



Care committed to me

Delivering high quality, personalised palliative and end of life care for Gypsies and Travellers, LGBT people and people experiencing homelessness.

A resource for commissioners, service providers and health, care and support staff.

Acknowledgements

The following organisations have been working together as the Tackling Inequalities in End of Life Care for Minority Groups VCSE project group: Hospice UK, Marie Curie, Together for Short Lives (as the Palliative and End of Life Care Consortium within the Alliance), along with Friends, Families and Travellers, Homeless Link and the National LGB&T Partnership (the LGBT Consortium led on this piece of work on behalf of the National LGB&T Partnership).

This project was funded by the Health and Wellbeing Alliance, a partnership arrangement between NHS England, the Department of Health and Social Care¹ and Public Health England.

Our thanks to the organisations which have provided case studies for this resource and those who participated in the focus group, workshop activities, or otherwise provided feedback and comment. At Friends, Families and Travellers, our thanks to Ivy for organising the focus group held in December 2017 and to Lucy for providing a transcript from the event. Thanks also to Dr Sarah Russell, former Head of Research at Hospice UK, for her support and feedback.

While great care has been taken to ensure the accuracy of information contained in this publication, it is necessarily of a general nature and neither Hospice UK nor the other contributors can accept any legal responsibility for any errors or omissions that may occur. The publisher and contributors make no representation, express or implied, with regard to the accuracy of the information contained in this publication. The views expressed in this publication may not necessarily be those of Hospice UK or the other contributors. Specific advice should be sought from professional advisers for specific situations.

© 2018 Hospice UK

Published by Hospice UK in December 2018

NHS England Gateway ref: 08440

Contents

Foreword.....	ii	Chapter 3. Personalising care for me: people experiencing homelessness.....	14
Introducing the organisations involved in the project	iii	People experiencing homelessness.....	14
A note about terminology	iv	End of life care	14
Executive summary	vii	Recommendations to improve care for people experiencing homelessness	15
Chapter 1: Introduction	1	Workshop insights.....	15
Inequities in access to end of life care	1	Helping to make the Government's commitment on end of life care a reality	17
About the project.....	2	Chapter 4. Personalising care for me: LGBT people	27
The six point commitment for end of life care from the Government.....	2	LGBT people.....	27
Personalised care.....	3	End of life care	28
Cross cutting themes.....	5	Recommendations to improve care for LGBT people	29
Chapter 2. Personalising care for me: Gypsies, Roma and Travellers	6	Helping to make the Government's commitment on end of life care a reality	30
Gypsy, Roma and Traveller communities.....	6	Summary	43
End of life care	7	Wider observations	43
Cultural awareness	8	A note on bereavement support	44
Focus group insights	8	Call for action.....	44
Improving care for Gypsies and Travellers	10	Recommendations for action.....	44
Helping to make the Government's commitment on end of life care a reality	11	Appendix 1: Southampton homeless end of life care plan	45
		Appendix 2: News resources from the project's partner organisations...	49
		References	50

Foreword

The Ambitions for Palliative and End of Life Care, co-produced by the National Palliative and End of Life Care Partnership in 2015, as a national framework for local action, states 'each person gets fair access to care' as one of its six ambitions, thus emphasising the importance of equitable access and provision of palliative and end of life care regardless of who the person is, where they live or the circumstances of their lives. In 2016 the Care Quality Commission published a report showing that certain groups in society sometimes experience poorer quality care at the end of life because providers and commissioners do not always understand or fully consider their specific needs.

Later in 2016, the Government made a national commitment that everyone should have access to high quality personalised end of life care built around their individual needs and preferences.

It is clear that more proactive engagement is required on behalf of commissioners, statutory and third sector service providers, practitioners and wider society to address the end of life care needs of everybody in our diverse communities. This practical report sets the wheels in motion. It examines a range of approaches and insights into delivering and embedding personalised care for children, young people and adults living with advanced illness towards the end of their lives. It focuses on people experiencing homelessness, people who identify as LGBT and Gypsies and Travellers, which were three of the groups highlighted in the 2016 Care Quality Commission report.

Everyone, no matter who they are, deserves the best quality care at the end of life, and it is our shared responsibility to tackle inequalities. This resource will help us all to make that a reality.

Professor Bee Wee, FRCP FRCGP FAcadMed Ma Ed SFFMLM PhD
National Clinical Director for End of Life Care
NHS England

Introducing the organisations involved in the project

Hospice UK

Hospice UK is the national charity for hospice and palliative care. They 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. The charity works with and supports hospice and palliative care providers to grow outstanding care for adults and children across the UK, championing the expert and compassionate care they provide.

Website: www.hospiceuk.org

Marie Curie

Marie Curie is the leading charity providing care to people with any terminal illness in their own homes or in one of the charity's nine hospices.

Marie Curie has almost 2,100 nurses, who work in the community providing free end of life care.

Website: www.mariecurie.org.uk

Together for Short Lives

Together for Short Lives is a UK-wide charity that, together with their members, speaks out for all children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families, Together for Short Lives is here to help them have as fulfilling lives as possible and the very best care at the end of life. They can't change the diagnosis, but they can help children and families make the most of their time together.

Website: www.togetherforshortlives.org.uk

Friends, Families and Travellers

Friends, Families and Travellers is a leading national charity that works on behalf of all Gypsies, Travellers and Roma regardless of ethnicity, culture or background. Friends, Families and Travellers seek to end racism and discrimination against Gypsies, Travellers and Roma and to protect the right to pursue a nomadic way of life. The charity provides advice and consultancy, promotes health and wellbeing, contributes to research and policy making, delivers training and much more.

Website: www.gypsy-traveller.org

Homeless Link

Homeless Link is the national membership charity for frontline homelessness agencies and the wider housing with health, care and support sector. Homeless Link represent over 700 organisations providing homelessness and supported housing services across England. They work to improve services through research, training and guidance, and to promote policy change that will ensure everyone has a place to call home and the support they need to keep it.

Website: www.homeless.org.uk

National LGBT Partnership

The National LGBT Partnership was established in early 2010, in order to reduce health inequalities and challenge homophobia, biphobia and transphobia within public services. The Partnership combines the expertise of eleven key LGBT organisations across England.

Website: <https://nationallgbtpartnership.org>

LGBT Consortium

The LGBT Consortium led on this piece of work on behalf of the National LGBT Partnership. The LGBT Consortium is a national membership organisation focusing on the development and support of LGBT groups, projects and organisations so they can deliver direct services and campaign for individual rights.

Website: www.lgbtconsortium.org.uk

How to cite this document:

Tackling Inequalities in End of Life Care for Minority Groups VCSE Health and Wellbeing Alliance Project Group (2018). Care committed to me. Delivering high quality, personalised palliative and end of life care for Gypsies & Travellers, LGBT people and people experiencing homelessness: a resource for commissioners, service providers and health, care and support staff. London: Hospice UK, on behalf of the Tackling Inequalities in End of Life Care for Minority Groups VCSE Project Group.

Project contact

For more information about this project and the publication, contact Melanie Hodson at Hospice UK. Email address: m.hodson@hospiceuk.org

A note about terminology

Gypsies, Roma and Travellers (GRT)

GRT refers to the Gypsy, Roma and Traveller communities which live in the UK. These are the main groups that people use to identify themselves, however, they are not complete and some vary according to personal family definitions:

- Romany Gypsies - sometimes called English Travellers or English Gypsies
- Irish Travellers (or Travellers of Irish heritage)
- Scottish and Welsh Travellers
- New Travellers
- Bargees (who live on the waterways in barges)
- Fairground and Show people

There are also Eastern European Roma who have settled in the UK in recent years. Certain cultural features are common to most Traveller groups. It is only ethnic Gypsies, Roma and Travellers who are protected by the Equalities Act, though there are many Travellers from non-ethnic groups who are in to their third generation and who share the experience of prejudice and discrimination and homelessness.

LGBT people

This resource uses the acronym, LGBT, to refer to lesbian, gay, bisexual and transgender (or trans) people, although it is recognised 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. Stonewall has a glossary of terms on its website² and the Gender Identity Research & Education Society publish a useful factsheet on terminology which explains what is meant by 'transgender' and other terms such as gender role and identity.³

Homelessness

The term homelessness is used in its widest sense in this document. It applies to people who are sleeping rough and those in hostels or other temporary supported accommodation. It covers those homeless households being supported by local authorities in temporary accommodation, known as statutory homelessness. It also covers 'hidden homelessness' i.e. people who become homeless but find a temporary solution by staying with family members or friends, living in squats or other insecure accommodation and who are not counted in official statistics on homelessness.⁴

End of life care

The National Council for Palliative Care (2011) provided a working definition of end of life care as care that helps 'all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'⁵

Palliative care

The World Health Organization defines palliative care as 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'⁶

Palliative care for children and young people

Together for Short Lives defines palliative care for children and young people as ‘an active and total approach to care, from the point of diagnosis, throughout the child’s life and death. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, care at the end of life and bereavement support.

Palliative care can be introduced at any point throughout a child’s life; it is completely individual. Some children may require palliative care from birth; others only as their condition deteriorates. Families may also vary as to whether they wish to pursue treatments aimed to cure or significantly prolong life. In practice, palliative care should be offered from diagnosis of a life-shortening condition or from recognition that curative treatment for a life-threatening condition is not an option. However, each situation is different and care should be tailored to the child.’⁷

End of life care for children and young people

For children and young people, the end of life stage begins when a judgement is made that death is imminent. It may be the judgement of the health or social care team, but it is often the young person or their family who first recognises its beginning. End of life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death and immediately afterwards. It enables the supportive and palliative care needs of both the child/young person and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and the provision of psychological, social, spiritual and practical support.⁸

Executive summary

“Don’t adventures ever have an end? I suppose not. Someone else always has to carry on the story.”

Bilbo Baggins, The fellowship of the ring, by JR Tolkien

This resource tells the story of work in progress to improve personalised end of life care for Gypsies and Travellers, LGBT people and people experiencing homelessness. Supported by a comprehensive literature review, focus group and stakeholder consultation, the project identified challenges in providing personalised end of life care for these groups. However, drawing upon real life case studies of emerging practice this resource shows how the Government’s commitment to end variation in end of life care can be made more achievable for people in these three population groups. The project was funded by the Health and Wellbeing Alliance, a partnership arrangement between NHS England, the Department of Health and Social Care, and Public Health England.

Offering top tips and describing simple effective approaches for success, this practical guide is intended for commissioners, service providers and those involved in caring for and supporting children, young people and adults living with advanced illness towards the end of their lives. Chapters 2, 3 and 4 also feature quick-read highlights on providing and commissioning personalised end of life care – look out for ‘The care I provide’ and ‘The care I commission’ summaries on pages 11, 17 and 28.

Whilst the case studies presented here invite you to explore different approaches to delivering and embedding personalised end of life care, it is evident that for each the foundations of success rely on the implementation of five key principles. These principles are:

1. Good communication which includes engaging with people in a way that is meaningful for the individual and so enables people to make informed decisions about their care.
2. An approach founded on dignity and respect, and investing in a relationship of trust.
3. The provision of workforce training and support.
4. Enabling partnership working at a strategic level.
5. Recognising that people are all different so inclusive, equitable care is not about treating everybody the same way.

Furthermore, the case studies show that ongoing strategic commitment is necessary. Support from senior management and continuity planning are required to ensure the work remains visible and present should critical staff members leave the organisation.

Better and stronger data to inform commissioning and service development also emerges as a key cross-cutting theme. For example, for Gypsy and Traveller communities, information needs include data on accommodation status, ethnicity and age. Effective commissioning will also be facilitated by identifying and understanding the key issues affecting each group.

During the preparation of this guide, we heard a clear call for networking to enable the sharing of practice, experience and ideas. The establishment of the London Hospices LGBT Network is an example of one emerging response to that need. Further work is under way to explore other avenues to support these needs.

In pulling together this report it became clear that evidence and case study examples of palliative and end of life care for children and young people in these communities was more challenging to find. We recommend further work be undertaken to develop mechanisms whereby these examples can be gathered, shared and learned from.

We invite you all to carry on the story to improve the care experienced at the end of life by some of our most vulnerable communities.

Chapter 1: Introduction

Set within the context of relevant research, this practical resource shares the learning from projects and emerging practice in the support of quality, personalised end of life care for Gypsies and Travellers, people experiencing homelessness and LGBT people.

Offering top tips and describing simple effective approaches for success, this practical guide is intended for commissioners, service providers and those involved in caring for and supporting children, young people and adults living with advanced illness towards the end of their lives. Further reading suggestions and details of useful resources accompany each chapter.

In examining what works in terms of providing good, personalised end of life care for Gypsies and Travellers, people experiencing homelessness and LGBT people, it is recognised that these are not homogenous groups. Personalised care sees each person as a unique individual with their own views, values, aspirations, needs, lifestyles, social and family circumstances.

Above all, we hope that this resource will inspire readers to take a closer look for hidden local communities, to reach out to other organisations and develop personalised models of care which will help realise the Government's six point commitment to end variation in end of life care due to geography, age, diagnosis, background or means across the health system by 2020 (see pages 2 and 3 for more information about the commitment).

Inequities in access to end of life care

Access to hospice and other forms of expert palliative and end of life care is currently inequitable.^{9,10,11,12} Many groups experience disadvantage towards the end of life and do not have easy access to appropriate services. These groups include certain faith groups, Gypsies and Travellers, LGBT people, people experiencing homelessness and prisoners. As Caper (2017) points out, 'such exclusion may be implicit or explicit, where a person may not feel able to be their whole self when using services, or that a referral was not forthcoming, or not taken up, because it was not understood that palliative and hospice care could support their needs'.¹³

In 2016 the Care Quality Commission (CQC) published 'A different ending'; an in-depth review of inequalities in end of life care in England.¹⁴ The report provided evidence of the experience of people who may be less likely to receive good care because of diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances. The report concluded that this may be because providers and commissioners do not always understand or fully consider specific end of life care needs in different groups.

About the project

In response to the CQC report, NHS England, the Department of Health¹⁵ and Public Health England funded this project with the aim of sharing emerging practice in the provision of personalised end of life care for three specific groups: Gypsies and Travellers, people experiencing homelessness and LGBT people.

The project was funded as part of the national Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance,¹⁶ which aims to bring the voluntary, community and social enterprise sector's voice and expertise into national policy making. The project leads (Hospice UK, Marie Curie and Together for Short Lives) partnered with other members of the Alliance: Gypsy and Traveller communities (Friends, Families and Travellers); People experiencing homelessness (Homeless Link); LGBT people (National LGB&T Partnership). This resource contributes to making the Government's six point end of life care commitment a reality for people from these groups.

The project was guided by an advisory steering group, with insights from a literature review.¹⁷ The work of the project team was further informed by a focus group with Gypsies and Travellers (December 2017) and a workshop (February 2018) bringing together palliative care professionals with colleagues from the homelessness and wider health sector to discuss established and emerging practice and identify further opportunities to work together.

This project takes an 'all ages approach' and focuses upon care for adults, young people and children in England. We do, however, recognise that gathering examples and case studies for children and young people has been more challenging and this is noted as an area for further work.

The six point commitment for end of life care from the Government

In 2016 the Government made a six point commitment to end variation in end of life care due to geography, age, diagnosis, background or means across the health system in England by 2020.¹⁸ The six point commitment is about making sure that every person – including children and young people – who is approaching the end of life should receive high quality care that is personalised and focused on their individual needs and preferences (see next page).

The six point commitment for end of life care

'Our commitment to you is that, as you approach the end of life you should be given the opportunity and support to:

1. have honest discussions about your needs and preferences for your physical, mental and spiritual wellbeing, so that you can live well until you die;
2. make informed choices about your care, supported by clear and accessible published information on quality and choice in end of life care; this includes listening to the voices of children and young people about their own needs in end of life care, and not just the voices of their carers, parents and families;
3. develop and document a personalised care plan, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness;
4. share your personalised care plan with your care professionals, enabling them to take account of your wishes and choices in the care and support they provide, and be able to provide feedback to improve care;
5. involve, to the extent that you wish, your family, carers and those important to you in discussions about, and the delivery of, your care, and to give them the opportunity to provide feedback about your care;
6. know who to contact if you need help and advice at any time, helping to ensure that your personalised care is delivered in a seamless way.'

The six point commitment was issued by the Government in response to the 2015 independent review into choice in end of life care which called for every person who may be in need of end of life care to be offered choices in their care focused on what is important to them.²⁰ The commitment also aligns with the five priorities for care of the dying person (published 2014) which set out the standards for caring for someone at the end of their life,²¹ and the 'Ambitions for palliative and end of life care' (see page 4).²²

Personalised care

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders

The emphasis in Dame Cicely Saunders' quote on the individual and their unique value and importance captures the personalisation (person-centred) focus of this resource. Whatever the setting, regardless of the circumstances, everybody matters.

What is personalised care?

"Person-centred care supports people to develop the knowledge, skills and confidence they need to more effectively manage and make informed decisions about their own health and care. It is coordinated and tailored to the needs of the individual, and healthcare professionals work collaboratively with people who use the services."

