<sup>81</sup>

In Northern Ireland

**36%**

of the population live in rural areas<sup>82</sup> and

**32.8%**

of the population in Wales are estimated to live in rural areas.<sup>83</sup>

## Older populations in rural areas

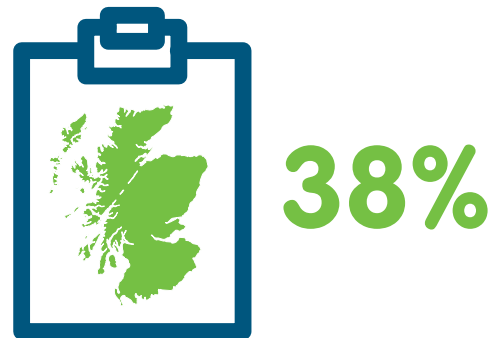
The proportion of people aged over 65 is higher in rural areas compared to urban populations, for example 25% of the population in remote rural areas of Scotland are over 65, compared with 21% of the population living in accessible rural areas and 18% in the rest of the country.<sup>84</sup> In England, 24.8% of the rural population are aged 65 and over compared with the urban population where 16.8 per cent are 65 and over.<sup>85</sup> The older population group is also growing faster in rural areas.<sup>86</sup> This is likely to mean there is an increasing need for palliative care in remote and rural areas.

There are particular challenges around social isolation and loneliness in remote and rural areas, which can negatively affect people's health and wellbeing. Life events such as bereavement can also add to social isolation. Thus it's worth noting that between 2018 and 2043, 'rural areas are projected to experience some of the largest increases in the proportion of one-person households containing an older person'.<sup>87</sup>

## Access to palliative and end of life care for remote and rural communities

The data from Scotland alone show that populations can be very dispersed and in the UK, most hospices and specialist palliative care units are located in or near cities which means that remote and rural areas can face particular challenges in terms of access. Indeed, Gatrell and Wood (2012) carried out an analysis to map and describe variation in geographic access to the 189 specialist adult inpatient hospices in England and Wales. Their findings suggest that rural and more deprived areas were comparatively under-served compared to urban centres and more affluent areas.<sup>88</sup> More recently the 'Scottish atlas of palliative care' (2016) showed variation in the availability of palliative and end of life care services across different health board areas in Scotland, for example the majority of charitable hospices are located in Scotland's central belt with limited access for remote and rural communities.<sup>89</sup> It is, therefore, not surprising that only a third (38%) of respondents to a 2020 Hospice UK survey on the future of

hospice care in Scotland thought that people in Scotland can access palliative and end of life care that meets their needs regardless of their geographical location. The survey also reported that geographical challenges, particularly relating to remote and rural areas, were identified as the greatest area of unmet need for palliative care in Scotland.



**Think people in Scotland can access appropriate care regardless of location**

The centralisation of specialist health services in urban areas can introduce structural inequalities which disproportionately impacts rural communities. People living in remote and rural communities face additional difficulties in accessing specialist palliative care due to having to travel greater distances to access services. For some, this will mean it's difficult or impossible to access some services; for example, access to day care services delivered via traditional models, is only viable for people living within a reasonable travelling distance of a hospice. Travel for patients and staff can also be hampered by poor weather in winter, the cancellation of ferries to island communities etc.

There are particular challenges facing the health and care workforce in remote and rural areas. This include recruitment issues, ensuring sustainable workforce models and rotas, out of hours cover, lone working and access to support and skills development.<sup>90</sup>

People living in remote and rural areas also face challenges in access to generalist services that are important in providing palliative and end of life care. There are long-standing issues around General





Practitioner (GP) recruitment in rural areas. In Scotland, for example, this has been a national priority area and some progress has been made. However, there are still challenges which means it can be harder for people in rural areas to access a GP or district nursing service. Social care services also face challenges around recruiting carers with appropriate expertise, travelling long distances and only having short visits available to care for patients.

The intersection of place and complex need can also impact on access to care. For example, a study on living with motor neurone disease and commissioned by Motor Neurone Disease Scotland found that the concern from some families about distances travelled by specialist nurses meant that the families limited their requests for visits.<sup>91</sup>

### How are services responding to meet palliative care need?

We have heard of innovative, creative and agile responses from hospices, especially in light of challenges presented by the pandemic. Indeed, Dunleavy et al (2021) note the demonstration by specialist palliative care services of 'considerable flexibility and 'frugal' innovation'<sup>92</sup> in the face of COVID-19 as hospices and others sought to re-frame services at pace. Equally, it's acknowledged that restrictions posed by the pandemic means that some services have had to pause for the time being.

### Shift to virtual services

The COVID-19 pandemic has accelerated a shift to virtual service delivery, and the use of digital technologies across hospice and palliative care. Whilst these developments have great potential to reach more people in remote and rural areas across the UK, it's important to note that they can also exacerbate existing inequalities when people lack equipment, resources or IT skills. However, we heard from numerous hospices which have successfully introduced virtual hospice services.

For example, in 2020 CHAS (Children's Hospices Across Scotland) launched the UK's first virtual children's hospice. The virtual hospice offers families a range of services including nursing, medical and pharmacy advice by phone and video; bereavement support; money and benefits advice; and practical advice around coronavirus. The service also offers a storytelling service for children at home; letter writing for children and parents; activity packs and art clubs; and virtual Clowndocor visits. Whilst this service was rapidly deployed in response to the pandemic, the virtual hospice is intended to be an integrated part of the service offering from CHAS going forward.<sup>93</sup>

The virtual hospice is helping CHAS to widen access to its services for families during the most difficult of times. For example, in May 2020 alone CHAS's virtual hospice supported 337 participants in online palliative care sessions and offered 17 different services. This new model has also been well-received with a very positive response from families to each episode of care, as well as in reporting improved quality of life following calls from CHAS.<sup>94</sup>

An exploration (conducted Summer 2020) of the responses from Scottish hospices to the COVID-19 pandemic identifies a number of positives relating to a shift to virtual service delivery models. These benefits include evidence of referrals from wider geographical areas, including from remote and rural areas. Hospices reported that virtual outpatient and day service sessions have been particularly useful for those who physically would not have been able to attend when delivered through more traditional methods.<sup>95</sup>

So that virtual service delivery models can offer fair and equitable choices for people, continued support for patients and families in using these services is important. This may include the loan of equipment, for example. Equally, a sustained move to virtual service delivery models requires good infrastructure, with access to good broadband, integrated IT systems, WIFI and access to appropriate equipment, digital platforms etc. Whilst training and support for staff and volunteers around remote working and digital technologies must also be considered.<sup>96</sup>

### Project ECHO

Conceived from the need to better support healthcare in remote communities, the Project ECHO model offers a transformational and democratic means of helping to open up care at the end of life.

