healthwatch
Brighton and Hove

"This is who I am. This is what I need"

How to deliver personalised end of life care for LGBTQ+ patients. Results from a Healthwatch review of published literature.

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1. Preface

Healthwatch: our aims for this project

This project builds on the foundations of two earlier reports from Healthwatch Brighton and Hove on end of life care, which were published in 2020 and 2021. As with our other reports, it is intended to support our local Trust – the University Hospitals Sussex NHS Foundation Trust - in developing a fully inclusive end of life strategy, including best practice.

This report is a compilation of national and international literature which has examined some of the specific end of life support needs for LGBTQ+ people.

This report has already stimulated a conversation with our hospital Trust about the needs of LGBTQ+ people who are at the end of their life, and they have agreed to conduct further work in this area, including a consideration of our recommendations (see page 2).

What is end of life (or palliative) care?

Palliative care helps people with advanced or terminal illnesses to have the best possible quality of life and provides support for their families. Specialist palliative care is typically delivered by a team with diverse expertise in caring for people with progressive and life-limiting illnesses.

It is for people living with a terminal illness where a cure is no longer possible. Palliative care treats or manages pain and other physical symptoms and helps with psychological, social, or spiritual needs. It can be delivered alongside particular treatments, such as chemotherapy or radiotherapy.

Who does the term LGBTQ+ describe?

The LGBTQ+ support organisation Stonewall, defines this as "The acronym for lesbian, gay, bi, trans, queer, questioning and ace."[1] There is also sometimes an 'A' for asexual and/or an 'I' for intersex.

Language is ever-changing, and a '+' sign at the end of the term LGBTQ denotes the range of other terms and descriptors used by people to define their sexual orientation and/or personal preferences.

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[1] Glossary of terms (stonewall.org.uk)

2. Healthwatch recommendations

Our recommendations to University Hospitals Sussex NHS Foundation Trust ("UHS") are based on the findings and themes identified by Healthwatch through this review. These are described in detail in parts 4 and 5 and Annex A of this report. Hyperlinks to the relevant sections are included.

1. We recommend that the UHS Trust should develop and embed palliative guidelines specifically for LGBTQ+ patients within their service model and practices.

2. We recommend that the UHS Trust should review its current policies and identify a core narrative around end of life care delivery for LGBTQ+ groups and use this as a building block for wider systematic change around inclusion and equity for all patients.

3. We recommend that the UHS Trust, as part of its regular review of staff training, should design modules which educate staff about the specific concerns and needs of LGBTQ+ patients. Healthwatch has identified several resources which may be of help to the Trust in this regard which can be found in part 5 and Annex B. Key areas of focus are:
    - tackling the well-intentioned '*we treat everyone the same*' approach to patient care which may not fully recognise diversity
    - supporting staff to develop inclusive and open communication skills
    - tackling any unconscious and conscious bias amongst staff
    - raising awareness around 'next of kin' and enabling effective conversations around these relationships.

4. We recommend that the UHS Trust should review all patient forms to ensure these capture data on sexuality/orientation, personal preferences, and next of kin. The focus could initially be on admission and discharge forms to improve and support these important processes.

5. We recommend that the UHS Trust should continue to promote the principle of inclusivity by ensuring that patient materials include diverse images of LGBTQ+ people and/or symbols such as LGBTQ+ flags and promote the use of pronoun badges amongst staff.

6. We recommend that the UHS Trust should work with local LGBTQ+ groups to understand more about the end of life care needs of LGBTQ+ individuals and create a LGBTQ+ working end of life palliative group.

7. We recommend that the UHS Trust should promote the importance to LGBTQ+ patients of having an Advance Decision in place to help them to express their needs and preferences, including around end of life. This will also help staff.

3. Response from University Hospitals Sussex Trust

We would like to thank Healthwatch Brighton and Hove for this latest report which builds on the foundations laid out in "A Good Send-off?" Patients' and Families' Experiences of End of Life Care" (September 2020). Since then, the Trust has embedded some formal processes into strategy and policy, and quality end of life care and dying well remains high on our agenda.