NHS England ²³

Personalised care is an 'approach to care which situates the person within the context of their own social relationships, networks and experiences.'²⁴ It's concerned with people having more choice and control over the way their health and care is delivered, taking into

account what really matters to them so that they can experience good quality care. It is an approach founded upon respect, dignity, trusting communication and clear, accessible information; themes which were reflected within the literature review and focus group feedback for *'Care committed to me. Delivering high quality, personalised care for Gypsies and Travellers, LGBT people and people experiencing homelessness: a resource for commissioners, service providers and health, care and support staff.'*

There is consistency about how views on personalised coordinated care are articulated and they are reflected in a narrative published by National Voices and the National Council for Palliative Care (2015):

*"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."*²⁵

This statement is also at the heart of the national Ambitions framework for palliative and end of life care (2015).²⁶ This framework for local action is based on six ambitions or principles about how high quality care for people of all ages nearing death should be delivered at local levels in England.

The six ambitions of the national framework

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

In setting out statements which describe the ambitions in practice, the importance of measures such as personalised care planning and joined up care, along with the need for

competent, empathetic health and care staff are highlighted.

The palliative care and end of life journey for children is much less predictable than with adults. For children and young people, giving families real choice in terms of place of care, place of death and for emotional and bereavement support is key. To plan for care that is right for them, the family must be at the centre of decision-making. Personalised care for children and young people needs also to be integrated; families can be in contact with more than 30 professionals from education, social care, health and other services and often inadequate levels of communication between these different agencies means that families can be further burdened with stress as they attempt to navigate through uncoordinated systems.^{27,28}

Also relevant is the human rights based approach illustrated by the recent Sue Ryder and British Institute of Human Rights guide in which dignity and compassion are embedded into providing end of life care and as such fits with the drive for personalised care.²⁹

This resource is about tackling inequalities in end of life care. Whilst it does not attempt to reflect the complete legislative framework underpinning this, it is worth keeping in mind the statutory duties under the National Health Service Act 2006 (as amended by the Health and Social Care Act 2012) for commissioning bodies to 'have regard to the need to reduce inequalities in the benefits which can be obtained from health services'.³⁰ The Equality Act 2010 is additionally relevant to any organisation offering services to the public. It creates duties for public, private and third sector organisations not to discriminate in the way that services are offered and to make reasonable adjustments. Public sector organisations must also take steps to narrow gaps in outcomes between different groups. The Act covers a range of personal characteristics, including sexual orientation, transgender status, health/disability and ethnicity (which includes Gypsies and Travellers).³¹

It may also be helpful to refer to a list compiled by Together for Short Lives of the public policies published by the UK Government, devolved governments and other statutory bodies that have an impact on children with life-limiting conditions, their families and the services and professionals who care for them.³²

Cross cutting themes

The case studies presented in the following chapters, considered alongside feedback from the accompanying workshop and focus group activity underline five key principles which are critical to success. These principles are:

1. Good communication which includes engaging with people in a way that is meaningful for the individual and so enables people to make informed decisions about their care.
2. An approach founded on dignity and respect, and investing in a relationship of trust.
3. The provision of workforce training and support.
4. Enabling partnership working at a strategic level.
5. Recognising that people are all different so inclusive, equitable care is not about treating everybody the same way.

Find out more

British Institute of Human Rights and Sue Ryder (2016). *End of life care and human rights: a practitioner's guide*. London: British Institute of Human Rights.

National Voices & National Council for Palliative Care (2015) *Every moment counts: a narrative for person centred coordinated care for people near the end of life*. [s.l.]: National Voices.

NHS England (2016). *Commissioning person-centred end of life care: a toolkit for health and social care*. [s.l.]: NHS England.

Together for Short Lives. *At a glance: the public policies affecting children in the UK who need palliative care* [Online]. URL: <http://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/at-a-glance-public-policies-affecting-children-in-the-uk-who-need-palliative-care/>

Together for Short Lives (2012). *A guide to end of life care: care of children and young people before death, at the time of death and after death*. Bristol: Together for Short Lives.

Chapter 2. Personalising care for me: Gypsies, Roma and Travellers

Gypsy, Roma and Traveller communities

Gypsies and Travellers have formed a vibrant part of British society for more than 500 years. Romany Gypsies and Irish Travellers are recognised as two distinct minority ethnic groups in law because they are recognised as members of communities with a shared history, culture and language; as such they are granted the full protection of the Equality Act 2010.³³ However, despite the existence of equality and human rights legislation and guidance, Gypsies and Travellers continue to experience wide-ranging discrimination and inequality.³⁴

There is some uncertainty over the population size of the Gypsy and Traveller communities; the 2011 national census was the first in the census series to enable Gypsies and Travellers to identify their ethnicity. However, under-reporting borne of experience of prejudice and hostility, amongst other reasons, is likely to help explain the huge gap between official figures and estimates. As it stands, the 2011 census for England and Wales reports that 58,000 people identified themselves as Gypsy or Irish Traveller.³⁵ Other sources estimate the population in the UK today to be nearer 300,000,³⁶ and of this figure around 200,000 live in houses and 100,000 live in trailers and caravans. Some continue to live a nomadic life, travelling from area to area for part or all of the year. Around 25,000 Gypsies and Travellers are estimated to be homeless and have nowhere legal to stop.

Findings from the 2011 census suggest that in comparison with the population as a whole, the Gypsy and Traveller communities are

younger (39% were under the age of 20 which compares to 24% of the overall England and Wales population who were under 20), with a median age of 26 years (compared with a national average of 39 years). They are also more likely to have children; nearly half (45%) of Gypsy or Irish Traveller households had dependent children whilst the average for the whole of England and Wales was 29%.³⁷

Within the last decade Eastern European migration has seen an increase in Roma moving to the UK, many of whom will describe themselves as Eastern European rather than identify their ethnic status as Roma, for fear of further prejudice and discrimination. Without clear ethnic monitoring and support to identify as Roma we can only estimate how many Roma are living in the UK, although current estimates place this at around 200,000. There are much less data and research on the needs of Roma within the UK, especially as data on Gypsy, Roma and Traveller groups are often lumped together. The lack of disaggregated data means that it is hard to clearly identify the needs of this much maligned community. We do know that they experience many of the issues faced by other Inclusion Health groups, and that language is also a barrier to accessing services.

Research evidence suggests that Gypsies and Travellers experience significant health inequality. Gypsies and Travellers are more likely to have long-term health conditions and to experience poorer health overall in comparison to the general population,³⁸ with shorter life expectancy.³⁹ There is also evidence of high levels of bereavement and of stress amongst carers.⁴⁰ Access to health services can be

difficult for members of these communities and hampered by enforced eviction from sites. But as Matthews (2008) points out, a lack of access can be an issue for both nomadic and sedentary Gypsies and Travellers – ‘caused in part by a complex relationship of multiple issues to do with discrimination, marginalisation, lack of trust and low expectations on the part of other agencies.’⁴¹

Gypsies and Travellers have distinctive cultures and heritages and as McQuillan (2011) notes, they are communities which can be considered collectivist rather than individualist.⁴² This means that great emphasis can be placed on families and these units are often viewed at an extended level to include more than just immediate family members.

With social and cultural concepts of extended family, and traditions of care and respect for older people, it is perhaps not surprising that the census also found that Gypsies and Travellers are among the highest providers of unpaid care in England and Wales and provided the highest proportion of people giving 50 hours or more of unpaid care.⁴³ This information set alongside what we know more generally in terms of caring having a detrimental effect on physical and mental health⁴⁴ and people from Gypsy and Traveller communities experiencing a poorer health status than the general population⁴⁵ suggests that support for carers is critical. Indeed, the MECOPP project found that Gypsy and Traveller carers may have ‘little or no knowledge of how health and social care staff can organise a package of care for elderly, ill or disabled relatives. Few have been involved with social work, or had, where appropriate, care assessments for the person they care for, let alone an assessment of their own needs.’⁴⁶

Find out more

Cemlyn S, Greenfields M, Burnett S, Matthews Z, Whitwell C (2009). *Inequalities experienced by Gypsy and Traveller communities: a review*. [Research report 12], Manchester: Equality and Human Rights Commission.

Friends, Families and Travellers. *Friends, Families and Travellers advice on inclusive commissioning* [Online]. URL: <https://www.gypsy-traveller.org/resource/friends-families-and-travellers-advice-on-inclusive-commissioning/> Advice from the FFT team on commissioning inclusive care.

Gill P, MacLeod U, Lester H and Hegenbarth A (2013). *Improving access to health care for Gypsies and Travellers, homeless people and sex workers: an evidence-based commissioning guide for Clinical Commissioning Groups and Health and Wellbeing Boards*. Royal College of General Practitioners.

End of life care

End of life care support for Gypsies and Travellers is lacking. The current evidence base is reflected in the findings from our own focus group which points to value placed on care at home, but experience suggests that this care can be disjointed for a number of reasons. Enforced mobility exacerbates problems in accessing health care, because as Matthews (2008) points out, ‘it limits access to GPs and makes it difficult to organise programmes of palliative care to support Travellers who wish to die at home.’⁴⁷

In 2017 the Learning Alliance for Palliative and End of Life Care Services held a conference on palliative and end of life care services for Eastern Europeans, Romany and Traveller communities.⁴⁸ At this event delegates heard that some individuals felt let down by health

care professionals in primary and secondary care settings, and this made them reluctant to engage with end of life care services. There was also a lack of awareness of 24/7 Out of Hours services provided by hospices and people did not know where to get help. Recognising that providing care to family members is an important part of the culture of Gypsies and Travellers, solutions put forward lay in healthcare providers enabling people to care for their family members, rather than taking duties and responsibilities away from them. In turn this highlighted the need for information to be conveyed in ways that are sensitive to varying levels of literacy.⁴⁹

Cultural awareness

Understanding Gypsies' and Travellers' culture is vitally important to the provision of personalised end of life care. Whilst by no means a homogenous group, there are particular beliefs, customs and traditions relating to health, medical care and death. Barriers to good end of life care for Gypsies and Travellers identified in the Care Quality Commission's thematic review on inequalities in health (2016) include a belief that there was a lack of cultural understanding from services and staff.⁵⁰ For example, the report provided evidence of hospital staff not understanding the need for all extended family members to pay their respects to the dying person and difficulties arising from restrictive visiting policies. Other issues identified in the Care Quality Commission's review included 'a failure to recognise the need for the quick release and burial of the body in Traveller culture.'⁵¹ This has resonance with the workforce development needs discussed within the Safe Harbour case study on page 11. A need for better cultural awareness training is also picked up in the research literature.⁵²

The case management experiences of the charity, 'Friends, Families and Travellers' provide further insight into the difficulties arising from a lack of cultural understanding.

In one instance, a family member whose parent had died approached the charity for advice as their low income meant there were no funds for a burial. Not unusually in the case of a culture that tends to be verbal rather than written, the deceased person did not have a written will. Many traditional Travellers prefer a burial which is seen as a final resting place and this family were facing a situation in which they could not get a State-funded burial because there was no written will stating that this was the wish of the deceased person. The value of a final resting place as 'the ultimate marker of the deceased' for a culture that traditionally travels is significant. The body remained in the morgue until the charity's case worker negotiated an agreement with the council for the person to be buried. The process leading up to this was a long and painful one for the family who were already struggling to cope with their bereavement.

Focus group insights

Alongside the literature review and call for evidence, a focus group convened by Friends, Families and Travellers⁵³ helped inform this exploration of what works to support personalised care for Gypsies and Travellers. While the participants were clear that they could not speak on behalf of others, the themes emerging from the discussions resonate with research findings,⁵⁴ with emphasis placed on service access, communication and cultural awareness – see Fig. 1 on page 9.

Overall, the focus group highlighted three key actions which underpin the provision of personalised end of life care:

1. Importance of being treated with dignity and respect
2. Clear communication and advocacy to support engagement with services
3. Increased awareness and knowledge among staff within services regarding the values and cultures of Gypsy and Traveller communities.

Fig. 1 Themes emerging from focus group discussion

Discussion themes and comments

Access to services	Limited access to continuing healthcare means diagnoses don't generally come until later in the experience of medical issues.
	Knowledge of local services and what they can offer. This can be a particular issue for nomadic Gypsies and Travellers who may arrive in a new area with no experience of the services on offer at a point when someone is very unwell which means there is little time to get information and plan care.
	A negative experience with a hospice/hospital/service will be shared among the communities.
Communication	Gypsy and Traveller families are not generally aware about what services are offered and can be accessed.
	Hospitals and hospices generally rely on written distribution of information. This shows a presumption about literacy levels.
	Positive and clear communication (without the use of jargon, which can be intimidating) would change the experience of hospital/end of life care
	Families may be wary of disclosing their Gypsy/Traveller identity for fear of discrimination, but this means that staff might not be aware that additional support might be required (e.g. access to literature)
	A lack of awareness about a complaints process or difficulty engaging with it may mean that people do not feel empowered to complain about poor care.
Cultural awareness	General misunderstanding/lack of knowledge about Gypsy and Traveller traditions.
	End of life rituals are very important to Gypsy and Traveller communities. Funeral poverty can also be an issue.
	Lack of sensitivity from care staff – including experiences of police and security being called when relatives and extended family visit the hospital
	Fear of hospitals and hospices for end of life care as there is a feeling they compromise dignity. This is particularly meaningful to Gypsy and Traveller communities due to ongoing lived experience of prejudice and discrimination.
	Advance care planning: there is cultural resistance to discussing end of life care or long term illness in general.

The focus group participants also proposed solutions for change:

- Advocates in hospital/hospices to support the sharing of knowledge/information in relation to services; someone to sit alongside family members and explain what's going on
- Videos could be useful for younger generations in helping to open up avenues for conversation, but would not necessarily be useful for older generations.
- Personal healthcare budgets
- A member of staff in hospices/hospitals trained in Gypsy and Traveller cultural awareness
- Options to receive care in the home and resources made available to support this.

The importance of gathering together as a support network for a patient and keeping vigil was also discussed in terms of being both a family and social need. Focus group members suggested that making a space available for families to wait would be welcomed not just by Gypsy and Traveller people, but also by members of other community groups who may need to be together in larger numbers. The availability of a space to accommodate a large family group is also discussed in the work of Jesper et al (2008) which touches upon the need for sensitivity and tact on behalf of care staff and the possibility of negotiating the use of a day room for the visit.⁵⁵

The points raised within the focus group discussions reflect wider research findings on barriers to health care access for Gypsies and Travellers. For example, the work of McFadden et al (2018) highlights health literacy - which encompasses 'knowing how to access and navigate health systems and being able to access and understand health information'⁵⁶ – as a barrier to health care. A lack of knowledge about local services and what they can offer was commented upon by the focus group, along with a reliance on written information by some health professionals which can be unhelpful to some Gypsies and Travellers. Fears of discrimination and previous

experiences or perceptions of negative attitudes on behalf of some health staff, resulting in a reluctance to disclose identities, in turn led to poorer communication experiences where the use of jargon, for example, was found to be intimidating. The research literature also points to difficulties which can be posed by health services' systems (for example, registering for services).⁵⁷ A reluctance on behalf of some health care professionals to visit sites is also cited and it's a point addressed in one of the case studies presented below.

Improving care for Gypsies and Travellers

The evidence base on end of life care for Gypsies and Travellers is limited and in acknowledgement of that, this section draws in part on findings from the wider research on healthcare support for people from these communities.

A systematic review (McFadden et al 2018) of access to health care services by Gypsy, Roma and Traveller people also considered the best ways to enhance their engagement with health services. Whilst acknowledging that the evidence base requires strengthening, the study found that there are 'promising strategies to enhance Gypsy, Roma and Traveller communities' engagement with health services' and these include specialist roles and outreach.⁵⁸

The evidence base and case studies presented here point to the need and importance of building relationships of trust. For example, a synthesis of the evidence on outreach programmes to improve the health of Travellers (Carr et al, 2014) found that the level of engagement with an intervention is influenced by the degree of trust between those delivering the outreach service and the community.⁵⁹

Outreach approaches along with the importance of culturally sensitive service provision and the building of relationships of trust are reflected in the case studies that follow.

The care I provide...

- is culturally aware⁶⁰
- recognises that information may need to be provided in different formats to accommodate literacy levels
- understands that it takes time to establish trusting relationships.

The care I commission...

- is based on evidence and Joint Strategic Needs Assessments of local population groups which include Gypsy and Travellers and are used by Clinical Commissioning Groups (CCGs) to develop local services and recognises that CCGs have a legal duty to reduce health inequalities in both access to services and health outcomes.
- recognises that outreach and peer to peer work facilitates co-production and health improvements
- collects and disaggregates data on Romany Gypsies, Travellers and Roma
- recognises that it takes time to establish trusting relationships
- recognises that flexibility around county boundaries due to evictions enables continuity of care.

Helping to make the Government's commitment on end of life care a reality

The Safe Harbour project, St Helena Hospice

The Safe Harbour project aims to improve access to palliative care and to support patients from under-represented and marginalised groups in north east Essex; an area which has a high population of Gypsies and Travellers. This is a phased project with a long term commitment and it begins with a focus on increasing access to therapies and wellbeing services. Underpinned by a detailed needs assessment, the outreach model features a Clinical Outreach Nurse Specialist who has worked successfully to build a caseload of patients from under-represented groups and communities who have not traditionally accessed the hospice's services.

The hospice is also working with Macmillan Cancer Support's local information service using a central hub model with offshoot spokes located in the heart of the most deprived and marginalised communities. This empowering model is based upon the premise of taking information to people and helping them to help themselves (for example, this may include support with reading if literacy levels require that).