Its founder, Sanjeev Arora, explains that Project ECHO (Extension of Community Healthcare Outcomes) is a 'low-cost, high-impact intervention' which 'links expert multidisciplinary specialist teams with frontline community healthcare providers via ongoing videoconference-enabled sessions (Arora et al, 2017).<sup>97</sup> This is an approach which Arora et al note; 'improves healthcare workforce capacity and increases access to specialty care for the world's rural and underserved populations'.<sup>98</sup>

The use of Project ECHO to support staff across the wider health system in delivering palliative and end of life care in rural and remote areas is demonstrated by Highland Hospice.<sup>99</sup> Project ECHO was established in Highland in 2016. The project has grown each year and in 2020 Highland Hospice supported almost 20 communities of practice across health and social care disciplines within and out with palliative care.<sup>100</sup> As one of the 'superhubs' across the world which are licensed to train other organisations to set up their own local hub, Highland Hospice has already trained eight hubs in Scotland across the NHS and independent sector.<sup>101</sup>

Remarkably, three separate COVID-19 knowledge ECHO networks were rapidly established within 72 hours to support primary care (out of hours GPs; rural GPs; and general GPs in the Highland area). Evaluation of this support found that 89% participants reported that their daily practice had changed as a result of the ECHO, whilst 93% felt the programme met their needs and expectations, and 80% reported an increase in clinical knowledge, confidence and skills. Furthermore, 77% said that the ECHO had influenced their relationships with colleagues in primary and secondary care.<sup>102</sup>

### Mobile outreach

Mobile hospice units offer a creative way of reaching more remote communities. In 2017, Ashgate Hospicecare joined a number of other hospices which have developed such services. The Specialist Palliative Care Mobile Clinic and Information Service for the High Peak and Derbyshire Dale area provides hospice care, information and assessment to patients and carers in rural areas furthest from Ashgate Hospicecare, as well as being a greater physical presence where people are less aware of the services they can access.<sup>103</sup>



Other examples include the Hospice Outreach Project provided by St Barnabas House in West Sussex. In more usual times this mobile vehicle unit offers a drop-in service at various venues, offering information and advice on symptom management, as well as emotional, spiritual, psychological and bereavement support.<sup>104</sup> Whilst in 2019, Farleigh Hospice launched its new Hospice Outreach Project (HOP) vehicle, providing accessible information and support locally in mid Essex towns and villages. Notably, over the 'eight years that the previous HOP was on the road the Information service supported over 50,000 people'.<sup>105</sup>

### **Partnership working**

To bridge the gap in inpatient end of life care on the island of Anglesey, St David's Hospice in North West Wales has established a satellite hospice in partnership with the local health board. While the health board made a redundant hospital ward available, St David's has refurbished and fully staffed the unit, meaning that people across the island have access to hospice inpatient care.

### **Looking forward**

In keeping with other aspects of inequalities addressed in this publication, the voices of rural and remote communities are not well heard and further research is needed to augment the 'limited published rural studies reporting on patient and family caregivers' experiences and perspectives on rural end-of-life care' (Rainsford et al, 2017).<sup>106</sup>

### **Population needs assessments**

Health and social care partners must carry out detailed population needs assessments to understand need and unmet need in palliative care in remote and rural areas and involve all stakeholders in the strategic planning and commissioning of palliative and end of life care services to meet the particular needs of people in these areas.

### **Invest in infrastructure**

Practically, it is necessary to address wider infrastructure issues such as access to broadband across the UK to support delivery of virtual services and invest in travel and transport links across the UK.

It is clear that successful models rely on a partnership approach and it is vital that this is fostered. Collaboration is to be encouraged between all partners delivering palliative and end of life care, including wider links with the local community.

In light of the increasing focus on community based care, and hospice at home type services, more energy needs to be invested in how community/home care models can work sustainably in more rural settings.

### **Supporting family carers and the professional workforce**

It is critical that unpaid carers are well supported and that resilience and capacity are nurtured in local communities based in remote and rural areas. Compassionate communities and existing community networks have important roles to play; often community support and networks are particularly strong in rural areas and consideration must be given to how to make the most of these assets.

More needs to be done to understand and address the challenges affecting the palliative and end of life care workforce in remote and rural areas across the UK.

Alongside addressing recruitment and retention of staff, different workforce models and greater use of virtual services and technology like ECHO for training and skills development must be explored to enable people living in remote and rural communities to access good end of life care.

## An ageing population, living with frailty and dementia

Age has been under the spotlight during the coronavirus pandemic, with older adults at greatest risk of both severe illness and death. People living with dementia have been particularly hard hit, with more than a quarter of COVID-19 deaths in the UK believed to have been from people living with the condition,<sup>107</sup> while the impact on the normal running of health services has contributed to diagnosis rates dropping to 61%, the lowest in many years.<sup>108</sup>

People in the UK are, as a whole, living longer lives than previous generations. The number of centenarians living in the UK has grown 85% in the past 15 years<sup>109</sup> and by 2030 one in five people in the UK (21.8%) will be aged 65 or over.<sup>110</sup> However, although life expectancy has increased, the rate of increase has slowed since 2011<sup>111</sup> while time spent in poor health has also grown.



**By 2030 one in five people in the UK will be aged 65 or over**

Most people die above the age of 80 and from chronic and degenerative diseases, after living for a number of years in increasingly poor health. Dementia and Alzheimer's disease is now recorded by the ONS as the leading cause of death in England and Wales, resulting in 12.7% of all deaths registered in 2018.<sup>112</sup> Despite being increasingly prevalent among the population and being closely linked to mortality, frailty is not currently captured by mortality statistic agencies across the UK.