Trust colleagues responded to the follow-up Healthwatch report "A Good Send-Off?" Patients' and Family's Experiences of End of Life Care. One year on" (March 2021) by highlighting the growing awareness of the needs and difference experiences of LGB+, trans and non-binary people in end of life care, particularly around cancer. It is therefore very positive that Healthwatch undertook this additional research.

Whilst this research reflects the national picture only, it nevertheless shines a spotlight on some important issues, and we look forward to working with Healthwatch to explore these further.

The research findings extend beyond end of life care and are reflective of health equity issues more broadly. The results from this Healthwatch report can be used by the Trust to identify a core narrative around end of life care delivery for LGBTQ+ groups but also used as a building block for wider systematic change around inclusion and equity that UHS is exploring.

Reflecting on some of the points raised by the Healthwatch report:

- A very effective and inclusive chaplaincy service operates Trust-wide and there are no obvious or known concerns.
- Integrated medication and care function training is supporting front line staff to respond to the individual in front of them.
- 'Call me' ID badges are being introduced which give preferred names which should support open and inclusive conversations with patients.
- The concept of 'next of kin' fall falls within existing 'nominated other' data capture.

Moving forward / next steps

This work reflects the national picture, and the next step is to understand more about the local situation. The Trust will conduct a review of people identified as LGBTQ+ who had died in the Trust's hospitals. This will incorporate a retrospective review of their healthcare records (anonymously). The findings will be shared with community colleagues to consider what they mean through a community lens. This work will be added to, owned and tracked through the Trust's end of life programme, and monitored through existing strategic channels. The report findings will be shared with the End of Life Steering Grp, Mortality Board, non-executive directors. and the learning from deaths program.

4. Introduction

Background

This is the third report produced by Healthwatch Brighton and Hove on end of life care.

The first of these was published in September 2020[2] - **"A good send-off?" Patients' and Family's experiences of End of Life Care",** and described the care which 15 patients who were at the end of their lives had received following their discharge from the University Hospitals Sussex NHS Foundation Trust (UHS). We delivered 10 recommendations designed to improve the care pathway for patients and correct elements of insensitivity and the absence of coordinated planning that we had identified. Our recommendations were accepted in full by UHS.

We followed this up with a 'one year on' report, published in March 2021 - **"A Good Send-Off?" Patients' and Family's Experiences of End of Life Care. One year on"**, which described how our first report's findings had been embedded into strategy and policy by UHS with an acknowledgment that work to improve end of life care remains in its infancy. Our review provided confidence that end of life care and the principle of dying well remains high on the agenda.

Healthwatch continues to work collaboratively with UHS on improving end of life care, and in response to our second report, we were contacted by representatives from their LGBTQ+ Network, who we met with in June 2021.[3] This discussion highlighted specific end of life considerations for people who identify as LGBTQ+. Healthwatch presented highlights from this discussion at the UHS Trust's Patient Experience and Engagement Group[4] on 21 June 2021 which generated support for creating more inclusive conversations around end of life between LGBTQ+ patients and staff. As a result, Healthwatch agreed to conduct this third project.

> ***"There's growing awareness of the needs and difference experiences of LGB+ and Trans & Non-Binary people in End of Life care, particularly around Cancer. So, it's really positive that Healthwatch will look to include reference to LGBTQ+ care."***
>
> - Nick Groves, LGBTQ+ Network Co-Convenor, June 2021

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[2] Publication of this report was delayed by the COVID 19 response. Healthwatch talked to 15 patients on the Oncology Ward at the Royal Sussex County Hospital about their discharge from hospital between November 2019 and January 2020 and followed up with them once discharged.

[3] We met with Nick Groves, LGBTQ+ Network Co-Convenor, Barbara Harris, Head of Inclusion, and Joanna Elliot, Pastor at UHS.