Cultural awareness

Consideration of workforce training needs is integral to helping staff feel more confident and competent to care for patients from communities who have been less well represented in the traditional hospice community. For example, insights into Gypsy and Traveller culture can help colleagues understand that a request for the immediate removal of equipment upon a family member's death is not showing a lack of respect and undignified haste, but for many Travellers is in fact an act of love and an upholding of tradition where personal grief is put to one side so the deceased person is not bound to this earth by material things and prevented from passing over.

Communication

The opportunity to discuss needs and preferences, and to make informed care choices depends upon trusting relationships. To that end, the Safe Harbour project notes that delivering on a promise is really important and advises not to offer more than you can provide. This means considering resources and capacity and being realistic about what can be offered. Strong oral traditions mean that experiences are remembered and recounted across and within Gypsy and Traveller communities. As literacy levels can be low, especially amongst older community members, personalised end of life care means also being aware of a potential need to provide information materials in alternative formats.

Top tips from St Helena Hospice:

- Keep on keeping on. There is no quick fix; it takes time to address fears and concerns and build trust. Don't stop after three, six or 12 months.
- Referrals may be low in numbers at the outset but it's important to hold on in there and allow momentum to gather
- What doesn't work provides valuable learning too
- Find neutral ground at which to meet rather than going straight to a Gypsy's family home
- Listen to the community and carry out a detailed needs assessment. This shows that you're prepared to talk openly about what you already do and offer support to community members with unmet palliative/end of life care needs.
- Be visible, present, consistent and ethical; establish the links and make sure these links are sustained.
- Be aware that there is an element of risk – this must be carefully assessed and thought out and staff need to be empowered and supported in this role. Organisational 'buy-in' is essential
- Map other engagement initiatives in the community and look to work with them and support existing relationships. This means that even though the hospice team may not be physically present, by providing information about its services, the hospice can make inroads.

For more information, contact
Dr Karen Chumbley at:
kchumbley@sthelenahospice.org.uk

Supporting a Romany Gypsy Family

As part of this project Friends, Families and Travellers interviewed a nurse working with children with complex health care needs. The nurse described the support offered by the team to a Romany Gypsy family who were living on a Local Authority Traveller site and dealing with the care of their child with a life-threatening illness. They supported the family for more than ten years, until sadly the young person died and to this day remain in touch with the family.

Helping to make the Government's commitment on end of life care a reality for a Romany Gypsy family

Whilst the child had a life-threatening condition, honest open discussions between the nursing team and family members were able to take place as there was opportunity to get to know the family and community and a mutual respect developed which enabled the family to make informed choices about their child's care. This established relationship meant that the family were involved in creating a care plan that worked for them on site, despite the reservations of a few health care professionals about staff safety particularly overnight. Discussion of the child's personalised care plan with the nurse meant that the family were supported with on-going complex medical care requiring complex technology which was delivered on site overnight and in the day. This is something that could cause anxiety for some health professionals unused to Traveller sites but the positive relationship with the family and respect of health professionals within the site community quickly helped them overcome initial doubts. The trusted relationship that developed meant that the family members knew who to contact at any time of day, or night should a problem arise.

Commenting on this case study, Matthews of Friends, Families and Travellers notes that this example shows that it is possible to support people in very different forms of accommodation. However, it is worth considering how a family forced to live on an unauthorised encampment could be supported. We know that there are an estimated 300,000 Gypsies and Travellers in the UK, two thirds of whom will live in bricks and mortar accommodation, leaving 100,000 people living in trailers and caravans, of those it is estimated that 25,000 people will have no legal stopping place to park up. This means that those families are evicted from place to place with nowhere that they can legally call home. Unauthorised encampments rarely have access to running water or toilets. Families with sick or dying relatives are often forced into bricks and mortar accommodation in order to manage certain health conditions or when they are dying. There is evidence to suggest that many Gypsies and Travellers have a cultural aversion to bricks and mortar accommodation and the majority of those that are still travelling would rather die with their community around them. This in turn emphasises the importance of outreach and community service provision in end of life care.

Find out more

A selection of further reading and useful resources to support Gypsies and Travellers.

Challenger G. [n.d.]. *Cemeteries and burial: culture and traditions for people from the Traveller communities*. Brighton: Friends, Families and Travellers.

A guide on Gypsy and Traveller burial customs.

Matthews Z (2008). *The health of Gypsies and Travellers in the UK*. [Better Health Briefing #12]. London: Race Equality Foundation.

A briefing on the health status of Gypsies and Travellers and their access to services, along with examples of good practice.

Welsh Government. *Travelling to better health: advice and guidance on culture and health needs for practitioners working with Gypsies and Travellers* [Online]. URL: <http://gov.wales/topics/health/publications/health/guidance/travelling/?lang=en>

A comprehensive guide for healthcare practitioners on working effectively with Gypsies and Travellers.

Chapter 3. Personalising care for me: people experiencing homelessness

People experiencing homelessness

People experiencing homelessness are amongst the most vulnerable in our communities today. Experiencing violence, poor health and a significantly lower life expectancy, being homeless is isolating, frightening and dangerous.⁶¹

The national charity Homeless Link reports that homelessness occurs because of a range of factors, complex life experiences and vulnerabilities including relationship breakdown, mental health problems, poor physical health, alcohol and drugs issues, bereavement, experience of care, and experience of the criminal justice system. Wider structural factors such as poverty and unemployment may also be involved.⁶²

Often facing high rates of morbidity with a significantly lower life expectancy in comparison with the rest of the population, people who are homeless experience some of the worst health outcomes in society. Research from Homeless Link found that 41% of people who are homeless reported a long-term physical health problem (compared to just 28% of the general population) and 45% had been diagnosed with a mental health problem (compared to 25% of the general population).⁶³

The hidden picture

Getting an accurate picture of the number of people who are homeless in England is not straightforward. In part measuring this population is difficult because people move about and may choose to sleep at different times, or they may be hidden away in derelict buildings, tents, barns and other less visible

locations. However, on any one night it is estimated that 4,751 people in England are sleeping rough.⁶⁴ Worryingly, this estimate represents an increase of 73% in just three years (from 2014 to 2017).⁶⁵

In addition, the number of homeless households in temporary accommodation is rising; with figures from 2017 (July-September) putting the total at 79,190 households (with more than 121,000 children), which represents an increase of 6% on the previous year.^{66,67} A further group of people do not show up in official figures as they may have found a temporary solution with friends and family, in squats or other insecure accommodation. This is referred to as 'hidden homelessness'. Research (2011) commissioned by the charity Crisis, reported that 62% of the single homeless people surveyed were hidden homeless on the night they were surveyed.⁶⁸

Find out more

For insights into why people become homeless, the number of people affected and what the latest research tells us about tackling the issue, see the 'Facts and figures' pages on Homeless Link's website: <https://www.homeless.org.uk/facts-figures>

End of life care

For people who are homeless the early identification of the approach of end of life is important, but this does not always happen in practice. As the Care Quality Commission's

review into inequalities in end of life care (2016) points out, it ‘takes a long time for people who are homeless to develop a trusting and nurturing relationship with services, so people need to be identified early to allow planning to happen and to have the opportunity to reconnect with family if possible.’⁶⁹ However, identifying people who are homeless who may be approaching the end of life is not straightforward. Whilst sudden deaths do happen, the presence of longer term chronic conditions which may lack clear trajectories means that deaths amongst people who are homeless can be unexpected and occur without a care plan in place.⁷⁰

The evidence base also identifies that access to palliative care can be challenging for people experiencing homelessness and those who are vulnerably housed; many people at risk of dying with very complex needs are without adequate care and support.^{71,72,73} Operating at individual and system levels, obstacles to palliative care are identified as arising from chaotic lifestyles and competing day-to-day priorities for people who are homeless, along with experiences of ‘stigma in mainstream settings, the high burden on hostel staff in supporting residents at the end of life and inflexibility in mainstream health care systems’.⁷⁴ Hudson et al (2016) map a way forward in which building trusting relationships between individuals and healthcare professionals, increasing flexibility and collaboration between services, along with training and support are all key to improving access to palliative care.⁷⁵

Recommendations to improve care for people experiencing homelessness

Recently published research from Pathway in collaboration with the charity and housing association St Mungo’s, Marie Curie, University College London and Coordinate My Care explored the challenges to palliative care for people who are homeless (2018).⁷⁶ At the workshop held for this resource in February

2018, Shulman and Hudson from the research team presented three key recommendations arising from this that could help services better support people with advanced ill health who are homeless. These actions are based on the recognition that everyone has a role in palliative care for people who are homeless and that there is a need for more collaboration and shared understanding between health, palliative care, drug and alcohol, social care, housing and voluntary sectors to achieve support within hostels.

Three ways to improve palliative care for people who are homeless⁷⁷

1. In view of uncertainty and complexity, shift the focus from trying to identify people at the end of life and make the point at which someone’s health is a cause for concern the trigger for action
2. Introduce multi-agency meetings to discuss clients of concern and provide person-centred care
3. Step up in-reach into hostels and day centres, from a range of professionals and services.

Reproduced with permission.

The research team identified a further need to develop specialised services for people with high support needs.⁷⁸

Workshop insights

In addition to the literature review and call for evidence, this exploration of what works to improve care for people experiencing homelessness was informed by a practical workshop.⁷⁹ The event brought together 33 palliative care professionals with colleagues from the homelessness and wider health sector to discuss established and emerging practice and identify further opportunities to work together.

The importance of partnership working

Participants highlighted the complexities of navigating the local health and homelessness sectors but there were many examples of strong local partnership working. These partnerships included a wide range of stakeholders from across the statutory and voluntary sector, such as health, housing and law enforcement agencies, through to volunteer befrienders and peer advocates. There was a strong focus on the importance of multi-disciplinary approaches and many participants had initiated local review meetings or forums to facilitate this. Other examples of the achievements of local partnerships included:

- Hospices training hostel staff on communications skills and end of life care conversations
- Hostel staff upskilling palliative care staff in the local homelessness sector and supporting people experiencing homelessness
- Analysis of local data to help identify gaps in current provision
- Simplifying local referral processes to ensure these were consistent across a local area
- Working together with local pet care organisations to ensure people's wishes regarding their pets can be fulfilled
- Reflective practice and bereavement support for people working in hostels.

Some barriers to partnership working were identified in the workshop. The strict geographical boundaries of some hospices means that hostels need to be aware of who covers what locally. A high turnover of staff across the homelessness and healthcare sector can lead to training and expertise being lost. A number of attendees highlighted that services do not always know what is available to them locally so are unsure about where to go to ask for help and support.⁸⁰ This can be exacerbated by services closing or being decommissioned.

The workshop also identified some key elements of successful partnerships. Effective communication is crucial, along with a strategic ongoing commitment to the partnership to counter staff turnover, changes in services etc. Many of these partnerships had been driven by a homelessness 'champion' or coordinator in palliative care services, able to share information, network and do outreach work locally. Many felt it was important not to get overwhelmed by the scale of the issue but to continue to make small steps to improve end of life care for people experiencing homelessness. All partners, including commissioners and funders, also need to understand the nature of personalised successes in which the outputs may look small (such as someone allowing their wounds to be dressed as a result of ongoing engagement with staff) but have huge impact for the individuals concerned.

Supporting choice

Feedback from the professionals attending the workshop chimes with research findings. There was a strong feeling that it is critical that the right person has the conversation about advance care planning and end of life care. They need to be trusted by the individual, have the necessary skills, be able to do something with the information and have the time to have conversations properly. There was an acknowledgement that a healthcare professional might not always be best placed to have this conversation, but that it was crucial that they were able to offer input and support as appropriate.

These are also not single conversations, but part of a continuum of support which should begin at an early point. The group recognised the difficulties raised by an uncertain prognosis, ongoing engagement with treatment and realistic advance care planning, and suggested an ethos of 'planning for the worst and hoping for the best' as a way of reconciling these. This concept of parallel planning – described as 'one that incorporates uncertainty and promotes well-being, dignity and choice' – as

part of a multi-disciplinary response which acknowledges the insights, concerns and wishes of people experiencing homelessness is also proposed by Hudson et al (2017) as a potential way of supporting a more person-centred approach to care within a context of deteriorating health.⁸¹

There was also a call for better shared understanding of other agencies' facilities across the homelessness and health pathways i.e. number of beds, level of support offered that would help present realistic options to people so they can make an informed choice. Equally, stronger links with medical teams could help support workers in hostels to better understand a prognosis and give appropriate support.

The care I provide...

- proactively engages with homelessness services in my area and makes time to build these relationships
- is based on developing a flexible and ongoing relationship with homelessness services and offering support and training as appropriate
- identifies opportunities to share my expertise around end of life care and advance care planning to improve care for people experiencing homelessness
- means I am involved in multi-disciplinary approaches to identifying and supporting people experiencing homelessness whose health is a concern
- is non-judgemental, flexible and tailored to each individual
- is supported by a range of professionals and services
- relies on developing trusting relations.

The care I commission...

- uses evidence and Joint Strategic Needs Assessments which include people experiencing homelessness to develop local services
- recognises that CCGs have a legal duty to reduce health inequalities in both access to services and health outcomes
- is about working with partners to co-produce commissioning outcomes for services providing palliative care to people experiencing homelessness so they are meaningful for this group
- ensures homelessness is reflected in strategic end of life networks locally
- facilitates closer working between palliative care professionals and the homelessness sector
- facilitates choice and supports individuals whilst respecting their wishes.

Helping to make the Government's commitment on end of life care a reality

Coordinating care at St Mungo's

Designed to offer temporary basic housing and working on a recovery based model, hostels were not envisaged as care settings for people at the end of life. However, for some people who are homeless and facing advanced illness, hostels can be a preferred place of care and death. This means that hostels with limited training and resources are supporting people at a young age with complex needs.⁸²

St Mungo's is a charity and housing association that works directly with people experiencing or at risk of homelessness. In 2007, St Mungo's began a dedicated programme of work around supporting residents with advanced ill health. The service, which was originally developed in partnership with Marie Curie, is led by the palliative care coordinator.

The service shows how a collaborative approach is enabling hostel residents to receive support whilst training, psychological and emotional support help hostel staff overcome the challenges of supporting people who are homeless at the end of their lives.

“St Mungo’s offers a unique service that works to ensure the most vulnerable members of our society can access palliative care, maintain their dignity and make informed decisions about their future. I am proud that the training we have developed has increased the confidence of so many of our staff; improving their knowledge and skills so they can better care for our residents, and themselves, at such difficult times.

I hope we can continue to build partnerships, working with our colleagues in the palliative care and homelessness communities to ensure all those experiencing homelessness can receive the quality end of life care they deserve.”

*Niamh Brophy, Palliative Care Coordinator,
St Mungo’s*

Tackling inequalities in end of life care for people experiencing homelessness

The palliative care service at St Mungo’s delivers a number of key activities to improve end of life care for people experiencing homelessness.

Supporting choice at end of life

The key aim of the programme is supporting residents to make informed choices about future needs and wishes and facilitating their access to supportive services. This includes close coordination with specialist palliative care services, GP and other primary care services, wider relevant health and social care services.

End of life care training

The palliative care coordinator delivers appropriate training to frontline staff in dealing with end of life issues, including bereavement support, identifying clients with advanced ill health and other issues tailored to individual services. Three hundred staff have been

supported in this way since the service began, which has increased their confidence in identifying and supporting people who would benefit from the service.

Partnership working

The palliative care coordinator chairs a multidisciplinary working group to identify residents whose health may be deteriorating and may require additional support. Membership of this group includes the local alcohol service, GP, hostel and hospice staff. This close partnership working also raises awareness more broadly about the end of life care needs of people who are homeless. In addition, St Mungo’s has also been a partner in a collaborative research programme with UCL, Marie Curie and Pathway that explores the challenges of palliative care for people who are homeless and how best to overcome them (see page 15).

Psychological and emotional support

In addition, the palliative care coordinator supports residents and staff to deal with the psychological and emotional aspects of approaching the end of life. As part of the wider palliative care service, bereavement support is also offered to frontline staff and residents through a volunteer-led bereavement befriending service.

Helping to make the Government’s commitment on end of life care a reality for people experiencing homelessness

The reach of the palliative care coordinator role has been significant, with more than 200 residents supported across 100 accommodation projects since the programme started. This has allowed people to make their preferences known and, where appropriate, remain and receive support in a setting they consider home. In addition to training staff so they have the confidence to have conversations, systems have been developed to support staff to more routinely embed this into their work. This includes case review prompts, an end of life care checklist and tools to help map an individual’s support needs and concerns.

Top tips from St Mungo's

- A palliative care coordinator role within a homeless service can offer dedicated support around end of life care to residents and staff, facilitate access to support services in line with individuals' wishes and needs, and develop key local partnerships.
- Supporting staff (through training and one-to-one) to have conversations with residents earlier on in their illness enables services to plan care in line with residents' wishes and anticipate challenges so care is not crisis led.
- A 'homelessness champion' within palliative care communities could raise awareness of the unique challenges faced by this group, develop local solutions to ensure access to services is improved and deliver training to bridge the gap in knowledge between homelessness and palliative care services.
- Regular multi-disciplinary meetings enable a broader focus on identifying people whose health is a concern and might require support, thereby reaching individuals earlier on in their illness and ensuring care is planned not crisis led, and palliative care be introduced when the time comes.

For more information, contact Niamh Brophy on niamh.brophy@mungos.org or 020 3856 6000.