The health of older people often requires management of frailty, disability and multi-morbidity. Although some factors shaping the health of older people are genetic there are also social, economic and political influences that have a cumulative effect on health in old age, meaning 'the life course is a useful lens through which to think about solutions, namely when and how to intervene to reduce inequalities in later life'.<sup>113</sup> Physical and social environments such as homes and communities, as well as personal characteristics explored elsewhere in this report have an impact.<sup>114</sup> We know for example that at least half of the 4.3 million homes in England failing to meet basic standards set by government are headed by someone aged 55 or older.<sup>115</sup> Older women are more likely than older men to live alone, an indicator of poorer physical and mental health, while women live a smaller proportion of their lives in 'good health' than men, in part because of a longer life expectancy and associated ill health.<sup>116</sup>



Good end of life care for older people and people with dementia often reflects good care for anyone else. It supports people and their families to preserve a good quality of life, retain dignity, manage symptoms and pain, while ensuring people are able to exercise choice and control over their lives and care. Hospice care and frailty in old age can both suffer from the same misconception that quality of life can no longer be maintained, when in fact the opposite is very much true with the right plans in place.

## What is the impact on people?

A secondary analysis of data from four studies on the end of life experiences of people with glioma, bowel cancer, liver failure and frailty suggests that people aged 70 and over have more untreated pain, less access to generalist and specialist palliative care, and greater information needs than younger people.<sup>117</sup>

The extended period of time associated with frailty and health deterioration in old age, compared to the often more immediate changes in health linked with conditions like cancer, might impact how older people and services interact towards end of life. For those able to access it, good quality health and social care can make a huge difference to those later years. However, people over the age of 85 are less likely to access palliative care than people below the age of 85<sup>118</sup> while people in older age groups receive a much shorter duration of palliative care prior to death. In one study that covered 42,758 people referred for hospice care, there were significant differences in the number of days between referral and death: for those under 50 years (78 days), 50–74 years (59 days), and 75 years and over (39 days).<sup>119</sup>

Older people often experience different end of life care outcomes compared to those in younger age groups or people living with conditions like cancer. A systematic literature review found evidence showed that the oldest old (aged 85+) are under-represented in hospice care provision.<sup>120</sup> Inadequate pain control, more regular hospital inpatient stays, and fewer palliative care interventions are all potential pitfalls. Even when the quality of care is equal for older people as it is for younger people in the last months of life, in the final days, older age groups may receive less emotional and spiritual support and be exposed to more unwanted treatment decisions.<sup>121</sup>

## End of life care for older people living with dementia

People living with dementia, both older and those with young onset dementia, may experience particular challenges around end of life care. Compared to those living without the condition they are less likely to be referred to specialist end of life care, prescribed fewer palliative care medications and are infrequently referred or considered for hospice care. People living with dementia are also more likely to experience invasive interventions at the end of life, such as blood tests, intravenous therapy and feeding tubes.<sup>122</sup>

There can be less obvious early signs of palliative care need for older people, in turn affecting chances of swift referral. In one study approaching death was frequently only recognised in retrospect by families of frail people. Recognition of the end of life phase of dementia is recognised as being particularly difficult due to issues with communication and how challenging it can be to predict deterioration of health. Hospital admissions and transitions between different settings can be particularly stressful for someone with dementia, and many admissions to hospital that occur are avoidable. One study found participants living with advanced dementia received visits from primary care and emergency paramedics but had little interaction with geriatric or mental health care professionals.<sup>123</sup>

These findings are reflected by another study which found local hospices and palliative care teams tended to be used to support generalist staff, through advice or formal training, often instead of being more directly involved in providing end of life care to people with dementia. Though the hospices in the research were keen to have greater involvement their role appeared unclear, underlining the importance of seamless and integrated care for people and their families.<sup>124</sup>

Research has helped to identify seven key factors associated with good end of life care for people living with dementia: timely and personalised planning discussions; recognition of end of life and provision of supportive care; co-ordination and continuity of care; effective working relationships with primary care; managing hospitalisation; continuing care after death; and valuing staff and ongoing learning.<sup>125</sup> Due to the nature of the condition and related symptoms, people with dementia may have a greater need for early and ongoing conversations about end of life care and treatment decisions, including decisions around Do Not Attempt CPR (DNACPR).

Guidance from NICE is clear that people living with dementia should be offered flexible palliative care based on needs, that considers how unpredictable progression can be from the point of diagnosis.<sup>126</sup> The Prime Minister's Challenge on dementia 2020 highlights that all people with dementia should be able to access high quality palliative care.

### **Place of care and death**

Place of death often differs for older people and those living with dementia compared to their younger counterparts. Nearly two-thirds of deaths with dementia for people aged 65 and over occur in care homes and account for around a quarter of all deaths for people aged 65 and over.<sup>127</sup> People aged above 80 are more likely to live and die in a care home than at home or in a hospice, leading one article to describe care homes as 'being de facto hospices'.<sup>128</sup>

Support for older and/or frail people is often associated with a social care need, yet this is a part of the health and care system where resources are particularly stretched. Though much of the sector continues to provide good care, scarce resource may contribute towards poorer ratings for providers from regulators, care deserts, limited training and unfavourable terms and conditions for care workers. A large and growing proportion of people using social care are required to fund, either partially or in full, their own care, in direct contrast to others in receipt of health care services free at the

point of use to support their needs. In turn this can lead people to delay or put off seeking social care support, or rely heavily on family members who may themselves be frail or in poor health. People who meet strict criteria for state funded social care may then find a lack of choice and control around their care, underlining the socioeconomic inequalities that can come into play around cost, quality and access of support.

In 2016 the Care Quality Commission reported that some hospices told them they "only accept dementia patients who are 'able to cooperate'." While we are confident significant progress has been made in the years since, the regulator's expectations for hospices to provide appropriate training for staff, support people whose behaviour challenges, help people to make decisions, and communicate appropriately with people with dementia and those who are important to them, remain relevant.<sup>129</sup>

### **How are services responding to meet palliative care need?**

Hospices have made us aware of an array of initiatives and projects designed to deliver quality end of life care for people who are older, frail and/or living with dementia. Some wrote of their involvement in grassroots initiatives including dementia friendly communities or as members of regional or national groups like the Dementia Action Alliance. Others described taking initial steps to ensure all staff, clinical and otherwise, are part of the Dementia Friends scheme and are provided with training specifically around supporting people living with dementia.

### **Expert led care**

Wakefield Hospice funds a Clinical Nurse Specialist who supports people living with late stage dementia with their end of life care and decision making. Key to this role has been projects to support care homes to recognise when a person is in the last year of life and to develop advance care plans with residents and their families and to prevent avoidable admission to hospital in the end stages of their life. The hospice has also established

pathways that enable residents to have their end of life care needs met within the hospice when that has been chosen as their preferred place of death. Currently the Hospice Admiral Nursing service supports 270 residents in 7 care homes. In addition, as one of two regional education hubs the Hospice delivers Advance Care Planning and Bereavement awareness training to Health and Social Care Professionals and the third sector.