[4] PEEG is a group of senior UHS staff committed to improving the experience of our patients, families, and carers. The group is continually learning from the feedback that they receive, and they actively listen to patients to understand what matters to them

Methodology used to produce this report

Healthwatch carried out a literature review. We conducted a web-based search using terms that included ‘end of life’ and ‘LGBTQ’. This identified a significant number of sources of information which are listed at Annex C. The UHS Trust’s library service supported us in his work.

From an indepth review of 20 publications, Healthwatch identified several key findings and themes, which we used to develop our recommendations. We hoped that these would form the basis of an ongoing conversation between UHS, Healthwatch and local voluntary organisations about how to embed these into practice.

Our findings and recommendations build on those described in our earlier reports. However, this report focuses on additional considerations which need to be taken into account when delivering end of life care to LGBTQ+ individuals.

There is no suggestion made by Healthwatch in conducting this work that the UHS Trust is failing to treat LGBTQ+ patients at the end of their lives with care and courtesy, and we have not received evidence to the contrary.

The rationale for undertaking this review

(a) The focus of this work is particularly important for Brighton and Hove which has a large population of LGBTQ+ individuals some of whom may require end of life care in one of our local hospitals. The Brighton and Hove Joint Strategy Needs Assessment[5] estimates that 10-15% of our residents identify as LGBTQ+, or between 34,000-43,500 people. Of these, it is estimated that 3,870 to 5,800 LGBTQ+ people are aged 65 and over[6].

(b) Early discussions between Healthwatch and UHS identified:

- the concept of ‘next of kin’ is broader for LGBTQ+ people and may not always include immediate family members, and that “families of choice” may include partners, ex-partners, and friends who may or may not always be welcomed into the healthcare setting by staff.
- trans people may not be recognised as their birth gender or a gender they identify with when they can no longer advocate for themselves. A dementia diagnosis requires additional sensitivity so that that staff can respond in an appropriate way to individuals whose condition may have caused them to regress to their younger selves.

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[5] http://www.bhconnected.org.uk/content/needs-assessments Brighton & Hove population: 290,885. The ‘best estimate’ is that between 11% and 15% of the population of the city identify as LGBTQ+

[6] UK population pyramid interactive - Office for National Statistics (ons.gov.uk) 10% of the 38,711 who are aged 65 and over in the city (2018)[6].

- there is the potential for this work to result in the personal wishes of LGBTQ+ patients' to be better collated as part of the admission process, ensuring that all staff involved in a patient's journey are aware of these.
- this work also has potential to support planned discharges through the enhanced collection of personal data and preferences.

Underpinning this review are the following findings which Healthwatch identified from the literature it reviewed:

> ***"Everyone has the right to expect services and support that help to achieve a good death and to choose how they are cared for in their final months and days. This should include access to high quality palliative care services which supports physical, psychological and spiritual needs, and respects personal choice."*** - Age UK, End of life care, May 2019

> ***For LGBT patients and their loved ones, [the] passage becomes fraught with many of the same issues that plague medical care throughout the LGBT patient s life.***
>
> - ***How safe is it for a patient to disclose their gender identity, sexual orientation, and who is considered as family?***
> - ***Will healthcare providers welcome the involvement of a same-sex or trans partner and/or shared parenthood with that partner in medical and psychosocial decision making?***
> - ***Will a home health aide treat their LGBT client with compassion?***
> - ***How can a dying LGBT patient who seeks spiritual guidance identify a supportive hospice chaplain?***
> - ***At each stage of this powerful passage, a new group of care providers may enter the scene, giving repeated rise to the same fears and possible discrimination."***
>   - The American National Cancer Network (no publication date)

Sharing our findings

Healthwatch shared our initial findings with leads at UHS who we met with in June 2021, including the Lead Clinical Nurse for Palliative & End of Life Care, the LGBTQ+ Network Co-Convenor, the lead Dementia Lead Nurse, the Head of Inclusion, and head Pastor at UHS. We met again to discuss our recommendations and draft report in November 2021, this time with the Director of Experience, Engagement and Involvement to agree next steps. This later meeting led to agreement by the Trust to conduct a further review of people identified as LGBTQ+ who had died in the Trust's hospitals to understand more about their experiences. Healthwatch will be following this work up with the Trust through their Patient Experience and Engagement Group and will monitor it through the Sussex Palliative and End of Care and End of Life Steering groups which we sit on.