A multi-agency approach to advance care planning

Advance care planning is key to the delivery of personalised care. Whilst there is currently little published evidence about the effectiveness of advance care planning for people who are homeless,⁸³ its conceptualisation by Russell (2016) as 'an activity within a philosophy of person-centered care, concerned with the complexity of the context of and relationships within an individual's life' highlights its value.⁸⁴

In Southampton a multi-agency approach to supporting advance care planning aims to ensure a proactive and consistent approach to supporting advance care planning for people who are homeless across the city. The project started in 2012, and continues to develop on an iterative basis and be embedded in local homelessness and substance misuse services. It is funded through Southampton City Clinical Commissioning Group and Southampton City Council.

"People who are homeless are often denied the choices that other people have when planning their end of life care. In Southampton patients always come first, regardless of their circumstances, and that is why we go to extra lengths to support people who are homeless to plan ahead. This includes supporting them to reconnect with their families, in addition to making practical arrangements, such as planning the future care for their pets. This can provide a great source of comfort to the individual at a very difficult time. The best way to improve end of life care for people experiencing homelessness is building a close relationship between all of the agencies involved. We have an excellent homeless healthcare team and we will continue to support them with sharing best practice."

Chrissie Dawson, Senior Commissioning Manager at NHS Southampton City Clinical Commissioning Group

A consistent approach to end of life care planning

The overarching aim of this approach is to provide individuals with the opportunity to consider, plan and document their choices around care and support at the end of their lives. The focus has been on supporting staff to identify opportunities to initiate end of life care discussions and developing a process for recording wishes in a way that is led by and progressed at the pace of the individual. Through the locally established homelessness and substance use end of life care forum, this process has been refined so that instead of

numerous agencies having separate ways of approaching these conversations, a single end of life care planning document has now been developed (see Appendix 1 on page 45). This has been co-branded by local homelessness agencies and the local NHS Trust.

Support for staff

The homeless healthcare team provide training around end of life care conversations in conjunction with hostel providers where a training need is identified. This training was developed following workshops with the local care home education team and also drew on information from St Mungo's end of life care work (see pages 17-19). In addition, Schwartz rounds are offered to staff to provide an opportunity to reflect on the emotional aspects of their work.

Memory boards

Memory boards have been introduced following the death of someone in a hostel to provide staff and residents with a chance to leave messages and memories, and reflect their feelings and thoughts about the individual who has died. These, where appropriate, can be shared with families and friends of the deceased.

Helping to make the Government's commitment on end of life care a reality for people experiencing homelessness

The locally agreed end of life care plan covers a range of issues around which people might want to record specific wishes and choices. Staff supporting the individual can then work with them to fulfil these wishes. While much of the impact of this work is anecdotal, a greater focus on advance care planning has provided people with opportunities to reconnect with estranged families, leave letters for loved ones to be passed on after their death and making future arrangements for the care of their dog. These plans are seen as fluid documents and change in accordance with the individual's circumstances.

Increasing staff confidence through training and a structured way to approach discussions around end of life care has also meant that people have been supported to die in the hostel when that is their choice, rather than being admitted to an unfamiliar acute setting.

Top tips from Southampton

- The development of a single shared advance care planning process ensures consistency across the different agencies that an individual might be in contact with.
- A local end of life care forum offers an opportunity for peer support, development of further initiatives to tackle inequalities in end of life care and can feed into wider strategic groups locally.

For more information, contact
Chrissie Dawson on chrissie.dawson@nhs.net

Strengthening links between hostels and hospices

"Hospices and hostels working together can really make a significant difference to homeless people living with a life limiting condition."

*Alison Colclough, Homelessness Project Lead,
St Luke's (Cheshire) Hospice*

Effective support for people who are homeless calls for collaboration, inter-professional working and cross-sectoral partnerships.⁸⁵ The model of care developing at St Luke's (Cheshire) Hospice shows how hospice, hostels and primary care can work together to provide the dignity of choice for people experiencing homelessness in the county.

St Luke's (Cheshire) Hospice is the local hospice for people living in mid and south Cheshire, supporting a community of around 280,000 people. The hospice secured funding from the Rayne Foundation to develop a dedicated homelessness project, including a

part-time homelessness project lead and two-part time counsellors. This project has grown significantly from its initial focus on staff training for hostels and has supported a significant amount of work across Cheshire to improve outcomes for people who are homeless at the end of life.

Tackling inequalities in end of life care for people experiencing homelessness

Strengthening links between hospices and hostels

The project lead's role, funded by the Rayne Foundation, is expansive and extends to supporting local hostels and services across Cheshire in a number of ways.

- Two counsellors are now available in St Werburgh's Medical Practice for the Homeless and a local Salvation Army hostel for a number of hours each week.
- Work has been undertaken with another hospice in the county and their local hostel to refer hostel residents into the hospice's Living Well programme and increase referral routes for hostel clients.
- In conjunction with the project lead, the day hospice at St Luke's (Cheshire) Hospice is working with local hepatology teams and consultants to raise awareness of hospices and referral routes, so that hospices are seen as an option for this patient group.
- The project lead role also includes carrying out significant event analyses with staff following deaths in hostels to give them an opportunity to reflect on and review individual cases.

Dedicated end of life care bed

The project lead worked with the management and staff at a homeless hostel in Chester, as they converted a room in their hostel into a dedicated respite and end of life care bed. The project lead provided training, support and advice as needed, and was also able to provide facilitation support when specific issues surfaced. The dedicated medical support for the bed is provided by staff from St Werburgh's Medical Practice for the Homeless, who have also developed guidance on the use of controlled drugs for the palliative care patients.

Helping to make the Government's commitment on end of life care a reality for people experiencing homelessness

The work done to strengthen links between hospices and hostels has broadened the support options available to people, so they have real choices about their care at the end of life. The ongoing offer of support from the hospice gives hostel staff the confidence to have the honest discussions needed, even if they do not take up that offer of support.

Top tips from St Luke's (Cheshire) Hospice

- Outreach/in-reach work in to hostels by hospices is key to increasing visibility and bringing the two sectors closer together. It is imperative that a proper amount of time is put in to building these relationships – a key part of this is sharing expertise but also acknowledging what you don't know.
- Support from hospices should be ongoing and flexible so that hospices can offer advice and input as issues arise.

For more information, contact Alison Colclough on alison.colclough@nhs.net

Jimmy's story

Jimmy* was in his mid sixties when he found himself homeless. The local authority placed him in a hostel in his own town.

Jimmy was acutely unwell. He had pain, nausea and vomiting and was grossly underweight. He told the hostel staff that he had a cancer diagnosis which was no longer treatable. The local out of hours GP was called out and felt that Jimmy was too unwell to be staying in a hostel, but not unwell enough for a hospital admission.

One of the senior support workers at the hostel had a good working relationship with the homelessness lead at the local hospice. The hospice was working towards offering choice and access for people experiencing homelessness with a palliative diagnosis. The hospice worker visited Jimmy at the hostel and Jimmy said he had a hospital appointment the next day. He agreed that both the hostel and the hospice workers could go with him.

At his outpatient appointment the medical staff could see that Jimmy had deteriorated. They had known him for some time, although he did not always attend all his appointments.

They asked the hospice worker if they could refer him for symptom management and respite. Jimmy agreed, and the hospice felt it was an appropriate referral. Jimmy stayed at the hospice for several weeks. His symptoms of pain and nausea were brought under control and he gained a little weight. Jimmy had an issue with alcohol, but it caused no problems during his stay in the hospice. He was also a very heavy smoker, and once an agreement was reached about where he could and could not smoke there were no real issues.

The hospice benefits worker was able to access Attendance Allowance for Jimmy, and a local authority social worker was able to get him into supported, independent living accommodation on discharge from the hospice. The hospice worker also referred Jimmy to the local district nurse team who made support visits and ensured he was on the Gold Standards Register at the GP surgery. He also had access to a local Macmillan nurse. The hospice homelessness worker continued to visit Jimmy regularly as it was understood that his condition would inevitably deteriorate. All physical care was managed by the district nurses, with the hospice worker providing emotional support visits, sometimes liaising with his social worker.

Jimmy deteriorated over the following six months. Early one month the hospice homelessness worker and a Macmillan nurse made a joint visit to Jimmy as the district nurses had reported a significant deterioration. Sadly, Jimmy was dying. He had four daily fifteen-minute visits from the carers from his accommodation, but this was no longer enough. Jimmy knew he needed more care and agreed to go into the hospice. Jimmy went the same day. The staff remembered Jimmy from his last visit and he remembered them and soon settled. Jimmy died peacefully eight days later.

*Name has been changed.

Local service collaboration

Alongside knowing and understanding the needs of individuals, knowing 'who else in the local 'system' has a responsibility for or an interest in meeting these needs' is an important principle in the care and support of people who are homeless.⁸⁶ A partnership between George House Hostel and St Luke's Hospice in Plymouth came about following an increase in the number of deaths in hostels locally. St Luke's Hospice worked to secure some funding for training and then worked with George House Hostel to work out how best that training could be run. There has also been a wider piece of work taken forward by the hostel to improve the end of life care offer for people experiencing homelessness.

"The opportunity for each individual to discuss their end of life options and life story alongside the choice to die in the place they call home is an offer we should all be entitled to – including when that is a hostel."

Sean Mitchell, Hostel Manager

Tackling inequalities in end of life care for people experiencing homelessness

Facilitating better advance care planning

The activities undertaken as part of work to improve end of life care have covered a number of pertinent issues. Key examples include being able to identify people who may require end of life support, although this can be difficult for conditions with an uncertain prognosis, such as liver disease. It also covered creating a life diary and exploring with someone how they would like their death to be managed, which appeared to really resonate with individuals. There was also training for staff around end of life conversations and the completion of the Treatment Escalation Plan (TEP) form.

Ongoing support from the hospice

The continued support from the palliative care nurse at St Luke's Hospice has been crucial to the success of this work. As well as advising on individual cases, they have worked to make arrangements with the local outreach GP so that support is available if this is necessary. The hospice has also been able to offer input on practical challenges, such as securing PIP (Personal Independence Payment) to help people fund packages of care, and medicine management.

Establishing a local end of life care group

Another key element of the work has been the development of a group that focuses on reviewing end of life support for people in contact with homelessness services. Attendees include representatives from St Luke's Hospice, the local hepatology team, outreach GP alongside the Substance Misuse Complex Needs Team. This group is developing a health matrix, including physical, psycho-social and practical elements, to help services identify people who might require palliative care input or those at risk from advanced ill health.

Helping to make the Government's commitment on end of life care a reality for people experiencing homelessness

This project has increased competence and confidence around supporting people experiencing homelessness at the end of their lives. There is a greater focus on talking to people about their wishes and these conversations involve all the relevant professionals, including the palliative care nurse and social worker from St Luke's Hospice, the outreach GP and others. One of the key successes from the hostel's perspective is that with the support of the local hospice, they have felt able to support someone to die in the place they felt safe and called home.

Top tips from George House Hostel and St Luke's Hospice

- Training around advance care planning is one key part of what hospices can offer to homelessness services, but there are a wide range of other issues where they can offer advice and practical support.
- Developing local networks across the homelessness, palliative care, health and social care sectors helps improve understanding around what different services can offer and how best to work together.

For more information, contact
SeanMitchell@BCHA.org.uk or
gbarringer@stlukes-hospice.org.uk

Sharing expertise and developing an academic link

"The opportunity to work in partnership with the Department of Health Sciences at the University of York has enabled us to develop and sustain initiatives in line with current research in relation to end of life care and homelessness, in turn, being able to put into practice gold standard care which has a solid research base."

*Alison Skelton and Lynda Ruddock,
St Leonard's Hospice, York*

"Our close collaboration with St Leonard's Hospice ensures that the research and teaching in palliative and end of life care in the Department of Health Sciences is fully guided by, and relevant to, contemporary health care practice, with the ultimate beneficiaries being patients and carers."

*Dr Kate Flemming, Senior Lecturer,
Department of Health Sciences,
University of York.*

Training was offered by St Leonard's Hospice to local hostel staff in skills such as recognising deterioration in a patient's condition and initiating conversations about end of life, and

this has been reciprocated with training from the hostel team on some of the issues that affect people experiencing homelessness and how services work to support them. Ripples from this work are now reaching across the city as GP interest has led to plans getting under way to develop a coordinated approach to care for people who are homeless in York.

St Leonard's Hospice is an independent charity, providing specialist palliative care and support for local people with life limiting illnesses in York and the surrounding areas. In 2015, as part of St Leonard's 30th birthday celebrations, the trustees funded a two-year project to enable two clinical nurse educators to provide end of life care training to the wider community. While this was originally focussed on care home staff, the need for dedicated support for people experiencing homelessness was soon identified.

Dr Kate Flemming, Senior Lecturer at the University of York provides further context and insight to this project, noting that the 'Department of Health Sciences at the University of York and St Leonard's Hospice, York have a long history of joint working with the aim of improving outcomes for patients and families receiving palliative care services provided by the hospice and beyond. The work spans research, teaching and clinical practice.' As part of this work they are working towards developing a service for people who are homeless and nearing the end of life to improve care provision.

The project began through research undertaken at the University of York⁸⁷ informing education in end-of-life care for Changing Lives hostel staff which was delivered by St Leonard's Hospice education team. The education programme had a positive impact on care, however, joint working across organisations highlighted that vulnerable individuals were falling through 'gaps' in end-of-life care provision. This was the catalyst to bring together both health professionals working with the homeless population of York and palliative care specialists to develop

processes of identification of individuals nearing the end of life, guidelines for symptom management, advance care planning and palliative care education.¹⁸⁸

Tackling inequalities in end of life care for people experiencing homelessness

Proactive approach

Once it had been identified that people experiencing homelessness faced a number of barriers in accessing palliative care, the clinical nurse educators at St Leonard's Hospice sought to proactively identify partners they could work with to address this. They approached ArcLight (now Changing Lives), a local homelessness hostel, and offered training around identifying symptoms that could limit a person's life expectancy and advance care planning. The hospice continues to offer input for the hostel, including signposting to local services and support and ad hoc advice as required. The relationship with the hostel is also two-way with a service manager from the hostel coming to train hospice staff on some of the issues that affect people experiencing homelessness and how services work to support them.

A coordinated approach to care

As the work between the hospice and hostel became better known, a local GP who is the specialist drug and alcohol GP in York approached the clinical nurse educators to discuss opportunities to be involved. Work is now under way to establish a coordinated approach to care with regular meetings to discuss and plan the care of people who are homeless and deemed to be in the last months of life. This would have a two-fold purpose. Firstly, it could identify individuals who may require end of life support and facilitate multidisciplinary conversations about their care by drawing on information from homelessness services, GPs, CCGs, specialist nurses etc. Secondly, it could take a more strategic overview of the provision of palliative care for people who are homeless.

Support from board level

A key driver behind the success of this project has been the support from the hospice's board. This work has been solely funded by the hospice, initially as part of a two-year project but it is now being more sustainably embedded within the hospice's community team. This strategic support for the work has also given the clinical nurse educators the opportunity to further develop their work in the community.

Helping to make the Government's commitment on end of life care a reality for people experiencing homelessness

As a result of the training offered by the clinical nurse educators at St Leonard's Hospice, staff at the hostel have felt more confident in supporting someone at the end of life. They have worked with them to communicate with family in line with the individual's wishes, supported the family following bereavement and were also able to ensure the funeral reflected the individual's wishes. By better being able to identify who might benefit from additional support, conversations about end of life care can happen in a more timely way to ensure people's wishes are recorded and acted upon.

Top tips from St Leonard's Hospice

- Securing support from the hospice's board of trustees can be critical in getting new projects started, and can also help this work become embedded in the way the hospice works.
- Utilising a coordinated approach to care provides a structure for multi-disciplinary work and regular reviews.
- Develop links with academic partners.

For more information, contact Alison Skelton, Lynda Ruddock or Dr Kate Flemming on:
Alison.Skelton@stleonardshospice.nhs.uk;
Lynda.Ruddock@stleonardshospice.nhs.uk
or kate.flemming@york.ac.uk

Find out more

A selection of further reading and useful resources to support people experiencing homelessness.

Further reading

Kennedy P, Sarafi C and Greenish W (2013). *Homelessness and end of life care: practical information and tools to support the needs of homeless people who are approaching the end of life and those who are bereaved*. [s.l.]. London: St Mungo's and Marie Curie Cancer Care.

National End of Life Care Programme (2010). *End of life care: achieving quality in hostels and for homeless people: a route to success*. [s.l.]. National End of Life Care Programme.

NHS England (2017). *Reducing inequality in end of life care for people who are homeless*. Dec 12, [Webinar]. Available at: <https://www.england.nhs.uk/ourwork/ltc-op-eolc/improving-eolc/resources-for-end-of-life-care/>

Pathway. *Homeless and palliative care* [Online]. URL: <http://www.pathway.org.uk/services/end-life-care-homelessness/>

Resources

Directory of homelessness services in England. Homeless Link. Search homelessness services in England [Online]. URL: <https://www.homeless.org.uk/search-homelessness-services>

Dying Matters (2011). *End of life choices: talking about end of life choices with people who are homeless*. London: Dying Matters.

A guide to support professionals in having conversations with people experiencing homelessness about end of life choices.

Dying Matters (2011). *My life, my choices: telling people what matters to me at the end of my life*. London: Dying Matters.