### **Holistic care from diagnosis to death**

Heart of Kent Hospice established their Dementia Service five years ago. At any one time their dedicated team now helps more than 300 people with dementia and their family carers to navigate the turmoil of the condition and the challenges this can create in the home environment. Unusually for a hospice, 40% of all the people currently on their caseload are referred because they have dementia – around the same number as those who have a cancer diagnosis. It is the only service in Kent and Medway where GPs can refer people for specialist, personalised dementia care which offers sensitive, clinical and emotional support immediately after a diagnosis and throughout their journey to and beyond death.

The hospice's Dementia Nurse Specialists liaise with other health professionals involved in the individual's care, and recognise that being involved as early as possible following a diagnosis can best enable the hospice to help people live well and independently for as long as they can. The Care Quality Commission described it as "an innovative response to the increase of dementia in the community" when awarding the hospice an 'Outstanding' rating.

During COVID-19 patients living with dementia and carers have been supported via online video consultation and the Dementia Cafe and Carers Group transferred to the Zoom web platform.

### **Collaborative initiatives**

Portsmouth City Council invited local charities to tender to provide services that would contribute to sustaining and improving dementia diagnosis rates and enable the city to become a dementia friendly city.

Initially three charities, including Rowans Hospice, came together to propose and create an initiative whereby a named contact would facilitate people living with dementia and their carers to access and use local services. The hospice, in partnership with the initiative, employs two Clinical Nurse Specialists who lead the complex dementia and end of life care support pathway aspect. Referrals are via a single point of access, including self-referrals and are prioritised according to a 'RAG' system leading to either 'social' support or the support of a CNS.

Support for patients with dementia and their carer is through a 'drop in' service where they can meet a member of the team, also through carer support groups, activity groups, training and weekend and evening coffee events for carers. The Clinical Nurse Specialist's role is to work alongside patients and their families ideally from early diagnosis to end of life; supporting those who have complex needs whatever those may be. Being involved early allows the person with dementia and their carer the opportunity to have sensitive conversations regarding future planning in a timely manner; enabling people to live as well and as independently as possible and when the time comes, to die well.

A key focus of the care that is offered is to support people to remain in their preferred place for care and the close connections established with loved ones continues following death where bereavement support is then offered. During the COVID-19 pandemic the service continued to offer safe face to face support – the CNS's were a life line for some people at a time when all structure and routine was stopped. An example of this was the Saturday morning 'support group' for women working full time who were caring for someone with dementia; this group continued to meet via virtual routes as opposed to meeting in person. At times during COVID the CNS's were the only people visiting a person's home; as the majority of the community work by other services moved to virtual support – these visits for some people in the community were a life line.

The service reports through Key Performance Indicators to the Clinical Commissioning Group; since 2016 the two CNS have seen nearly 400 people with complex dementia, and have supported many people to die within their appropriate 'preferred' place of care, working alongside the carers pre and post bereavement. Despite the increased volume of work with people affected by dementia, the numbers of those people with dementia needing in-patient care through the hospice has not increased, highlighting that quality care can continue to be delivered in the community, even for people with complex conditions, where the majority of people want to be for as long as is feasibly possible.

### **Creating the best possible environment**

Prospect Hospice has undertaken a programme of work to ensure support is tailored for local people living with dementia. They have delivered end of life care dementia training to health care professionals across Swindon and sought different ways to increase their own staff's understanding of the perspectives and experiences of those living with the condition, through innovative training tools like the 'dementia bus'. The hospice has been proactive in purchasing equipment and making improvements around the hospice to enhance the care of patients within the In Patient Unit. This included new signage which has clear directions, with words and a picture and contrast with the background. People in their care are supported to create Memory Boxes, which can be effective in helping people living with dementia to settle into a new environment by establishing a familiar landmark for individuals. These can be filled with treasured possessions that have special meaning, provide important information for staff about the person and can trigger conversation for visiting family and relatives.

## **Looking forward**

### **Mapping and commissioning services to meet projected growth in need**

The huge increase in people dying in older age, of dementia and with complex co-morbidities, expected over the coming decades demands policy focus. More services, centred on what people want and focused on quality of life, will be required to meet need. The associated uncertainty about the timeframe leading to death and the changing needs along the way also needs to be taken into account in both the planning and delivery of services.

It remains unclear as to how that additional need might best be met, whether through specialist palliative care provision, through upskilling the wider health and social care workforce or, as is most likely, a combination of the two.

### **Research on care as well as cure**

There is also concern that existing policy, guidance and recommendations are based largely on expert opinion because of a shortage of high quality, empirical research.<sup>130</sup> The ratio of researchers working on dementia to those working, for example, on cancer is roughly 1:6. In 2012 dementia research received six times less funding than cancer research.<sup>131</sup> Research on dementia care as well as cure will continue to be of great importance.

Equally both policy and research should be mindful of who is requiring end of life care in older age as demographics change, such as an expanding older community of LGBTQ+ people or individuals living with a disability. As in so many other areas of the community explored in this report, ageing and ageism often runs together with different forms of discrimination.

### **Supporting staff awareness**

Health and social care services, particularly in primary care and social care, should challenge perceptions and assumptions where they exist among staff that deterioration and pain are an expected part of older age.



## People living in poverty, deprivation, and with lower socioeconomic status

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Alongside income, socioeconomic status (SES) comprises educational attainment, financial security, as well as subjective perceptions of social status and social class. Poverty, specifically, is not a single factor; it is characterised by multiple physical and psychosocial stressors. SES is a reliable predictor of physical and psychological health, and low SES is consistently recognised as a risk factor for worse health outcomes.

Where quality indicators for end of life care are identified, they often include:<sup>132</sup>

- receipt of palliative care;
- avoiding hospital admissions in the last months of life;
- emergency hospital admission in the last months of life; and
- whether people are supported to be cared for in their place of residence rather than in hospital.<sup>133</sup>

The latter has long been considered a cultural marker of a “good death,” as “home” is often presumed to fulfil the ideals of comfort, privacy, security, and autonomy. It is critical to acknowledge that there are some obvious assumptions embedded in the concept of what home looks and feels like. How home is experienced is likely to be quite different for people experiencing poverty.

In more deprived areas, housing is often poor quality, to the extent that evidence indicates that it can lead to an excess of winter deaths.<sup>134</sup> For those in rented and temporary accommodation, there is also housing insecurity to contend with. Overcrowding is also more prevalent in more deprived areas.<sup>135</sup> All of this challenges the ideal of what dying well at home might be like for those living in these areas.