4. Key findings identified through this review

The sources of information used to identify these findings are contained in Annex B.

(1) No specific guidance is produced by University Hospitals Sussex

A search conducted by the University Hospitals Sussex library service revealed that the Trust does not currently have any published guidelines specifically on palliative care for LGBTQ+ patients, and that all patients are treated in accordance with overarching guidelines.

(2) Nationally, there is a lack of data about palliative LGBTQ+ experiences

- **A 2015 report by the London School of Economics** found a startling lack of evidence about LGBT people's experiences of palliative and end of life care.

- **A 2016 report by Marie Curie found:**
    - *"While the research available on the experience of LGBT people at the end of life is sparse, policymakers have begun to understand that LGBT people do experience additional barriers to receiving high-quality palliative and end of life care."*

(3) LGBTQ+ people face discrimination in healthcare settings

- **A 2008 publication from the Department of Health stated:**
    - *"The End of Life Care Strategy Equality Impact Assessment (DH, 2008a, 27) identifies sexual orientation and gender identity as the most likely area for inequality and discrimination to occur. The Strategy (DH, 2008b, 28) highlights that the nature of LGBT relationships may be concealed, with the consequence that practitioners and staff may exclude key individuals from involvement in a person's care"*
    - *"Despite the wealth of policy documents on access to palliative care for LGBT people, providers of care have been slow to make changes that would make their services more accessible for LGBT people and their families."*

- **A 2015 report by the London School of Economics also found that**:
    - LGBT people worry about experiencing discrimination from health and social care staff and often do also experience it.
    - 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.
    - Older LGBT people may worry that palliative and end of life care services are simply 'not for them', or that they will receive worse treatment than their straight peers.

- **A 2016 Care Quality Commission (CQC) review found:**
    - *"that commissioners and providers do not always have a good understanding of the end of life care needs of different groups in their community. Many commissioners said that sexual orientation had no bearing on access to end of life care and there was limited evidence of services engaging proactively with LGBT people or considering their specific needs."*

- **A 2016 report by Marie Curie (quoted above) states:**
    - *"Service providers and health and social care professionals can do significant and long-lasting damage to people by being insensitive or actively hostile to people's sexuality or gender identity at this time."*
    - *"the knowledge and attitudes of healthcare professionals played a central role in terms of LGBT peoples' access to, and experiences of, services."*
    - *"LGBT people often require additional or different considerations related to their sexual identity or gender history, but which often goes unrecognised by healthcare professionals.*

- **Nearly three-quarters (74%) of lesbian, gay, bisexual and trans (LGBT) people are not confident that health and social care services provide sensitive end of life care for their needs. As a result, they often delay accessing the care they need** and are more likely to experience unmanaged symptoms and pain at the end of their lives. This places increased pressure on LGBT informal carers to meet the caring needs of LGBTQ+ individuals who are at the end of their lives.

(4) Enhanced privacy rights exist to protect Trans people

- **The Gender Recognition Act (2004)** provides transgender people with enhanced privacy rights which means anyone who has learnt about a person's transitioned status in an 'official capacity' (such as health and social care workers) is not able to disclose this information without the person's express permission. To share this information without permission would be a criminal offence.

(5) It is unclear if the spiritual needs of LGBTQ+ people are met

- Anecdotal evidence suggests that palliative and end of life care services may not always ensure LGBT patients and their families have the same spiritual needs addressed at end of life as any other patient.