A booklet for people who are homeless which outlines the choices available to them at the end of their life.

Chapter 4. Personalising care for me: LGBT people

“The prevalence of ongoing discrimination and marginalisation based on sexual orientation and gender identity directly affects the health and well-being of many LGBT people. Experiencing this at the end of life can have a devastating impact. It could mean that someone will spend their last days feeling isolated, alone, angry and unwelcome. All people need to be confident about approaching services for assistance... Addressing the distinctly complex and multiple needs of LGBTQ people holds the potential to develop services that will benefit all.”

*Alice Wallace, Director,
Opening Doors London.*

LGBT people

LGBT people are more likely to have poorer physical and mental health than heterosexual people.⁸⁹ The report from Marie Curie ‘Hiding who I am’ (2016), points to research suggesting ‘that LGBT people have a higher incidence of life-limiting and life-threatening disease than people who are not LGBT. The risk of smoking and alcohol abuse is higher among LGBT people, and is attributed to stress from homophobia, discrimination and marginalisation.’⁹⁰

Discrimination has a significant impact on health and wellbeing outcomes for LGBT people. As Williams et al (2013) point out LGBT people are ‘less likely to engage with health interventions and screening programmes if they are not explicitly recognised by the service.’⁹¹ The Care Quality Commission’s review of inequalities in end of life care also highlighted the ongoing adverse impact of discrimination on ‘people’s access, needs and experience of services.’⁹²

For older LGBT people in particular, it’s important to recognise the social context of their lives. As the ‘LGB&T Companion Piece to the Public Health Outcomes Framework’ points out ‘many LGB&T older people will have come of age before the decriminalisation of homosexuality in 1967, and have lived in fear of the discovery of their sexual orientation, or censure of their gender identity expression. The implications of expressing one’s sexual orientation and/or gender identity included: imprisonment; experimental treatments, including electric shock therapy and hormone injections; losing homes and jobs; and losing relationships with friends and family.’⁹³ Isolation and loneliness are also more likely among older LGB people in comparison to heterosexuals and research shows that trans people can experience high levels of isolation.⁹⁴

A population of uncertain size

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. However, latest figures from the Office for National Statistics, indicate that around 2% of the UK population (or just over 1 million people) aged 16 and over identify as lesbian, gay or bisexual. This percentage comprises 1.2% identifying as gay or lesbian and 0.8% identifying as bisexual.⁹⁵

There are no official figures on the size of the trans population in the UK. It is estimated that there are 130,000 trans people in the UK, although probably only 40,000 have sought medical assistance to transition to live in another gender role.⁹⁶

Find out more

Acquaviva K D (2017). *LGBTQ-inclusive hospice and palliative care: a practical guide to transforming professional practice*. New York: Harrington Park Press.

Almack K, Yip A, Seymour J, Sargeant A. et al (2015). *The Last Outing: exploring end of life experiences and care needs in the lives of older LGBT people: a final report*. Nottingham: University of Nottingham.

Marie Curie (2016). *Hiding who I am: the reality of end of life care for LGBT people*. London: Marie Curie.

National Council for Palliative Care and LGBT Consortium (2011). *Open to all? Meeting the needs of lesbian, gay, bisexual and trans people nearing the end of life*. London: National Council for Palliative Care.

End of life care

Choice is at the heart of LGBT inclusive care. As Acquaviva (2017) points out ‘unless palliative care and hospice providers make a conscious choice to engage in LGBTQ-inclusive practice, they are, by default unintentionally choosing to exclude LGBTQ people from receiving the high-quality care that all people deserve.’⁹⁷

It is not enough to say that all service users are treated equally because this fails to acknowledge different needs. In her foreword to Marie Curie’s report on end of life care for LGBT people (2016), the journalist and broadcaster Sandi Toksvig remarks that ‘many health and social care professionals say that they treat everyone the same. This

is well intentioned. However... sometimes for everyone to be equal, differences need to be acknowledged and given space to be celebrated’.⁹⁸ The point is echoed by Acquaviva in a reminder that ‘being inclusive is not the same as treating everyone the same. In fact, treating everyone the same is an approach that rarely benefits patients, regardless of whether they are LGBTQ, because patients aren’t all the same.’⁹⁹ There is clear evidence that end of life care service providers are committed to the principle of treating everyone with equal dignity, respect and worth, however, this doesn’t mean that a person’s sexual orientation or gender identity is irrelevant to the delivery of fair treatment.¹⁰⁰

Providing personalised care to LGBT people is not necessarily about creating bespoke services, rather it requires that ‘health-care professionals may need to think carefully, and perhaps a little differently, to ensure equity in care delivery’ (Bristowe et al, 2018).¹⁰¹ Outlining simple and effective measures to put into practice, this chapter provides insights from seven organisations which are working to enable personalised care for LGBT people.

The care I provide...

- is consciously inclusive
- is based upon open and sensitive communication
- acknowledges and involves an individual’s partner or chosen family
- recognises and celebrates diversity.

The care I commission...

- actively considers the needs of LGBT people
- is based upon equalities monitoring data
- embeds sexual orientation and gender status monitoring
- encourages engagement with local LGBT communities.

Recommendations to improve care for LGBT people

'Simple changes to practice could markedly improve care experiences for LGBT people, including avoiding heterosexually framed, assumption-laded questions; sensitivity in exploration of identity; careful exploration of intimate relationships; and explicit inclusion of partners or significant others.'

Bristowe et al (2018) ¹⁰²

As the first national study to explore in depth the experiences of LGBT people facing the later stages of life-limiting illnesses, the ACCESSCare project has identified ten simple and low-cost recommendations to improve care.¹⁰³

10 recommendations to improve care for LGBT people facing advanced illness

Individual level

1. Avoid using heterosexually framed or assumption-laden language
2. Demonstrate sensitivity in exploration of sexual orientation or gender history
3. Respect individuals' preferences regarding disclosure of sexual identity or gender history
4. Carefully explore intimate relationships and significant others, including biological and chosen family (friends)
5. Explicitly include partners and/or significant others in discussions

Service/institutional level

6. Make clear statement of policies and procedures relating to discrimination
7. Include content regarding LGBT communities in training on diversity and discrimination
8. Increase LGBT visibility in materials (in written content and images)
9. Provide explicit markers of inclusion (e.g. rainbow lanyards or pin badges)
10. Initiate partnerships and/or engagement with LGBT community groups.

Reproduced from: Bristowe K, Hodson M, Wee B, Almack K, Johnson K, Daveson B A, Koffman J, McEnhill L, Harding R (2017). Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. Palliative Medicine, 32(1): 23-35. <https://doi.org/10.1177/0269216317705102> Published by SAGE Journals.

The ACCESSCare project

ACCESSCare aimed to improve demand for, and supply of palliative care for people who identify as lesbian, gay, bisexual and/or trans (LGBT) and are in the later stages of a life-limiting illness. This joint project was led by King's College London with the University of Nottingham and the Gay Men's Health Charity (GMFA). ACCESSCare ran from 2014 to 2016 and it was funded by Marie Curie. For more information visit: <https://www.kcl.ac.uk/nursing/departments/cicelysaunders/research/living/access/index.aspx>

The case studies that follow show these recommendations in practice in the delivery of personalised care.

Helping to make the Government's commitment on end of life care a reality

*"When facing advanced illness, there is a need for person-centred care, to ensure preferences and priorities for care and decision-making are met."*¹⁰⁴

ACCESSCare study

Good quality, personalised end of life care requires commissioners, service providers and healthcare staff to consider the needs of LGBT people in planning and delivering care. It is not enough to say that all service users are treated equally because this fails to acknowledge different needs. As the ACCESSCare study points out, when 'facing advanced illness, there is a need for person-centred care, to ensure preferences and priorities for care and decision-making are met.'¹⁰⁵ This care is characterised by open and sensitive communication by health and care staff about sexual orientation and gender identity. It's recognisable by its enablement of candid discussions about needs and preferences, which in turn supports informed decision-making and care-planning.

The case studies presented here provide practical examples of ongoing work to deliver care and support that helps make the Government's commitment on end of life care a reality.

Creating the space for communication

The befriending scheme at Opening Doors London is helping to bring about honest discussions about an individual's needs and preferences for their physical, mental and spiritual wellbeing, and so helping people to live well until they die.

Background

Opening Doors London [ODL] is the largest provider of information and support services for

older lesbian, gay, bisexual and trans [LGBT] people in the UK. They exist to let all older LGBT people in London and beyond know that they are not alone. ODL aims to ensure that older LGBT people live happy, healthy and independent lives that are free from loneliness, isolation, prejudice and discrimination. They want all older LGBT people to have access to the right information so that they can make informed choices about their own care.

Supporting older LGBT people with end of life care

ODL frequently provides support to members reaching the end of their life via a Befriending Service. All befriending volunteers have a realistic understanding of the befriending pathway, including having to deal with the death of a client. ODL ensure that volunteers have access to appropriate support so they can have honest discussions with clients about their care needs and preferences, can involve those important to them in all aspects of their care and know who to contact for help with emotional and practical support.

Often a client will have been referred or self-referred because they are isolated and lonely, perhaps following the death of their partner. They might have health issues which means that they are not able to get out and about, so having a volunteer visit them regularly is incredibly important to them. Sometimes, the volunteer can encourage them to become more active.

Frequently volunteers are asked for advice or information. The Befriending team are able to refer to local organisations where they will be able to access information and support in order to make the decisions required. This might include making a power of attorney and/or living will, writing a will, or accessing supportive palliative care.

As a client's health deteriorates the ODL Befriending Service will ensure, where possible, that clients continue to receive visits from a volunteer. Sometimes a client is referred to ODL by social services, a healthcare provider or a hospice, when they know that the

person is dying. ODL does all it can to ensure the person has the support they need at the end of their life.

Working with other organisations

ODL have built good working relationships with many local authorities across London, particularly Adult Social Care Teams. Relationships are maintained by regularly mailing out publicity, leaflets and referral forms to Adult Social Care, Housing Teams, Occupational Therapists, GP Surgeries, libraries and LGBT Police Liaison Officers – anywhere that older LGBT people might visit.

Talks have been given to various organisations about the work, including social service teams, local Age UKs and other organisations providing services to older people. These relationships have proved extremely successful in generating awareness of the ODL Befriending Service and reaching out to the more isolated and vulnerable members of the older LGBT community. ODL regularly receive emails and telephone calls from referrers wanting to chat about particular clients, before they make the referral. All this helps to ensure those LGBT people who are approaching the end of their life have support mechanisms for them to be themselves to the very end.

Real-life evidence

Trevor,¹⁰⁶ a gay man in his eighties, was referred to the Opening Doors London Befriending Service by his Social Worker. Trevor had recently returned home from having cancerous tumours removed from his stomach. Although the tumours had been removed he still had cancer in his lung for which he had received a terminal diagnosis.

Until his cancer diagnosis Trevor had been very independent and lived alone for many years. He went to the gym regularly and was very socially engaged. He lives on an upper floor of a Housing Association property with no lift to the property. After his surgery, Trevor found himself at home convalescing alone – with several flights of stairs it was impossible for him to leave his home.

His Social Worker spoke to him about the work of ODL and a referral was made to the Befriending Service. Before the ODL Befriending Coordinator visited Trevor, his Social Worker related that because he had been so fiercely independent most of his life he was quite reluctant to admit that he now needed some support. Trevor informed the ODL Befriending Coordinator that since becoming ill his world had suddenly become very small and he was now spending all day everyday alone apart from the visits from his Community Nurses. He said he was feeling lonely and distant from the outside world.

Initially, the ODL Befriending Coordinator worked with Trevor himself, in order to build a relationship created on trust and also to get him used to the idea of a Befriender visiting regularly. A Befriender was placed with Trevor within a couple of months who visited weekly. The Befriender supported Trevor throughout a period of chemo, which Trevor said had made all the difference.

He said, 'You cannot imagine what a difference it made to have a friendly face come visit me and allow me to talk through everything I was feeling, which wasn't always positive, over a cup of tea. It was a huge distraction from the awful treatment I was going through'.

The relationship has enabled a good working relationship with Trevor's Social Worker and Housing Association, which has been invaluable in ODL being able to support the client in accessing all the services that have improved his personalised care, including his living conditions and day-to-day support at home.

Recently, Trevor began to receive palliative care at home. His relationship with his Befriender continues, and the Befriender recently informed the ODL Coordinator that he had spent a lovely evening at Trevor's home whilst Trevor read him some of his love letters from an old lover. The Befriender said that Trevor became very emotional whilst reading the letters but had said what a joy it was to be able to share them with the Befriender.

Trevor is now approaching the end of his life. He is becoming very disorientated and feels he is no longer able to complete simple tasks like laying the table. He finds this very upsetting and frustrating as his independence is fading.

Working with ODL's Befriending Coordinator Trevor talked about the importance and relevance of the ODL Befriending Service. He was so grateful for his Befriender and doesn't think he could have got through this period without his smiling friendly face turning up at his door once a week for a chat and a cup of tea.

Helping to make the Government's commitment on end of life care a reality for LGBT people

ODL's befriending service supports people in having honest discussions about their care needs and preferences, helping them to involve those important to them in all aspects of their care and to know who to contact for help with emotional and practical support.

Top tips from Opening Doors London

- Be open to discussing anything the person may wish to talk about – there is often a lot of reminiscing and memories of past loves, etc.
- Provide an LGBT befriender to support people who may be isolated as they often feel more comfortable opening up to another LGBT person.

For more information about Opening Doors London, go to www.openingdoorslondon.org.uk

Royal Trinity Hospice

Royal Trinity Hospice explain here how they are increasing staff ability to proactively deliver more inclusive services and ensuring LGBT service users can develop personalised care plans and feel listened to when determining the right care for them.

"Royal Trinity Hospice prides itself on providing specialist patient centred palliative and end of life care, this is only possible if we recognise and celebrate diversity and seek to be accessible and inclusive of all those who need us, and of the staff and volunteers who work for us, regardless of their personal characteristics. I am delighted that Trinity is leading the way and working with other London hospices to improve the experience of LGBT people in hospice care."

Dallas Pounds, Chief Executive

Background

Royal Trinity Hospice is a leading provider of end of life care in Central and South London, aiming to be the local hospice of choice for all those who need them. As part of their equality and diversity work, Royal Trinity Hospice recognised that individuals from specific communities, including LGBT people, may inadvertently feel excluded and isolated when accessing services. To achieve their desire for truly great care for all, the hospice wants to be actively inclusive and treat everyone as individuals. So, they set out to put their heads above the parapet, reach into the local LGBT communities and open a conversation on how they could be more LGBT inclusive and support people to make informed choices.

Being LGBT Inclusive

Royal Trinity Hospice has pioneered a number of practical actions to address barriers LGBT people may face and help maintain an LGBT-friendly focus:

Staff engagement and internal work

The hospice collects a range of demographic information but realised early on that information in relation to sexual orientation and gender identity wasn't always collected. Setting out to change this practice, both sexual orientation and gender identity are now captured, helping to build a complete picture of their staff and patient base. This information means Royal Trinity Hospice can better understand staff and patient needs and ensure everyone counts and is counted within all their work.

As part of their efforts to consider LGBT needs, Trinity also reviewed their internal policies and procedures to ensure they are actively inclusive of LGBT people and take account of any specific needs. Alongside this, the hospice has invited in LGBT organisations and individuals to provide staff awareness training, increasing staff ability to proactively deliver more inclusive services and ensure LGBT service users can develop personalised care plans, feel listened to when determining the right care for them.

The internal work has helped the hospice with becoming a Stonewall Diversity Champion, a benchmarking programme tool for employers to measure progress on LGBT inclusion in the workplace. Royal Trinity Hospice were the first hospice in the country to sign up to this scheme and it now forms part of their regular equality and diversity planning.

The care environment

Trinity recognise that to be inclusive you need to be visible with that inclusivity and efforts are made to ensure staff, patients and visitors can see this in action. This has included rainbow pins for staff to wear if they choose and rainbow stickers being placed within the hospice - both clear visual indicators and recognisable to LGBT people and communities.

Community engagement

Engaging with the local community has helped Trinity build a successful LGBT Friends Group, with particular links forged with their local Wandsworth LGBT Forum. The Group meets regularly and gives opportunities to explore issues surrounding death and dying in an open and honest environment, also allowing discussion around how services and communications can better support and engage LGBT people and communities. Importantly, it also affords the right environment for the Group to discuss areas for improvement or to identify learning from issues that have arisen.

Trinity were also the first hospice to march at Pride in London back in 2014 to further increase their visibility to LGBT communities and now helps lead a group of London hospices in the annual parade.

Helping to make the Government's commitment on end of life care a reality for LGBT people

Royal Trinity Hospice now have a reputation for being inclusive and find they have staff wanting to come and work at the hospice because of its LGBT inclusion programme, building a team that is able to provide appropriate help and advice needed by LGBT service users.

Through their engagement with local LGBT communities, further barriers to inclusion have been identified, enabling Trinity to embed LGBT inclusion within their work rather than see it as a one-off action, helping LGBT people feel confident in talking about their personalised care needs.

Some staff at Trinity were wary to begin with as to why the hospice was singling out LGBT people but over time staff have understood that LGBT patients may have specific needs and in order to treat those patients as individuals, a greater understanding and knowledge-base was needed. It has helped Trinity to provide the best care possible for LGBT patients without those patients worrying whether their sexual orientation or gender identity will be a barrier for them to have honest discussions with care professionals about their individual needs. Working for LGBT inclusivity has also opened up a better appreciation of equality, diversity and inclusion across the hospice, for all communities and people.