Alongside physical infrastructure, the social relations that facilitate dying at home are an equally important consideration. Having someone who is able to support your care is a pre-requisite for dying well at home. For those with low SES, there is a high chance that family members are also experiencing poverty. They may not have the option to refuse paid work to undertake caring responsibilities. Without this or without the ability to pay for a professional carer, it is much more difficult to die at home.

### What does this look like in real terms?

In the UK, low SES is associated with increased risk of death in hospital rather than in the community<sup>136, 137</sup> and more emergency hospital admissions in the final months of life.<sup>138, 139</sup> In real terms, those living in the most deprived areas are 33% less likely to die at home and those in the second most deprived areas are 18% less likely.<sup>140</sup> Improvements in where people die (with more people dying at home or in a hospice rather than in hospital) have been significantly greater for those with high SES, the least deprived.<sup>141</sup>

Analysis from Imperial College London and published by the IPPR found that despite spending more time in hospitals, which is associated with being a more expensive setting for care, people in the most deprived parts of the country receive almost £400 less healthcare investment per person in their last year of life.<sup>142</sup>

Many hospices are required to provide consistent services to both the most affluent and most deprived in the country. For example Hospice UK’s PopNAT tool shows that Dove House Hospice in Hull provides services in an area where one CCG has an IMD (Index of Multiple Deprivation) of 5 while at the CCG next door it is 146. Despite being one hospice, the terms and conditions of contracts in different areas might contrast significantly. In terms of deaths occurring within hospices, the gap between the least and most deprived grew by 25% between 1993-1997 and 2008-2012.<sup>143</sup>

## How are services responding to meet palliative care need?

### Outreach and partnership working:

Over half of service users at St Luke's Hospice in Sheffield's are from deciles 1 - 4 of the Index of Multiple Deprivation, with 1 representing the most deprived; nearly a quarter (23%) are from decile 1. They have conducted outreach across the more deprived areas of the city to heighten awareness of their services. The hospice has also forged links with Manor & Castle Development Trust, a local charitable organisation working with highly deprived communities in the city; together they are working to address issues related to sex workers, women in hostels, and asylum seekers and the traveller community across the city. In addition, special emphasis has been placed on supporting the homeless community in Sheffield with dedicated members of the specialist palliative care community nursing team actively involved with individual cases, and during the pandemic the hospice was also engaged with the citywide response to provide housing to homeless people including advice on the safe use of PPE and the safety of the accommodation provided.

### Support for carers:

In 2020, St Christopher's Hospice in London created a guide for hospice and palliative care staff aimed at supporting carers with no recourse to public funds (NRPF) who are supporting loved ones at the end of their life. It identifies welfare benefits people may not be able to access, the different barriers they may face along the way and affords new partnership working between people who are expert around end of life and those who feel confident working with people with no recourse to public funds.<sup>144</sup>

## Looking forward

### Intersectional approaches

Evidence<sup>145, 146</sup> shows that racialised and disabled communities are significantly overrepresented in low income groups and are more likely to be living in poverty compared to their white and able-bodied counterparts. It is critical that outreach work and interventions account for the multiple ways in which those with low SES are marginalised.

### Tackling digital exclusion

In the wake of Covid-19, we have seen hospice care providers innovate and reconfigure their services virtually to reduce the risk of viral transmission. While this has improved accessibility of support for some, it has reduced it for others, with those experiencing poverty less likely to have internet access.<sup>147</sup> As services adapt and potentially make permanent some of their digital innovations, they must ensure that those with low SES are not left behind.



## Patient advocacy

Links have been identified between good care and strong patient/care advocacy, something which may partly explain differences in end of life care observed amongst the most deprived communities in England. Evidence is clear that people from more affluent parts of the country are more likely to be able to advocate effectively for their care. People who have fewer financial or social means to do so, or whose families and carers have less time, resource or recognition of the workings of the health and care system, are less likely to get the best care.<sup>148</sup> Commissioners and service providers should consider how to best deliver information and advocacy services, delivered through a range of digital and in person platforms, taking requirements like language into consideration.

## Supporting carers

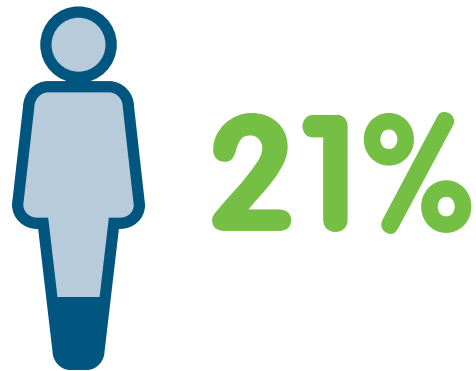
As previously stated, the family members of those with low SES are also likely to be experiencing poverty. Hospice and palliative care providers need to support unpaid carers with low SES as a priority. There is also a need to build resilience and capacity in local communities as well as uplift and support the role of existing community networks and compassionate communities.

## Improve care in all settings

While we should be supporting people to die in a place of their choosing, the reality is that those with low SES are more likely to die in hospital. Alongside interventions to enable those who want to die at home or in a hospice to do so, palliative care providers should identify what we value about these environments and seek to reflect this in how the terminally ill are cared for in hospital.<sup>149</sup> This could create an additional role for hospices in training hospital and community-based healthcare professionals.

## People living with learning disabilities

There are around one and a half million people with a learning disability diagnosis in the UK, but it is suspected that many more people live with some level of undiagnosed learning disability, with only 21% of people known to health and care services.<sup>150</sup>



**People with a learning disability known to health and care services**

The coronavirus pandemic demonstrated stark differences for people with a learning disability, with a report from the UK Government suggested that people with learning disabilities in England died from coronavirus at a rate over six times higher than the general population.<sup>151</sup>

The Care Quality Commission expressed concern that they had been told by people with learning disabilities they 'were not supported to the extent they needed to be in advance care planning conversations'. Those with a learning disability were identified as having been failed in efforts to include people and families in making Do Not Attempt CPR (DNACPR) decisions, with a lack of understanding about their care and assumptions about people's quality of life as key barriers to involving them appropriately in decisions about their own support.<sup>152</sup>

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) states that people with disabilities have the right to enjoy the 'highest attainable standard of health without discrimination on the basis of disability'.<sup>153</sup> In the UK health services are required by law, including the Equality Act 2010, to make reasonable adjustments where necessary in order to support access to services by people with a learning disability. Despite this a review from the Equality and Human Rights Commission found that while 'there is increased recognition of the disadvantages that people with learning disabilities face... change has been slow and many people with learning disabilities are still 'cared for' rather than 'supported with'.<sup>154</sup> A recent evidence review from the National Institute for Health Research (NIHR) found that people with a learning disability experience poorer physical and mental health than the general population, with issues arising all the way through the life course.<sup>155</sup>

Following the abuse scandal at the privately run hospital Winterbourne View in 2011, the Department of Health's Transforming Care programme committed to ensure that care for people with learning disabilities would be based on the needs and wishes of individuals and their families and provided as far as possible by general and specialist services in the community. Health policy in England has since sought to take this further, with the NHS Long Term Plan pinpointing learning disabilities and autism as one of the five top clinical priorities for attention.