(6) LGBTQ+ people need support to express their needs and wishes

- **A Marie Curie report found that:**
    - *"Sharing information about who is close to you, can not only help to make sure their needs are considered, but will also help health and social care professionals to know who you would like involved in*

discussions and decisions about your care. Sharing your gender identity may be important in relation to treatment preferences"

- **Research by the University of Nottingham showed that LGBTQ+ people want significant others in their lives to be acknowledged and involved in their care.**

- In terms of what is needed, **an NHS National End of Care Programme leaflet (see Annex B) states** that guidance and best practice should:
    - *"Encourage LGBT people to be confident in being open about their relationships and needs."*
    - *"Guide organisations and people within them to have an LGBT friendly culture and highlight constructive key messages for everyone to act on."*

5. Themes identified from the literature which form the basis of our Healthwatch recommendations

Several key themes were repeated in the literature reviewed by Healthwatch. 'Top tips' were also identified, and we have summarised these below. We used these to develop our recommendations (see above). Please note that references to the sources of information quoted below are contained in Annex B.

Recommendation one. Produce LGBTQ+ specific guidance

Healthwatch has identified potential benefits to our Trust of producing dedicated and inclusive end of life LGBTQ+ guidance which can be delivered in part through enhanced staff training (see also Recommendation 3 below):

- **helping staff to deliver a person-centered approach to care which recognises individuality.** Guidance can help to combat heterosexual assumptions and limit any negative impacts arising from the well-intentioned *'we treat everyone the same'* approach if this fails to take account of the person's past experiences or preferences which may exacerbate inequality. Guidance can also support staff who are caring for LGBTQ+ patients during the end of their life which, by the nature of the illnesses or conditions involved, is a challenging and sometimes overwhelming experience.

- **helping patients to understand what to expect from their care**. Specific guidance can support the patient to receive effective, high-quality care. It can also **avoid the risk of people delaying seeking care** due to a perception that healthcare staff will discriminate against them because of their sexuality. Distrust may result in important information about the patient being withheld by the individual and/or their partners, affecting long term prognosis.

- **there is the potential for guidance to support the collation of** patient data which can support both admission and planned discharge processes, and also the patient's whole care experience and pathway. High quality guidance and support has the potential to foster better patient/carer trust, encouraging patients to open up about their needs, preferences and wishes.

Recommendation two. A review of internal UHS Trust policies

- The Trust already has policies in place to tackle discrimination but there may be merit in reviewing these to ensure they are explicit as regards LGBTQ+ patients and recognising diversity.
- A whole system approach is needed to be able to respond to the unique needs of LGBTQ+ people.
- Lessons learned from considering LGBTQ+ people are transferable for all protected characteristics, and this can be used as a building block for wider systematic change around inclusion and equity for all patients.

Recommendation three. Additional staff training

- There is immense benefit to had from including within any existing training modules which discuss the specific concerns or needs of LGBTQ+ patients, training around end of life care. Examples of how this has been successfully delivered and embedded are given on pages 24-26.

Training could cover:

(a) Helping staff to avoid the well-intentioned 'we treat everyone the same' approach

- This principle may fail to take account of the person's past experiences or preferences which may exacerbate inequality. It is important for training to challenge the following finding identified through the literature:

> *"health and social care professionals wrongly understand sexuality purely as who someone has sex with, and not an aspect of someone's identity that plays a large role in determining who they love, who is important to them, who is a part of their family, and the way they need to be cared for at the end of life"*.

- In this regard, it is worth noting that in 2015, Stonewall (a LGBTQ+ charity) charity found that 57% of health and social care practitioners said they did not consider someone's sexual orientation to be relevant to a person's health needs.[7] For many LGBTQ+ people, the opposite may be true.