Top tips from Royal Trinity Hospice

- Demographic data collection: It is important to collect data on sexual orientation and gender identity to build a better picture of your client and staff base. Stick with it so that information on these characteristics becomes normalised and just part of the picture
- You may have low numbers of LGBT staff in your organisation, but ensuring you support them to be their true selves will reap benefits for the organisation and those who use it. Consider joining a network for support
- You will get it wrong sometimes – use of language or an image perhaps – just acknowledge it and find an alternative. Links with your local LGBT Forum will help
- Don't expect all your staff 'to get it'. Be tenacious and demonstrate how crucial inclusion is for all people and for them.

Training for culturally competent care

The ACCESSCare study found that LGBT people's experience of clinical care can be 'negatively affected by interactional (created in the encounter) and service-level barriers and stressors.' As these experiences may also be 'positively affected by interactional and service-led facilitators, the research team highlight the importance of training for health and social care professionals.¹⁰⁷

Saint Francis Hospice in Romford have developed a training module which provides health and social care professionals with a unique opportunity to explore the impact of sexual orientation and gender identity on palliative and end of life care. It also offers the space to reflect on and identify ways of creating LGBT-inclusive care.¹⁰⁸

"People accessing health services should not have to worry about being treated fairly and with respect, let alone when they are dying or facing advanced illness. Given the long-standing history of discrimination and stigmatisation amongst the LGBT community, it is no longer enough to say that we do not discriminate and that we treat everybody the same. If we are to provide individualised care in line with the philosophy of palliative care, then it is our responsibility to ensure that we proactively engage with this community. We anticipate that this module will help health and social care professionals to recognise, understand, and respond to the unique needs of LGBT people within a palliative care context. We also envisage that this module will inform future activities which will further support the development of an inclusive culture within palliative and end of life care services."

Claude Chidiac, Lecturer in Palliative Care, and Programme Director of Palliative and End of Life Care.

Background

In response to the report published by Marie Curie,¹⁰⁹ and the thematic review from the Care Quality Commission on inequalities in end of life care,¹¹⁰ Saint Francis Hospice in Romford set out to develop a training module for health and social care professionals providing palliative and end of life care for LGBT individuals. The training module became embedded as a core unit on the BSc Nursing programme, and the interdisciplinary MSc Palliative and End of Life Care course, and it is hoped that other universities will adopt similar approaches.

Being LGBT inclusive

Individuals providing palliative and end of life care may have first-hand experience of the challenges and barriers LGBT people face and so can be passionate about creating positive environments so LGBT people feel safe in having honest discussions with care professionals about their needs and preferences. The development of staff and

student training is helping to make this a reality for all.

Training module

Led by Claude Chidiac, Lecturer in Palliative Care, and Programme Director of Palliative and End of Life Care, the team developing the training module had already identified and reviewed the range of data on LGBT palliative care but were conscious of the need to translate theory into practice, and provide training that is aimed at changing attitudes and beliefs. With knowledge of a similar activity in Ireland, Claude Chidiac had a discussion with one of the project leads in Ireland to get a sense of what worked well and what could be improved, applying this to their own training development.

The training has been designed to be as interactive as possible, with changing attitudes and beliefs at its heart. Discussions and roundtables are used as a tool for people to share their knowledge, and experience in a supportive environment, allowing participants to ask the right questions to help with their own development.

Pilot sessions and evaluation

Training has been piloted across several hospices, with more than 140 health and social care professionals participating. As part of the training, both pre- and post-session questionnaires were completed, with questions focussed on attitudes and levels of knowledge, comfort and confidence in addressing LGBT issues and will be used to help inform an evaluative report on the project. It is hoped the learning from this will help other providers to take action and start working towards an LGBT inclusive service delivery environment, so helping to make the Government's commitment on end of life care a reality for LGBT people.

Part of a wider picture

The development of an LGBT specific training module is just one activity in a series of work the hospice is undertaking to ensure LGBT people can have honest discussions about their needs with those caring for them. The next steps for the hospice will involve an audit

of their documents, policies and physical environment, helping create a wider cultural change within the organisation.

As part of the hospice's Widening Access Management Group, they have also included sexual and gender minorities as a specific area to focus on, with a staff lead having oversight and reporting responsibilities.

Helping to make the Government's commitment on end of life care a reality for LGBT people

A system that creates a safe environment for LGBT people to have honest and open conversations about their personal care needs and preferences is at the heart of the work Saint Francis Hospice is undertaking. Focussing on the development needs of their workforce will ensure everyone providing care feels confident and is equipped with the skills, knowledge and tools to discuss personalised care and help LGBT people make informed choices about their care.

Top tips from Saint Francis Hospice:

- Identify an external or internal 'go to' person who has knowledge and expertise in LGBT issues and needs
- Establish a 'go to' point within your organisation for staff and LGBT service users to approach with any questions in relation to LGBT issues. Do ensure that this person is happy to take on this role and that you advertise this role publicly. Involve as many people as you can within your organisation to make the change happen.
- Don't worry too much if everyone isn't responsive straight away. Change takes time and as you embed LGBT inclusive work if people can see positive change they are more likely to engage with it.
- A whole system approach is needed to be able to respond to the unique needs of LGBT people.

For more information on Saint Francis Hospice visit www.sfh.org.uk

An embedded approach across the organisation

This case study from Wigan and Leigh Hospice shows how an LGBT-inclusive approach is being embedded across the organisation. The Top Tips also highlight the importance of building links with local LGBT organisations; engaging with local LGBT groups is recommended as a means of improving care for LGBT people facing advanced illness and a knowledge of local LGBT friendly services means that professionals can signpost people to appropriate support services.¹¹¹

"If something is finite, people are far more likely to forget about it. Keeping LGBT issues on the agenda, in a manageable way, will mean people keep talking about it and it becomes part of daily working life."

Rebecca Lennon, Project Lead

Background

Wigan and Leigh Hospice are undertaking a long-term strategy of being more LGBT-inclusive thanks to a project which helped understand the issues their LGBT staff, patients and carers face when using the hospice's services. The project also explored service development ideas with staff and external stakeholders to develop accessible and inclusive palliative care for LGBT patients and their carers, helping make the Government's commitment a reality.

Being LGBT inclusive: local links

In order to create something that was going to be long-lasting, the hospice set up a multi-disciplinary group including medical and nursing staff, communications manager, volunteer chaplain, and external representation from the local LGBT community. Expert advice was also sought from other experts in the field, including the LGBT Foundation, LGBT Cancer Support Alliance and Marie Curie. This diverse pool of expertise enabled the hospice to confirm the need for LGBT inclusion work and with the support of the group produce a set of initial actions, including a literature review, service audit and staff survey.

Everyone engaged

During the project, staff explored how they felt about doing specific work around LGBT issues and there was overwhelming support for it. The process involved staff from across all levels of the organisation, giving everyone better opportunity to feed into the process and raise their questions, concerns and suggestions. This approach has set the tone for embedding LGBT issues into the work of the hospice with everyone knowing there is a safe environment to raise questions and queries, resulting in a working environment where staff can be confident in having the discussions needed about LGBT patients' own care needs and preferences.

Understanding specialist needs

As part of the project the hospice undertook a service audit and staff survey to increase their knowledge of where the organisation was at. Using an online toolkit from LGBT Health and Wellbeing (an LGBT charity in Scotland), and questions from Marie Curie's own survey, the confidential staff survey achieved a 62% return rate, highlighting positive support across the staff team. As a result of these project elements, 25 recommendations were put forward by the multi-disciplinary group for the hospice to consider. These have been summarised in to six core areas:

- 1. Education:** On both LGB and Trans issues
- 2. Resources:** Accessible and relevant materials available for staff and patients
- 3. Support:** Safe Space commitments to ensure all staff and patients feel safe and supported
- 4. Monitoring:** Increasing knowledge of LGBT population in hospice
- 5. Visibility:** Making LGBT inclusion visible throughout the hospice
- 6. Sustainability:** Creating long-term relationships and embedding best practice.

Getting it right

With 25 key recommendations for the hospice to consider, implementation in the right way is critical. The hospice is viewing implementation as part of a five-year plan to keep it firmly on the agenda and part of wider hospice development rather than being a standalone issue to tackle. Responsibility lies with the Clinical Director so there is leadership on implementation from the top of the organisation.

Using a longer-term approach will also allow the hospice to gain further knowledge and expertise on LGBT issues and ensure they can offer the best care possible for LGBT individuals. The hospice recognises that change cannot happen overnight and it was important that the bedrock of education around LGBT issues is in place ahead of more in-depth work such as data monitoring and safe space commitments.

Top tips from Wigan and Leigh Hospice

- Having a mix of working roles in the development of specialist issues yields the best results. It has made the process more inclusive, with buy-in at all levels.
- Reaching out to the local LGBT community can take time but keep at it. Most are volunteers and run their organisations in their spare time but are likely to want to help. Building those strong local links helps with long-term planning.

Embedding care, visibly

Accessible and sensitive services are essential to enabling people to have choice and control about their care and support. Concerns that they are not welcome or will be treated poorly mean that LGBT people access palliative care services late or not at all.¹¹² This highlights the importance of providing services which are explicitly LGBT friendly so that people feel comfortable and safe.¹¹³ The recommendations

to improve care for LGBT people facing advanced illness (ACCESSCare, 2018) call for services to increase LGBT visibility in materials (for both written content and use of images), as well as providing explicit markers of inclusion (such as rainbow lanyards or badges).¹¹⁴ The importance of visibly demonstrating that the hospice is inclusive is highlighted in the 'top tips' from Woking and Sam Beare Hospices as part of their holistic and inclusive approach to personalised care.

"Reaching out to underrepresented groups and being more inclusive is a priority for us and we are keen to develop further contacts with other organisations working with people who identify as LGBT and who want to work in partnership. We cannot achieve a fully inclusive end of life sector on our own – there is strength and power in collaborative efforts."

Caroline Hodgson, Social Work Lead.

Background

Woking & Sam Beare Hospices' services are primarily community-based (70%) with more than 600 patients, their partners and families being cared for at one time. The hospice has been working hard to reach out to seldom heard groups, including those who identify as LGBT, ensuring that learning and development is embedded throughout the organisation so LGBT patients can be confident their informed choices are listened to and respected by their care-givers.

Being LGBT inclusive: a holistic approach

The hospice has found the best approach to LGBT inclusion is to ensure LGBT people are considered and engaged with, alongside other minority groups, across each area of service delivery and development. From operational delivery planning to education and support for team members to be sensitive and recognise an individual's needs, the hospice takes a whole organisation approach to embedding equality and diversity. The hospice also undertakes equality impact assessments when considering any additional projects or services to ensure equality and diversity remains a central thread.

LGBT expertise

Strong links have been developed with local LGBT organisation Outline, which provides support and information to LGBT communities in Surrey. LGBT training has been sourced from Outline and delivered to the staff team. Through the training developed, awareness and understanding of LGBT clients, communities and issues have been discussed, establishing an open and honest environment for the team to talk about these issues and feel properly supported. The hospice and Outline have also worked together to develop a Safe Space for people who identify as LGBT and their partners/families, providing access to the right help and advice so personalised care can be delivered in a seamless way.

An open environment

The hospice strives to consistently build on what has already been achieved and is well aware there is always more than can be done. Staff have been fully supported to become actively aware of the unconscious bias that they may carry and to recognise the importance of equality and diversity. Staff are encouraged to be curious and ask questions to keep people wanting to learn more. The Executive team within the hospice also continue to work to make the public face of the hospice more welcoming to people from LGBT communities.

Work in practice

As a result of the work to ensure LGBT clients are considered throughout the organisation, a positive example highlights how this is put into practice. The hospice's community team worked with a trans woman who had been admitted into hospital from home and was being mis-gendered. She then moved to a nursing home where she continued to be mis-gendered. The community nurse discussed with the client how she felt very depressed. Due to the open environment created by the community nurse, the client felt able to explain that she had been living as a woman for over a decade, yet institutions continued to mis-gender her. The community nurse worked closely with the nursing home

to support the trans woman in her assigned gender, including assurance that all her notes referred appropriately to the correct gender. The community nurse was also supported by a senior member of the hospice team to aid their general trans knowledge and make connections with local support for trans people.

The patient reported she was so much happier following this intervention and was able to enjoy her remaining time.

Top tips from Woking & Sam Beare Hospices

- Visibility is an important consideration: on your website, within information literature and in welcome packs – will LGBT people feel included just by looking?
- Inviting local LGBT people and communities to be part of the equality and diversity development process, and in the internal engagement processes (e.g. service users group) helps to create an open and inclusive hospice environment

For more information on Woking & Sam Beare Hospices visit www.wsbhospices.co.uk

Information for informed choices

"We know that people from LGBT communities experience barriers to accessing end of life care. While most people have an opinion about how they want to be treated at the end of life, there was previously no LGBT specific information on how to think about, and plan for this. At Compassion in Dying we believe everyone should have access to information about their rights to plan for their treatment and care. We also believe this information should feel relevant to each individual, addressing their concerns, and supporting them to make plans in line with their values and beliefs. Our booklet, 'Your treatment and care: planning ahead for the LGBT community' was written specifically for this reason."

Jennifer Noel, Information and Partnerships Lead, Compassion in Dying

Clear and accessible information to support decision making is key to the Government's end of life care commitment. The LGBT community can face specific and significant barriers which prevent them from getting the end of life care they want. This may include healthcare professionals making assumptions about preferences for care and a lack of understanding about what or who is important to LGBT people. As the first of its kind in the UK, a booklet published by Compassion in Dying enables people to let those responsible for their care know what and who is important to them and helps to ensure that a person's wishes are followed.

Background

Compassion in Dying is a charity helping people to plan so that their wishes and values are known, and that they receive the end-of-life care that is right for them. Through their Big Lottery funded My Life, My Decision project, Compassion in Dying produced materials for less heard groups to ensure that the information created was relevant and accessible to diverse faith and BAME groups, and LGBT communities. The information produced included a booklet for LGBT people focussing on how to record their preferences for treatment and care called 'Your treatment and care: planning ahead for the LGBT community'.

Making informed decisions

Compassion in Dying were aware that whilst several publications existed which were aimed at healthcare professionals working with LGBT people at the end of life, there were no similar publications aimed at helping LGBT people plan ahead for the end of the life and dealing with the issues specific to them. Research for the booklet identified some specific needs of LGBT communities, including

issues surrounding next of kin and significant others. As such, this publication explores these areas in relation to the Mental Capacity Act and the tools available for recording people's preferences for treatment and care, and for legally appointing someone to make decisions on their behalf. All this enables LGBT people to make informed choices and decisions, supported by clear and accessible information on quality and choice in end of life care, with further information provided on who to contact for further help and advice when needed.

Being LGBT inclusive

- Co-production. Compassion in Dying worked in partnership with Opening Doors London (ODL), a leading LGBT charity with expertise in older LGBT people's issues, throughout the research and development of the publication. Meetings were held with ambassadors from ODL to discuss the needs and values of older LGBT people and what, in their experience, should be included in a publication aimed at helping LGBT people to plan for their future treatment and care. Drafts were also shared with Stonewall, another leading LGBT charity, for feedback.
- Being LGBT-specific. The illustrations and case studies throughout the publication are LGBT-specific, with people from LGBT communities contributing to the development of the booklet throughout the production process. Their input ensured that the real-life examples would resonate with the LGBT community, and that they would be able to identify with the accompanying illustrations.
- Promotion. An on-going working relationship with Opening Doors London means the publication keeps a firm footing within a specialist LGBT organisation and retains further dissemination channels.

Top tips from Compassion in Dying

- Don't make assumptions about someone's LGBT identity or next of kin. Ask questions to understand who is important to that person and should be included in decision-making, what a person prefers to be called, what pronoun they use, and anything else which matters to their identity. Agree with them how this information will be shared across your service to ensure that they do not need to explain this more than once, or in case they would like to keep the information confidential from their family
- Have a range of publications visible to immediately signify that your service is LGBT-friendly. This could include posters and booklets which are available from a wide range of sources.

Sharing good practice

Enabling LGBT people to feel safe and confident in discussing and planning the care they need to live well until they die is at the heart of the newly established London Hospices LGBT Network. The Network aims to promote equality, diversity and inclusion of LGBT people, provide leadership, support and education for all staff and volunteers on relevant LGBT issues, and raise awareness of hospice care in LGBT communities.

"The London Hospices LGBT Network wants to help develop and support hospice care that is truly accessible and inclusive for LGBT people and their families, and to allow LGBT staff to be themselves at work so they can be the best they can be and deliver excellent care."

Dallas Pounds, Network Chair

Background

The London Hospices LGBT Network launched in October 2017 as a partnership of 13 London hospices, having been founded to improve access to palliative and end of life care for LGBT people and better support for LGBT hospice staff and volunteers.

Being LGBT inclusive

Individual hospices are already undertaking a range of work around LGBT inclusivity, but the Network offers unique opportunities to share these examples of good practice and organically develop initiatives that go far beyond any one organisation. Although only recently launched, it has plans to develop a series of work streams in the hope of getting the message out that hospices aren't places to fear, either as a service user or a member of staff. Some of the work in development includes:

- **Sharing best practice**

Each organisation will have its own policies, practice and procedures, however, the Network recognises that there are some common threads to these, such as the use of language, where guidance might be of benefit. Through sharing of resources and working practices, benchmarks can be established and collective expertise can ensure that very best practice occurs across all hospices in the Network, so LGBT people feel safe and confident in having the discussions they need to live well until their die.