### What is the impact on people?

Although life expectancy has improved over recent decades, people with learning disabilities continue to have a shorter life expectancy and increased risk of early death compared to the general population. The Confidential Inquiry into the Premature Deaths of People with a Learning Disability (CIPOLD) found women with a learning disability on average died 18 years earlier, and men 14 years, than the general population in England. It also found that 38% of people with a learning disability die from avoidable causes,

compared with 9% of the general population. The Inquiry identified issues with end of life care, including identifying when the end of life was approaching, problems co-ordinating end of life care, and with accessing NHS Continuing Healthcare (CHC) funding. Recommendations included changes to advanced care planning and how people's care is managed at end of life in an emergency.<sup>156</sup>

Palliative and end of life care needs of people with learning disabilities might be no different from those of the wider population. Yet planning and delivery of support can be more complex due to difficulties with cognition, understanding and communication including preferences, challenges in decision making processes, co-morbidities and mental health issues.<sup>157</sup> Health and social care staff may lack confidence in leading interactions, while a shortage of specialised equipment, time and task driven commissioning and varying emphasis from services to ensure accessibility can all negatively impact the quality of service provision and the experience of those in receipt. People with learning disabilities are also more likely to be vulnerable and socially isolated, and experience high rates of cancer and dementia as they get older.

There is cause for concern in that many people with learning disabilities in the last stages of life still do not have equal access to palliative care and are less likely to be referred to or receive specialist palliative care services than the wider population.<sup>158</sup> There are also issues about the quality of palliative care they receive, contributing to poorer outcomes that are often avoidable.

One challenge frequently repeated within research is the difficulty in predicting when someone may be approaching the last year of their life, particularly where there may be unidentified health issues. In turn this may mean people only connect, if at all, with relevant palliative and end of life care services at a late stage, impacting the ability to plan and make informed choices as well as resulting in limitations in the services that can then be offered.

## How are services responding to meet palliative care need?

A study that analysed ten years of awards in the UK for outstanding provision of end of life care for people with learning disabilities identified four themes among the winners.

### 1.

Good practice was dependent on 'champions' with drive, enthusiasm and determination, supported by committed organisations and managers. Collaboration was essential, including collaboration with families.



### 2.

Care was highly individualised, putting the person's story at the centre.



### 3.

There was a focus on staff training and use of specifically designed or adapted tools.<sup>159</sup>



In submissions to us, hospices across the UK demonstrated that central to good care for people with learning disabilities were qualities often reflecting good care for everyone. People should be empowered to have choice and control over personalised care and support, delivered where possible in the community by a workforce with appropriate training and a commitment to good communication. Also expertise should ensure end of life care needs are identified as early as possible, in turn triggering a series of conversations and opportunities to make plans with the individual and their families.

Hospices reported involving people with learning disabilities to peer review new and updated resources and information leaflets, as well as annual reviews of their services as a whole. Bespoke training programmes for staff supporting people with learning disabilities in their own home and supported housing and sessions to support family carers recognise and negotiate changing needs were also highlighted.

Some hospices have earned accreditation, such as the Purple Star quality mark developed in Hertfordshire, in recognition of quality care and making reasonable adjustments for people with a learning disability. The Hospice of St Francis in Berkhamsted is one to have been awarded this quality marker. The Hospice has collaborated with Herts County Council and other providers to design, co-ordinate and deliver a dedicated and fully evaluated programme of training in palliative and end of life care for local care home staff, earning disability nurses and Allied Health Professionals who support people with a learning disability. The training is designed to enable staff to support residents to plan ahead and be able to be in their usual place of residence at the end of life, to know what to do to ensure a dignified death, when and how to ask for specialist palliative care assistance and who to call. The Learning Disability Mortality Review (LeDeR) programme identified excellent practice where people with a learning disability have been able to die in their care home.

Last year the Mary Stevens Hospice in Stourbridge was shortlisted for a Guardian Public Service Award having pioneered a number of initiatives to improve access to hospice care for people with learning disabilities. In 2019, the hospice joined Birmingham City University to form the Midlands Palliative and End of Life Care for People with Learning Disabilities Network. The Network now has over 100 members, including clinicians, primary care, academics, allied health care professionals, hospices, students, residential care and importantly, people with learning disabilities themselves.

Following consultation and grant funding, the hospice purchased a range of mobile specialised equipment and software. The equipment includes a deluxe sensory unit, bubble tubes, lights, aroma diffusers, music, projectors, a virtual reality headset, weighted duvets, and a sensory chair.

The hospice also received funding from The Masonic Charitable Foundation and Hospice UK for No Barriers Here, a project that focuses on advance care planning for people with learning disabilities through the co-production and co-delivery of creative compassionate community art workshops, in partnership with people with learning disabilities. This project adopts a public health approach to palliative care, encourages and empowers advance care planning conversations about future care and helps people to better understand and engage in early discussions whilst increasing awareness of palliative care.

No Barriers Here commenced September 2020 and the team have co-facilitated two cohorts of creative workshops, with people with learning disabilities receiving boxes of art supplies and supported to use Zoom to participate in these important conversations. In addition, educational webinars have been co-delivered to health care professionals.

Through partnership working with a people using services, commissioners and other health and social care services, St Luke's Hospice in Plymouth are a key part of local plans to achieve a person-centred end of life care strategy for people with learning disabilities. Through an end of life steering group created as part of the partnership a future end of life care plan document for individuals with learning disabilities has also been launched. The visually-driven booklet supports people to think, talk about and write down how and where they would like to be cared for in the future. It also helps to inform future decision making if they are not in a position to either make and/or communicate their health or social care choices at a later date.