- **Training and events**

The Network has already held a launch event in late 2017, drawing together representatives from hospices, palliative care, researchers and other voluntary sector organisations. It is hoped further events and training sessions will be developed to increase knowledge and expertise around the issues and barriers LGBT people face when accessing end of life and palliative care and identify further ways of providing personalised care plans and providing access to the right help and advice.

- **Peer support**

Having a safe environment in which to share ideas, concerns and talk through complex issues is a vital part of everyone's individual development. The Network will look to provide peer support and leadership to hospice workers across London so staff can feel more confident in delivering high quality care to all LGBT individuals.

Top tips from London Hospices LGBT Network

- Don't think about special services for LGBT people, but more about how to make existing services accessible and inclusive
- Lessons learned from considering LGBT people are transferable for all protected characteristics: it's about equality, diversity and inclusion
- If you think your organisation is delivering great care because you treat everyone the same think again – we are not all the same!
- The use of language within communities can change, and the 'ownership' of terms can be complicated – check it out before you use it
- Your staff will give you the most if you support them to come to work as the best selves they can be.

For more information about the London Hospices LGBT Network contact Dallas Pounds on dpounds@royaltrinityhospice.london

Find out more

A selection of further reading and useful resources to support LGBT people.

Further reading

Knocker S, Smith A [n.d.]. *Safe to be me: meeting the needs of older lesbian, gay, bisexual and transgender people using health and social care services: a resource pack for professionals*. London: Age UK.

This resource guide offers practical advice on providing the kind of service in which older lesbian, gay, bisexual or transgender (LGBT) people can feel safe to be themselves.

Marie Curie. *Caring for LGBT people at the end of life* [Online]. URL: <https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/equality-diversity/lgbt-end-life#I6KI5H5EyuS5kIES.97>

Part of the Palliative Care Knowledge Zone, this information is intended to help healthcare professionals be aware of end of life care issues for LGBT people.

St Helena Hospice, University of Nottingham, National End of Life Care Programme (2012). *The route to success in end of life care: achieving quality for lesbian, gay, bisexual and transgender people*. [s.l.]. National End of Life Care Programme.

A practical guide for practitioners to raise awareness of the unique issues faced by LGBT people and how these can impact on end of life care.

Together for Short Lives and The Open University (2016). *Talking about sex, sexuality and relationships: guidance and standards for those working with young people with life-limiting or life-threatening conditions*. Milton Keynes: The Open University, 2nd ed.

This guide sets out principles, guidance and standards for health, social care and education practitioners who support young people with life-limiting and life-threatening conditions. It aims to help break down taboos and enable professionals to gain skills and confidence in exploring sexuality for these young people safely and legally.

University of Nottingham and National Council for Palliative Care (2016). *Being accepted, being me: understanding the end of life care needs for older LGBT people: a guide for health and social care professionals and carers*. London: NCPC.

This guide is intended to help health and social care staff and volunteers to learn more about listening, understanding and responding to the unique needs of LGBT people.

Resources

ACCESSCare (2017). *Palliative and end-of-life care for LGBT people: a guide for lesbian, gay, bisexual and / or trans people facing advanced illness*. London: [ACCESSCare].

This booklet is designed for people who identify as LGBT and are facing advanced illness, and those close to them. It aims to help individuals to think about: why sexual orientation or gender identity may be important in relation to care needs; the care individuals are entitled to receive; what to do if you think you have been discriminated against because of your sexuality or gender identity; where to go for more help and information.

Compassion in Dying (2016). *Your treatment and care: planning ahead for the LGBT community*. London: Compassion in Dying.

A booklet providing information for LGBT communities on thinking about and recording their wishes. Produced by Compassion in Dying in collaboration with Opening Doors London.

Summary

Sharing learning from a range of approaches including outreach models, training programmes and information resources, along with insights from the research literature and lived experiences, this project highlights a variety of work which is under way to improve access to personalised end of life care for Gypsies and Travellers, LGBT people and people experiencing homelessness.

The case studies presented here, considered alongside feedback from the workshop and focus group underline five key principles which are critical to success. These principles are:

1. Good communication which includes engaging with people in a way that is meaningful for the individual and so enables people to make informed decisions about their care.
2. An approach founded on dignity and respect, and investing in a relationship of trust.
3. The provision of workforce training and support.
4. Enabling partnership working at a strategic level.
5. Recognising that people are all different so inclusive, equitable care is not about treating everybody the same way.

Furthermore, the case studies demonstrate a requirement for strategic ongoing commitment with support from senior management, and continuity measures to ensure the work remains visible and present should critical staff members leave the organisation.

It is also clear that although there are commonalities (for example, in terms of a need for better data and in support of collaborative cross-sectoral working), there may be different emphases in the design and delivery of personalised care to support a reduction in inequalities in end of life care.

This is evident, for example, in the call for the provision of culturally aware care for Gypsies and Travellers, whilst for people experiencing homelessness a parallel planning approach which accommodates complexity and uncertainty may be a way forward.

Wider observations

This project also highlights wider observations for the system, services and knowledge base.

Better evidence base

Whilst there have been recent and hugely welcome insights from research into end of life care for people experiencing homelessness and LGBT people which also explicitly support the implementation of knowledge into practice, the literature review highlights the paucity of end of life care research overall for the three groups, and most especially in meeting the end of life care needs and models of care to meet the needs of Gypsies and Travellers.

This challenge was also apparent across all three groups when seeking to understand the experiences of children and young people.

More priority at local levels

This publication highlights some of the great work that is going on around the country to support the provision of good, personalised end of life care for people of all ages who may be less likely to receive good care because of their ethnic background, sexual orientation, gender identity or social circumstances.

However, more needs to be done at local levels. It is essential that end of life care needs for the whole population, including the groups covered by this report, are included in Joint Strategic Needs Assessments, and that tackling inequalities in end of life care is identified as an action in local Health & Wellbeing Strategies. As a means of local NHS organisations and councils working together

to improve NHS services and outcomes for people in their area, Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) can help make sure that local end of life care is made as effective and efficient as possible, so that people everywhere get the care they need wherever they are. STPs are required to take account of the Government's end of life care commitment¹¹⁵ and guidance published by Hospice UK (2017) gives advice about asking what the local STP is doing on end of life care. This includes asking if it has 'thought about the needs of the whole community it serves... What has it done to make sure that people whose needs are often overlooked, for example homeless people, people from ethnic minority backgrounds, or older people living alone, get the end of life care they need?'¹¹⁶

Meanwhile, research from Together for Short Lives shows that only a third (35%) of CCGs are implementing the Government's end of life care choice commitment for children. A further 19% stated that their plans to do so are in development. This means that nearly half (46%) of CCGs currently have no formal plans to meet the choice commitment.¹¹⁷

Stronger data

We need to know more about who needs and who uses care. Better and stronger data to inform commissioning and service development emerges as a key cross-cutting theme. For example, for Gypsy and Traveller communities information needs include data on accommodation status, ethnicity and age. Effective commissioning will also be facilitated by an identification and understanding of key issues affecting each group.

Networking to make a difference

In compiling this resource, the project team have come across some inspiring work delivered with huge motivation and energy. Often this work is taking place in isolation and there has been a strong call to find and facilitate opportunities to share learning and experiences about what works in practice.

Efforts to support networking are being taken forward – contact Melanie Hodson at Hospice UK to find out more: m.hodson@hospiceuk.org

The project partner organisations also produce e-newsletters or online resources to help keep you up to date with news from their fields – see Appendix 2 for further details.

A note on bereavement support

The experiences of, and support for grief and bereavement amongst Gypsies and Travellers, LGBT people and people experiencing homelessness are recognised as vitally important issues which were beyond the scope of this report.

Call for action

We invite you to take inspiration from the projects presented here, and other great work that is taking place to enable Gypsies and Travellers, LGBT people and people experiencing homelessness to access personalised end of life care. Do get in touch with us if you have projects or practice to share.¹¹⁸ Take heart that the steps forward might sometimes appear small, but tenacity and commitment will help realise the Government's end of life care commitment.

Recommendations for action

1. Understand the needs of your local community
2. Involve your local community in the design, planning, delivery and evaluation of care
3. Use the relevant evidence and existing models of care to inform your service model
4. Ensure workforce training needs are fully explored and met
5. Implement and review
6. Share your learning and experience.

Appendix 1: Southampton homeless end of life care plan



Southampton Homeless Services End of Life Care Plan

Name Date of birth

End of life can happen to us all at any time.
This plan ensures **you can be in control** and **your wishes are fulfilled**.

Do you understand your diagnosis and what is going to happen?

Have you had any thoughts about what lies ahead for you?

How do you feel about this?

Do you understand why we are asking questions about your end of life?

Would you like anyone else involved in your end of life care planning?

Do you have any spiritual wishes?

What are your hopes and aims?

Where would you like to be living approaching the end of your life?

What could be done to improve your life now?

These questions are about your wishes if you were close to the end of your life.

What would you like to happen?

Would you want medical treatment if you are apparently dead or dying or if your breathing has stopped?

Where would you wish to be when you die? For example: home, hostel, hospital, street, another place?

Who would you like to be around you? For example: family, friends, staff, no one?

Would you like us to contact anyone at any point now, before, or after you have died (for example a significant other or next of kin)?

Have you, or would you like to, make a will?

These questions are about your wishes when you have died.

What would you like to happen?

Do you have a wish to be buried or cremated?

Do you have any special requests?

Is there a special or particular place you would like your body or ashes to be laid to rest?

What would you like to happen to your possessions?

Do you need to make arrangements for any pets?

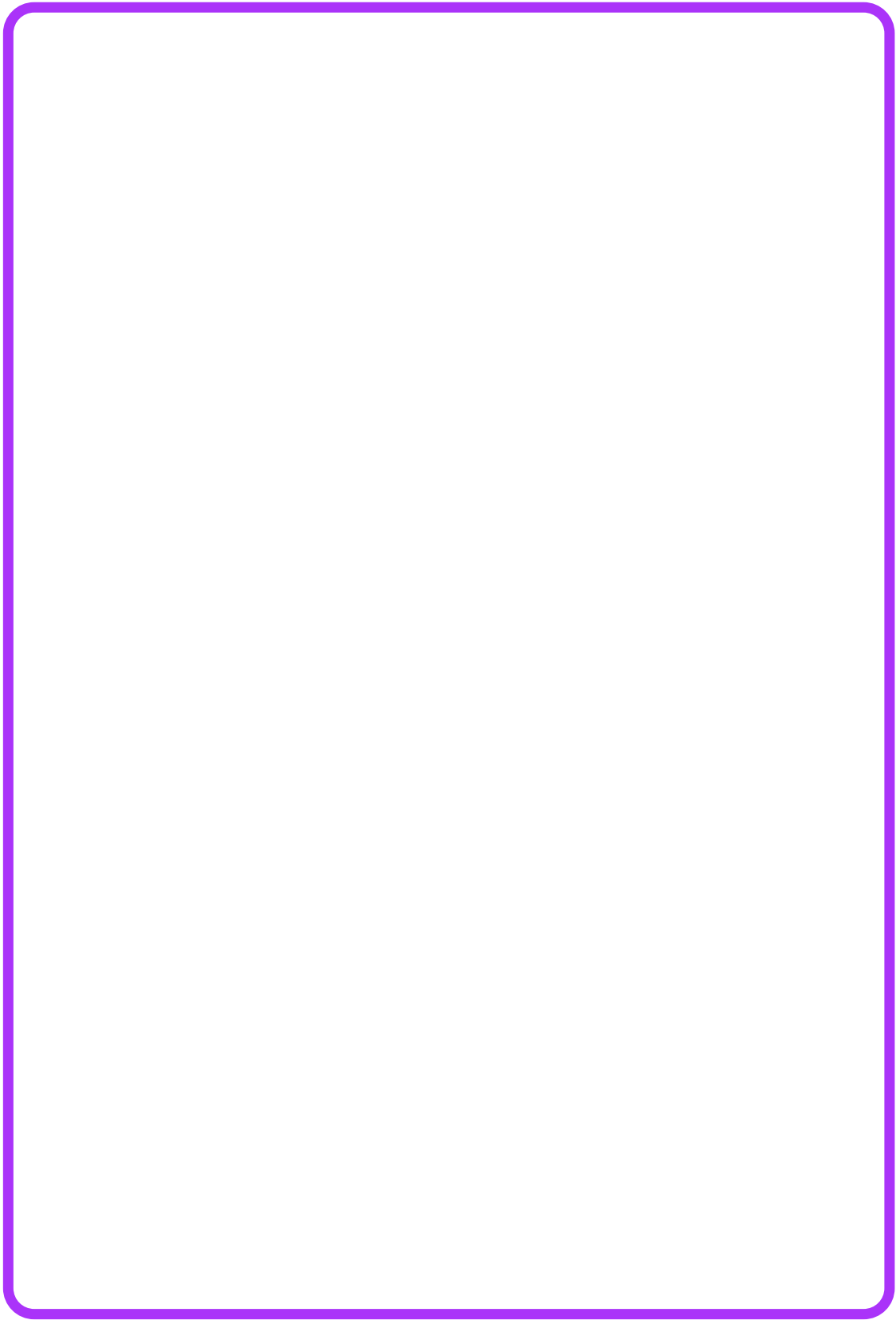
Date

Signed

Client

..... Support worker

The following two pages can be used if you need more space.
This is your plan, and you can express yourself however you feel best, for example using mind maps, diagrams, or drawings.



Reproduced with permission.

Appendix 2: News resources from the project's partner organisations

ehospice

ehospice is an online international news and information service run by a range of national and international palliative care organisations across the world, which aims to share knowledge and best practice among hospice and palliative care professionals.

ehospice is aimed at anyone with a professional or personal interest in palliative care. It offers a single point of access to information and good practice, with the broader aim of helping to improve patient care globally. It is a multi-platform service which is available on mobile and desktop websites, as well as on iPad and iPhone and Android apps. It is a registered charity in England and Wales, which was set up in 2012.

Hospice UK produces and manages content for the UK edition of ehospice. Find at: www.ehospice.com/uk

Friends, Families and Travellers

Sign up for the monthly e-newsletter at: www.gypsy-traveller.org/news/

Homeless Link

Keep up to date with news, opinion and features from Homeless Link and the wider homeless sector at: www.homeless.org.uk/connect

LGB&T Partnership

The LGB&T Partnership produces a monthly bulletin on LGBT health and wellbeing news. Find at: <https://nationallylgbtpartnership.org/bulletins/>

Marie Curie

'Marie Curie People' is a printed and electronic newsletter produced 10 times a year and distributed to staff and active supporters of the charity. A Policy and Public Affairs Newsletter – sent by email to interested individuals – provides headline information on developments in the political and healthcare environment in each of the four home nations. To sign up for either newsletter, email your request to: simon.jones@mariecurie.org.uk

Together for Short Lives

Together for Short Lives publishes a fortnightly e-bulletin features news, resources, events and jobs for professionals who work with children with life-limiting or life-threatening conditions and their families. Sign up at: <https://www2.togetherforshortlives.org.uk/portal/public/register/group.aspx?group=g00001>

References

1. At the point at which this project began, the Department of Health had not yet changed its name to become the Department of Health & Social Care.
2. Stonewall. Glossary of terms [Online]. URL: <http://www.stonewall.org.uk/help-advice/glossary-terms>
3. Gender Identity Research and Education Society (2015). Terminology. [Online] URL: <http://www.gires.org.uk/resources/terminology/>
4. Fitzpatrick S, Pawson H, Bramley G et al (2017). The homelessness monitor: England 2017. London: Crisis.
5. National Council for Palliative Care (2011). Commissioning end of life care: initial actions for new commissioners. London: National Council for Palliative Care.
6. World Health Organization. WHO definition of palliative care [Online]. URL: <http://www.who.int/cancer/palliative/definition/en/>
7. Together for Short Lives. Introduction to children's palliative care [Online]. URL: <http://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/>
8. See also: Together for Short Lives (2012). A guide to end of life care: care of children and young people before death, at the time of death and after death. Bristol: Together for Short Lives.
9. Hospice UK (2017). Hospice care in the UK 2017: from numbers to insight. London: Hospice UK.
10. Care Quality Commission (2016). A different ending: addressing inequalities in end of life care. Newcastle upon Tyne: CQC.
11. Dixon J, King D, Matosevic T et al (2015). Equity in the provision of palliative care in the UK: review of evidence. [s.l.]: Personal Social Services Research Unit, London School of Economics and Political Science.
12. Cooper J (2016). Seriously ill children face a postcode lottery. Together for Short Lives [News item] July 10. [Online] URL: <http://www.togetherforshortlives.org.uk/seriously-ill-children-face-postcode-lottery/>
13. Hospice UK (2017). Hospice care in the UK 2017: from numbers to insight. London: Hospice UK
14. Care Quality Commission (2016). A different ending: addressing inequalities in end of life care. Newcastle upon Tyne: CQC.
15. At the point at which this project began, the Department of Health had not yet changed its name to become the Department of Health & Social Care.
16. NHS England. Voluntary, Community and Social Enterprise (VCSE) Health and Wellbeing Alliance [Online]. URL: <https://www.england.nhs.uk/hwalliance/>

17. This rapid review of the literature to synthesise evidence used the following databases: British Nursing Index, CareSearch (Systematic Review Collection), CINAHL, Cochrane Library, ehospice, Embase, ETHOS (British Library database of UK theses), King's Fund Library database, Leeds University Library: Special collections: Romany collection, Medline, NHS Evidence, PsychLit, Research Abstracts (Together for Short Lives resource), TRIP medical database (open access version). Limits applied: English language material only and published 1997 to date.
18. Department of Health (2016). Our commitment to you for end of life care: the Government Response to the Review of Choice in End of Life Care. London: Department of Health.
19. Department of Health (2016). Our commitment to you for end of life care: the Government Response to the Review of Choice in End of Life Care. London: Department of Health.
20. The Choice in End of Life Care Programme Board (2015). What's important to me: a review of choice in end of life care. [s.l.]: The Choice in End of Life Care Programme Board.
21. Leadership Alliance for the Care of Dying People (2014). One chance to get it right: improving people's experience of care in the last few days and hours of life. Leadership Alliance for the Care of Dying People.
22. National Palliative and End of Life Care Partnership (2015). Ambitions for palliative and end of life care: a national framework for local action 2015-2020. [s.l.]: National Palliative and End of Life Care Partnership.
23. NHS England. Involving people in their own care [Online]. URL: <https://www.england.nhs.uk/ourwork/patient-participation/>
24. Russell S J F (2016). Advance care planning and living with dying: the views of hospice patients. Unpublished PhD thesis, University of Hertfordshire.
25. National Voices and National Council for Palliative Care (2015). Every moment counts: a narrative for person centred coordinated care for people near the end of life. [s.l.]: National Voices.
26. National Palliative and End of Life Care Partnership (2015). Ambitions for palliative and end of life care: a national framework for local action 2015-2020. [s.l.]: National Palliative and End of Life Care Partnership.
27. Together for Short Lives (2013). Together for Short Lives response to the NHS Commissioning Board consultation: a narrative for person-centred coordinated (integrated) care. Together for Short Lives.
28. McNamara K (2013). Standards framework for children's palliative care. Bristol: Together for Short Lives.
29. British Institute of Human Rights and Sue Ryder (2016). End of life care and human rights: a practitioner's guide. London: British Institute of Human Rights.
30. Department of Health (2012). Reducing health inequalities: the Health and Social Care Act 2012. [Factsheet]. URL: <https://www.gov.uk/government/publications/health-and-social-care-act-2012-fact-sheets>

31. Government Equalities Office and Equality and Human Rights Commission. Equality Act 2010: guidance. [Online]. URL: <https://www.gov.uk/guidance/equality-act-2010-guidance> Published 27 February 2013, last updated 16 June 2015.
32. Together for Short Lives. At a glance: the public policies affecting children in the UK who need palliative care [Online]. URL: <http://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/at-a-glance-public-policies-affecting-children-in-the-uk-who-need-palliative-care/>
33. Friends, Families and Travellers. Equality Act 2010 [Online]. URL: <https://www.gypsy-traveller.org/advice-section/report-racism-website-for-gypsies-and-travellers/>
34. Cemlyn S, Greenfields M, Burnett S, Matthews Z, Whitwell C (2009). Inequalities experienced by Gypsy and Traveller communities: a review. [Research report 12], Manchester: Equality and Human Rights Commission.
35. Office for National Statistics (2014). 2011 Census analysis: What does the 2011 Census tell us about the characteristics of Gypsy or Irish Travellers in England and Wales? ONS.
36. Information from Friends, Families and Travellers. The 300,000 figure refers to the number of Gypsies and Travellers estimated by Government by combining direct counts of caravans, school records and other recording.
37. Office for National Statistics (2014). 2011 Census analysis: What does the 2011 Census tell us about the characteristics of Gypsy or Irish Travellers in England and Wales? ONS.
38. Parry G, Van Cleemput P, Peters J et al (2007). Health status of Gypsies and Travellers in England. *Journal of Epidemiology and Community Health*, 61(3): 198-204.
39. Equality and Human Rights Commission (2009). Gypsies and Travellers: simple solutions for living together. [s.l.]: Equality and Human Rights Commission.
40. Matthews Z (2008). The health of Gypsies and Travellers in the UK. [Better Health Briefing #12]. London: Race Equality Foundation.
41. Matthews Z (2008). The health of Gypsies and Travellers in the UK. [Better Health Briefing #12]. London: Race Equality Foundation.
42. McQuillan R (2011). Travellers' and Gypsies' death and dying. In Oliviere D, Monroe B and Payne S (eds). *Death, dying and social differences*. Oxford: Oxford University Press.
43. Office for National Statistics (2014). 2011 Census analysis: What does the 2011 Census tell us about the characteristics of Gypsy or Irish Travellers in England and Wales? ONS.
44. Carers UK (2017). *State of caring 2017*. London: Carers UK.
45. Cemlyn S, Greenfields M, Burnett S, Matthews Z, Whitwell C (2009). Inequalities experienced by Gypsy and Traveller communities: a review. [Research report 12], Manchester: Equality and Human Rights Commission.
46. MECOPP. [n.d.] *Hidden carers: unheard voices: informal caring within the Gypsy/Traveller community in Scotland*. Edinburgh: MECOPP.
47. Matthews Z (2008). The health of Gypsies and Travellers in the UK. [Better Health Briefing #12]. London: Race Equality Foundation.

48. Learning Alliance for Palliative and End of Life Care Services. 'Working with and for Eastern Europeans, Romany and Traveller communities: how to engage in palliative and end of life care services.' University of Greenwich Medway Campus, 2017 Sept 15 Cited in: Healthwatch Kent. (2017) How do you get care for terminal illness or end of life? [Steve's blog post] Jul 28 Available at: <http://www.healthwatchkent.co.uk/news/how-do-you-care-terminal-illness-or-end-life>
49. Leung J (2017 Nov 28). Re: Email intro re Travellers. Email to M. Hodson at Hospice UK.
50. Care Quality Commission (2016). Gypsies and Travellers: a different ending: addressing inequalities in end of life care. Newcastle Upon Tyne: Care Quality Commission.
51. Care Quality Commission (2016). Gypsies and Travellers: a different ending: addressing inequalities in end of life care. Newcastle Upon Tyne: Care Quality Commission.
52. McFadden A, Siebelt L, Gavine A et al (2018). Gypsy, Roma and Traveller access to and engagement with health services: a systematic review. *European Journal of Public Health*, 28(1): 74-81.
53. The focus group comprising eight people and convened by Friends, Families and Travellers took place over a half-day in December 2017.
54. McFadden A, Siebelt L, Gavine A et al (2018). Gypsy, Roma and Traveller access to and engagement with health services: a systematic review. *European Journal of Public Health*, 28(1): 74-81.
55. Jesper E, Griffiths F and Smith L (2008). A qualitative study of the health experience of Gypsy Travellers in the UK with a focus on terminal illness. *Primary Health Care Research and Development*, 9(2): 157-165.
56. McFadden A, Siebelt L, Gavine A et al (2018). Gypsy, Roma and Traveller access to and engagement with health services: a systematic review. *European Journal of Public Health*, 28(1): 74-81.
57. McFadden A, Siebelt L, Gavine A et al (2018). Gypsy, Roma and Traveller access to and engagement with health services: a systematic review. *European Journal of Public Health*, 28(1): 74-81.
58. McFadden A, Siebelt L, Gavine A et al (2018). Gypsy, Roma and Traveller access to and engagement with health services: a systematic review. *European Journal of Public Health*, 28(1): 74-81.
59. Carr S, Lhussier M, Forster N et al (2014). Outreach programmes for health improvement of Traveller Communities: a synthesis of evidence. *Public Health Research*, 2(3).
60. See for example, the online cultural competency training provided by Friends, Families and Travellers: <https://www.gypsy-traveller.org/fft-training/online-cultural-competency-training/>
61. Sanders B and Albanese F (2016). "It's no life at all": rough sleepers' experiences of violence and abuse on the streets of England and Wales. London: Crisis.
62. Homeless Link. Causes of homelessness [Online]. URL: <https://www.homeless.org.uk/facts/understanding-homelessness/causes-of-homelessness>
63. Based on 2,590 responses from people using services in 19 areas across England.

64. Homeless Link (2017). Rough sleeping statistics: an analysis of 2017 rough sleeping counts and estimates. London: Homeless Link [Online]. URL: <https://www.homeless.org.uk/facts/homelessness-in-numbers/rough-sleeping/rough-sleeping-our-analysis>
65. Homeless Link (2017). Rough sleeping statistics: an analysis of 2017 rough sleeping counts and estimates. London: Homeless Link [Online]. URL: <https://www.homeless.org.uk/facts/homelessness-in-numbers/rough-sleeping/rough-sleeping-our-analysis>
66. Homeless Link (2017). Statutory homelessness data: July-September 2017 (Q.3). London: Homeless Link [Online]. URL: <https://www.homeless.org.uk/facts/homelessness-in-numbers>
67. Wilkins M (2018). What's behind the growing number of rough sleepers? National Audit Office Blog, Jan 26 [Online]. URL: <https://www.nao.org.uk/naoblog/growing-number-of-rough-sleepers/>
68. Reeve K and Batty E (2011). The hidden truth about homelessness: experiences of single homelessness in England. London: Crisis.
69. Care Quality Commission (2016). People who are homeless: a different ending: addressing inequalities in end of life care. Newcastle Upon Tyne: Care Quality Commission.
70. Hudson B, Shulman C and Kennedy P (2016). BMA calls for changes to end of life care: challenges for homeless people. Rapid Response. BMJ 352:i1527.
71. Hudson B F, Flemming K, Shulman C and Candy B (2016). Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research. BMC Palliative Care, 15:96.
72. Shulman C, Hudson B F, Low J, Hewett N et al (2018). End of life care for homeless people: a qualitative analysis exploring the challenges to access and provision of palliative care. Palliative Medicine, 32(1): 36-45.
73. Shulman C and Hudson B F (2018). Palliative care for homeless people. [Powerpoint presentation] Homeless Link and Hospice UK. Homelessness and end of life care workshop, Feb 19.
74. Hudson B F, Flemming K, Shulman C and Candy B (2016). Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research. BMC Palliative Care, 15:96.
75. Hudson B F, Flemming K, Shulman C and Candy B (2016). Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research. BMC Palliative Care, 15:96.
76. Shulman C, Hudson B F, Low J, Hewett N et al (2018). End of life care for homeless people: a qualitative analysis exploring the challenges to access and provision of palliative care. Palliative Medicine, 32(1): 36-45.
77. Shulman C and Hudson B F (2018). Palliative care for homeless people. [Powerpoint presentation]: Homeless Link and Hospice UK. Homelessness and end of life care workshop, Feb 19.
78. Shulman C and Hudson B F (2018). Palliative care for homeless people. [Powerpoint presentation]: Homeless Link and Hospice UK. Homelessness and end of life care workshop, Feb 19.

79. The event was hosted by Homeless Link and Hospice UK and took place on Feb 19, 2018.
80. Homeless Link provide a directory of homelessness services in England – see the Resources section on page 49 for more information.
81. Hudson B F, Shulman C, Low J et al (2017). Challenges to discussing palliative care with people experiencing homelessness: a qualitative study. *BMJ Open* 7:e017502.
82. Shulman C and Hudson B F (2018). Palliative care for homeless people. [Powerpoint presentation]: Homeless Link and Hospice UK. Homelessness and end of life care workshop, Feb 19.
83. Sumalinog R, Harrington K, Dosani N et al (2017). Advance care planning, palliative care, and end of life care interventions for homeless people: a systematic review. *Palliative Medicine*, 31(2): 109-119 (first published 3 June 2016).
84. Russell S J F (2016). Advance care planning and living with dying: the views of hospice patients. Unpublished PhD thesis, University of Hertfordshire.
85. Academy of Medical Royal Colleges and Faculty for Homeless and Inclusion Health (2017). Inclusion Health. Academy of Medical Royal Colleges and Faculty for Homeless and Inclusion Health joint position statement. [s.l.]: Academy of Medical Royal Colleges.
86. Public Health England (2016). Guidance: homelessness: applying All Our Health [Online]. Updated 6 Oct 2016. URL: <https://www.gov.uk/government/publications/homelessness-applying-all-our-health/homelessness-applying-all-our-health#guidance>
87. Skelton A (2017). A literature review to investigate the barriers and facilitators experienced by people who are homeless or vulnerably housed when accessing specialist palliative care services. Dissertation submitted for BSc Health & Social Care Practice.
88. Flemming K (2018). Case study for Homeless Link from The Department of Health Sciences at the University of York and St Leonard's Hospice [submitted 15 March 2018].
89. Bristowe K, Hodson M, Wee B, Almack K et al (2018). Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. *Palliative Medicine*, 32(1): 23-35.
90. Marie Curie (2016). Hiding who I am: the reality of end of life care for LGBT people. London: Marie Curie.
91. Williams H, Varney J, Taylor J, Fish J et al (2013). The Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document [s.l.].
92. Care Quality Commission (2016). Lesbian, gay, bisexual or transgender people: a different ending: addressing inequalities in end of life care. Newcastle Upon Tyne: Care Quality Commission.
93. Williams H, Varney J, Taylor J, Fish J et al (2013). The Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document [s.l.].
94. Williams H, Varney J, Taylor J, Fish J et al (2013). The Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document [s.l.].
95. Office for National Statistics (2017). Sexual identity, UK: 2016. ONS.

96. LGBT Consortium (2016). Trans briefing sheet: gender recognition in the UK. [Exeter]: LGBT Consortium [Online]. URL: <http://www.lgbtconsortium.org.uk/transuk>
97. Acquaviva K D (2017). LGBTQ-inclusive hospice and palliative care: a practical guide to transforming professional practice. New York: Harrington Park Press.
98. Marie Curie (2016). Hiding who I am: the reality of end of life care for LGBT people. London: Marie Curie.
99. Acquaviva K D (2017). LGBTQ-inclusive hospice and palliative care: a practical guide to transforming professional practice. New York: Harrington Park Press.
100. National Council for Palliative Care and LGBT Consortium (2011). Open to all? Meeting the needs of lesbian, gay, bisexual and trans people nearing the end of life. London: National Council for Palliative Care.
101. Bristowe K, Hodson M, Wee B, Almack K et al (2018). Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. Palliative Medicine 32(1): 23-35.
102. Bristowe K, Hodson M, Wee B, Almack K et al (2018). Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. Palliative Medicine, 32(1): 23-35.
103. Bristowe K, Hodson M, Wee B, Almack K et al (2018). Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. Palliative Medicine, 32(1): 23-35.
104. Bristowe K, Hodson M, Wee B, Almack K et al (2018). Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. Palliative Medicine, 32(1): 23-35.
105. Bristowe K, Hodson M, Wee B, Almack K et al (2018). Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. Palliative Medicine, 32(1): 23-35.
106. Name has been changed.
107. Bristowe K, Hodson M, Wee B, Almack K et al (2018). Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. Palliative Medicine, 32(1): 23-35.
108. Stephenson S (2018). Encouraging progress by project to achieve culturally competent palliative care for LGBT people. ehospice [UK ed.] Jan 25.
109. Marie Curie (2016). Hiding who I am: the reality of end of life care for LGBT people. London: Marie Curie.
110. Care Quality Commission (2016). Lesbian, gay, bisexual or transgender people: a different ending: addressing inequalities in end of life care. Newcastle Upon Tyne: Care Quality Commission.

111. Bristowe K, Hodson M, Wee B, Almack K et al (2018). Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. *Palliative Medicine*, 32(1): 23-35.
112. Marie Curie (2016). *Hiding who I am: the reality of end of life care for LGBT people*. London: Marie Curie.
113. Social Care Institute for Excellence and Consortium of LGBT Voluntary and Community Organisations (2011). *Personalisation: Working with lesbian, gay, bisexual and transgender people*. [SCIE At a glance 42], SCIE.
114. Bristowe K, Hodson M, Wee B, Almack K et al (2018). Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. *Palliative Medicine*, 32(1): 23-35.
115. Hospice UK (2017). *Achieving excellent end of life care locally: how can the public work with Sustainability and Transformation Partnerships to achieve excellent end of life care locally?* London: Hospice UK.
116. Hospice UK (2017). *Achieving excellent end of life care locally: how can the public work with Sustainability and Transformation Partnerships to achieve excellent end of life care locally?* London: Hospice UK.
117. Together for Short Lives (2017, Nov 12). *Most vulnerable families failed in community care postcode lottery* [Online]. URL: <http://www.togetherforshortlives.org.uk/vulnerable-families-failed-community-care-postcode-lottery/>
118. If you have projects or practice to share, contact Melanie Hodson, Hospice UK: m.hodson@hospiceuk.org



Professional Networks

Benchmarking Intelligence

Income ehospice Events

International Publications

Families Governance

Donate

National Charity Care Hospice

Advocacy Hospice Care Finance

Care Campaigns Voice Challenges

Patients Volunteering Grants Commission

Training Education Recruitment Policy

Palliative Care Conference Members Income

www.hospiceuk.org 020 7520 8200

 @hospiceuk  /hospiceuk

Hospice UK, Hospice House, 34 – 44 Britannia Street, London WC1X 9JG