## Looking forward

As has been noted elsewhere in this report, getting care right for people who may have complex needs can act as an appropriate benchmark to aim for care provided to everyone else. For example, the ability to assess and act on symptoms and needs for non-verbal people with learning disabilities could benefit patients who are unable to communicate their symptoms for reasons other than a learning disability.<sup>160</sup>

### Mapping population need

With a growing and ageing population of people with learning disabilities, palliative and end of life care services will need to respond. End of life and palliative care services should not wait for people with learning disabilities to find them, but instead actively search to find the population of people with learning disabilities within their local areas. Understanding the makeup and care needs of local populations through data and information that is increasingly available, detailed and up to date, is key to understanding what is needed to provide choice and quality of service.

### Personalised, co-ordinated care

The National Institute for Health and Care Excellence recommends that multiagency approaches, co-ordinated around the wishes, needs and preferences of the individual, are needed to support quality end of life care of people with learning disabilities and their families within the community. Palliative and end of life care and wider learning disability services benefit from working closely together, sharing resources and education. Accessible and timely information about all the potential care options available for end of life care, including hospice services, should be made available. Efforts need to be made to understand people's cultural background, how people may feel most comfortable in communicating their likes and dislikes or when they experience pain, their health conditions and the medication they are taking, to make it easier to identify when the person's health is deteriorating and act accordingly.<sup>161</sup>

## Expand academic evidence

Evidence on access to effective end of life care by people with learning disabilities is limited, while there is a dearth of representation of and people with learning disabilities themselves, and their families, within much of the available research.<sup>162</sup> One study argues existing guidance to improve palliative and end of life care for people with learning disabilities is overly reliant on theoretical or anecdotal evidence, expert opinion and case reports. As it stands, much of the academic research in this area has been too focused on describing the problem.<sup>163</sup> In future research, guidance and resulting practice should be more solutions focused, centred on evidence taken from practice and placing people who use the services at the heart of it.

## Appropriate training for staff

In light of concerns about the use of DNACPR decisions during the COVID-19 pandemic, the CQC flagged the importance of appropriate training for health and care workers. Without it, they may not be aware of when it is, and is not, appropriate and lawful to be holding discussions about DNACPR decisions. This includes whether it may potentially be discriminatory for people in some equality groups, such people with a learning disability, who are not at the end of their lives.<sup>164</sup>



## People living with non-malignant conditions

A key feature of this document is the resolute belief that palliative and end of life care should be made available according to need, regardless of who or where you are or what conditions you might live with.

Palliative care evolved from the hospice movement in the UK, making swift progress in the 1960s primarily to support the end of life care needs of people with cancer. Patients who were believed to be at a stage where the condition had become incurable. For many years the ways in which cancers develop have been viewed as being more consistent than non-malignant diseases, with defined palliative care stages that in turn opened the door to the practice and research that we have access to today.

Research has shown that health systems and healthcare pathways for cancer treatment are often well placed to recognise cancer as being potentially terminal and to identify and manage associated care needs. This is not always the case for people undergoing treatment for a non-malignant condition, which can be compounded when patients themselves might be less likely to associate their condition with death.

A Health Select Committee report in 2004 claimed the lack of palliative care for people with non-malignant conditions in England constituted a major and recurrent theme of the evidence it had gathered. It highlighted that the Department of Health itself had admitted it was 'the greatest inequity of all in palliative services...cancer dominates the structure through which palliative care is mapped and distributed.' At the time the Department website even had palliative care indexed within the cancer pages.<sup>165</sup>

Since then there has been increased recognition of both the need and benefits of palliative and end of life care for people living with conditions other than cancer, something which is reflected in national end of life care strategies across the UK. They demonstrate that people living with all conditions can benefit from support that goes far further than terminal care in the last few days or hours of life. Instead there is much to be gained from understanding and responding to the emotional, physical, spiritual and practical needs and goals of people and those around them, including planning potential future care options. An approach that centres on the management of symptoms, maintaining quality of life, planning and good communication is widely recognised to have potential benefits for anyone.

However, although evidence shows specialist and generalist palliative and end of life care services are increasingly engaging people with conditions other than cancer, they continue to fall short of population need in the UK. People with non-cancer life-limiting illnesses often have comparable symptom burden and care needs to people with cancer but are less likely to access palliative care support.<sup>166</sup> In addition Allsop et al. found there are significant differences in referral to specialist hospice services to death days for those with cancer (53 days) and non-cancer (27 days).



**Referral to specialist hospice services to death (with cancer/non-cancer)**

Their study also identified clear differences in the duration of hospice-based palliative care for those with cancer (around 7 weeks) and others (less than 4 weeks).<sup>167</sup> Another study, conducted across nine Scottish general practices, showed that relatively few non-cancer patients were identified for palliative care, and placed on the palliative care register, before dying.<sup>168</sup> With changing demographics and people living with increasingly complex co-morbidities, it is clear there will be a growing need for integrated, multi-disciplinary approaches to support more people with a range of conditions.

Of the nearly 530,000 deaths in England and Wales in 2019, 71.5% were from non-cancer conditions and 28.5% from cancer.<sup>169</sup> Tobin et al. found hospices were the place of death for 1.2% (4,503) of non-malignant deaths and 16.5% (24,925) of cancer deaths that same year. In total 85% of deaths in hospices in 2019 were from cancer and 4503 (15.3%) from non-cancer,<sup>170</sup> though it is important to recognise that more than 80% of hospice support is delivered in the community.



**Hospice support is delivered in the community**

Figures also vary depending on geography, service structure and commissioned contracts, with referrals at St Joseph's Hospice in London and patients accessing services at St Michael's Hospice in Hereford just two examples where almost half of the people they support live with non-malignant conditions. The Hospice of St Francis Berkhamsted used additional grant funding to build clinical capacity to care for people with non-malignant conditions, which changed from 4% of people using their services in 2016/17 to 38% in 2019/20.



## What is the impact on people?

For people that die of, or with, conditions like lung disease, their final months may follow a progressive decline in health, their symptoms and increased reliance on family and carers to perform daily activities such as washing and dressing. Despite having care and support needs, there is inequitable access to specialist palliative care services, often with no formal process for identifying people at end of life.<sup>171</sup>

A study that included a large number of patients with chronic obstructive pulmonary disease (COPD) in the UK found that while there was a progressive increase in the use of palliative care over a decade to 2015, people with COPD and lung cancer were 40% more likely to be offered palliative care than those with COPD alone.<sup>172</sup>

Liver disease has led to an increase in mortality in the UK in recent decades, and despite being linked to significant pain, high proportions of hospital based deaths and regular inpatient stays, referral to palliative care remains low.<sup>173</sup>

Progression of ill health and support needs to manage symptoms might be very different for someone with a non-malignant condition. In some cases identification of the final stages of life can be more challenging for health and care professionals, particularly where care pathways are less defined or training is lacking. A Care Quality Commission report found people with conditions other than cancer may be less likely to have an identified professional co-ordinating their care, meaning they have little support in identifying progression towards a palliative stage, as well as less continuity of care and a notable absence of forward planning.<sup>174</sup> An editorial in *The Lancet* highlights periods of deterioration and stabilisation, the often young age of people in need of support, and lingering hope for a transplant as reasons that might delay or complicate referral and management of palliative care of those with liver disease.<sup>175</sup>

One study found having open end of life conversations was particularly challenging in patients with non-malignant conditions. This can be made more complicated when those patients are often unaware of their own prognosis, or of the options that are available to them regarding future care. Professionals interviewed within the study expressed a need for simpler, practical guidance on how and when to identify patients. They also underlined the need for more training in identifying and managing the palliative care needs of patients in the community. Many highlighted the importance of open end of life care conversations across society which would in turn make it easier to discuss palliative care with patients.<sup>176</sup>

The CQC recommended a shift in focus away from only identifying people who clearly have less than 12 months to live, towards having conversations about a person's wishes and preferences for care over a longer period, running across the last phase of life and regardless of diagnosis. Such an approach would assist in situations where conversations with patients who have an uncertain prognosis may be particularly difficult. As it is the regulator found advance care planning is often delayed or conversations about end of life care do not happen at all. Training in communication skills was highlighted as a way of supporting health and care staff to develop their skills and help them to talk about end of life care. They found some hospices provided training in holding difficult conversations. In one area, a local GP was leading a training programme for staff in care homes and nursing homes, which included good communication about end of life and life limiting illness.<sup>177</sup>

## How are services responding to meet palliative care need?

Multi-disciplinary team and partnership working to build local care pathways is a key feature of good practice across a range of conditions. Starting in August 2010, a tripartite partnership between Marie Curie, the British Heart Foundation and NHS Greater Glasgow and Clyde was established to develop cardiology-led models of care (the Caring Together and Better Together programmes) to improve the quality of, and access to, palliative care for any patients in the advanced stages of heart failure. The Caring Together heart failure and palliative care service is provided by a consultant cardiologist with an interest in palliative care and a heart failure palliative care nurse consultant.

The core components of care included early identification based on needs rather than a specific diagnosis or prognosis, a comprehensive cardiac and generalist palliative assessment to identify and manage needs, and advance care planning culminating in a patient specific Medical Anticipatory Care Plan (MACP). A further core component is the development of cohesive multi-professional relationships across all care settings through a weekly palliative-cardiology multi-disciplinary team meeting attended by the cardiology medical team, heart failure nurse consultant, the heart failure liaison nurses, senior cardiology ward nurses, specialist palliative care, care of older people team, occupational health, physiotherapy, pharmacy, chaplaincy team and hospital discharge planners. The programme is underpinned by service evaluation and research.

In 2017/18 Dorothy House Hospice undertook a detailed mapping of the needs of the local population (550,000 people across 3 CCGs) to uncover the diversity, ethnicity and specific palliative and end of life care needs. The findings of this work, which was stress tested by the local CCG, demonstrated they had to increase:

- a) The reach and breadth of their services to provide the right care, at the right time from the right team. This was based on the work of Marie Curie where it showed that approximately 0.67% of the population were in the last year of life (regardless of diagnosis) requiring some level of input from the hospice.
- b) Their non-cancer activity to a minimum of 56% of people seen per year.

As a result, they piloted a strategic alliance in one CCG area (focused on meeting the local needs identified through the completion of a survey completed using a “community development” approach), employed a MND Specialist Practitioner in partnership with the local acute Trust and the Motor Neurone Disease Association, linked in with the local heart failure teams and agreed to apply the Marie Curie profile to their plans across all localities and emerging Primary Care Networks (PCNs).

Looking ahead the culmination of this work means the hospice has identified a strategic need to effectively double the amount of care provided by 2025 whilst seeking to halve their cost per patient cared for. This will be achieved through partnership working, the development of new models of care, supporting the creation of an Integrated Care System level alliance of palliative and end of life care providers focused on reducing inequity, mapping pathways of care and identifying the associated person centred outcomes required across the ICS.

## Looking forward

### A priority in national policy

National programmes and strategies on end of life care in the UK should continue to emphasise the need to support those with non-malignant conditions. Gadoud et al. (2019) found that in the five years following the launch of the End of Life Care Strategy in England, primary care records of palliative care increased for people with COPD from 13.6% to 21.2%; dementia from 20.9% to 40.7%; and heart failure from 12.6% to 21.2% of cases.<sup>178</sup> Equally national, accessible and practical guidance should include focus on support for people living with non-malignant conditions including early identification of potential end of life care needs.

### Develop the evidence base

There is a clear need for additional research in this area. NICE guidance published in 2019 on service delivery for adults at end of life made four recommendations for further research, two of which focused on people with non-malignant conditions. The first centred on a need to better understand if early review of service provision and referral to additional specialist palliative care services improves outcomes for people with progressive non-cancer disease. The second aims to find out if there is an optimum frequency of reviews of people and if there are benefits of planned, regular community based reviews compared to holding them as required. The former, they argue, could avoid unrecognised deterioration of symptoms, prevent crises and pre-empt the need for acute care, but equally could lead to additional and unwanted demands on people, their families and the health system.<sup>179</sup>

### Mapping a steady, anticipatory approach

A steady, holistic and anticipatory approach to end of life care, rather than a sudden start of palliative care, may be more acceptable to patients with non-malignant conditions as well as their families and the staff who support them. Further work to map this informal phase could help to clarify existing patterns of care, as well as lead to a framework for how best to introduce palliative and end of life care for different patient groups.<sup>180</sup>

### Encouraging a public conversation

A national conversation, aided by the Dying Matters campaign, which promotes conversation around end of life care is needed. Open, normalised discussions will assist both public and professionals to tackle ongoing reluctance to discuss issues around death and dying, helping to break down barriers and reticence in approaching the topic around conditions currently less associated with death.

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