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[7] Stonewall and YouGov (2015) Unhealthy Attitudes: The treatment of LGBT people within health and social care services, http://www.stonewall.org.uk/sites/default/files/unhealthy__attitudes.pdf

(b) Supporting staff to practice-inclusive and open communication skills with patients

- Equipping staff to have open conversations (and replicating aspects of this data capture in patient forms) supports people to more easily self-identify as LGBTQ+ which facilitates the sharing of information. A focus on the use of inclusive language is recommended e.g., this can be as simple as staff learning to ask if someone has a ‘partner’, rather than a ‘husband or wife, boyfriend or girlfriend’. There must be avoidance of heterosexually framed or assumption-laden language.

- **Staff should feel comfortable asking someone what pronouns they use.** This could be he/him, she/her, they/them, or others. Staff can tell the patient what pronouns they prefer as well. **If a trans person uses a name** that is different from the name on their records, staff should make sure they use the name that they prefer.

(c) Tackling unconscious and conscious bias.

- Training may be needed to help staff learn how to avoid making assumptions about someone’s sexual orientation or gender identity, and for staff to learn to ask the question. To achieve this, staff need to be **familiar with terms that people may use to identify their sexual orientation and gender identity.** If someone is unsure what they mean, they should be equipped with skills that enables them to sensitively ask the patient to explain. It is important to be aware that common terms that people use to describe themselves can change over time, so UHS and staff need to keep up to date. It is also vitally important that if someone reveals their sexual orientation or gender identity, that staff respect their wishes and get into the practice of **asking them for their consent before sharing information with colleagues or writing it in their care plan.**

(d) Next of kin

- The patient should be empowered to define family and the role of family, in their care and not the hospital (NB, this should be the gold standard in as many cases as is both possible and practicable i.e., where the patient can advocate for themselves).
- All the literature reviewed is clear that next of kin has no legal or clear definition, and that this is not limited to those who are related by blood or marriage but is in fact anyone whom the patient nominates. Key to delivering high-quality person-centred end of life care, is for staff to understand complexities around family dynamics.
- For staff, this can be a difficult path to tread as it is not always clear who the next of kin may be, and ‘best guesses’ may need to be made. But what the Trust could focus any training on is tackling conscious and unconscious biases in this area, to remove the automatic assumption that next of kin for an LGBTQ+ individual is a blood relation.

- Instead of asking someone who their family is, or who their next of kin is, staff could ask “who is important to them” and “who they would like to be involved in their care”. This may include partners, family members, and friends who should be involved their care as much as the person would like them to be.

(e) Staff need to aware that an LGBTQ+ patient may have had difficult experiences in the past.

- Staff need to alive to the fact that some LGBTQ+ people will have experienced homophobic, biphobic, or transphobic abuse which may make them wary of opening up about their sexuality. Staff must be sensitive and tactful to this fact. In this regard, a focus on displaying extra sensitivity towards older people is needed as the evidence is that this group may feel that palliative care isn’t for them.

Healthwatch has identified a number of existing resources which may help our Trust to develop training materials (see also the examples of how other organisations have achieved greater inclusivity on pages 24-26):

(a) Marie Curie have produced information for staff and health organisations including “Marie Curie nurse Tracey’s blog – Supporting LGBTQ+ people at the end of life” (4 July 2018). In this, Tracey identifies six learning points for staff. Sections of this are reproduced in Annex A.

(b) Saint Francis Hospice in Romford developed a training module for health and social care professionals providing palliative and end of life care for LGBTQ+ 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 which we believe is delivered by London South Bank University.

(c) The Trust should consider adopting guidance contained in “The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people”. This guide states it is intended to:

> *“support practitioners and staff to develop their understanding of the unique issues faced by LGBT people, and their families and carers within our community, and how these issues impact on end of life care”.*

It is however nine years old so may need updating, which could be achieved locally by UHS working in collaboration with LGBTQ+ organisations in Brighton and Hove, or across Sussex.

The guide follows six steps of the end of life care pathway, beginning with initiating discussions as the end of life approaches and concluding with care after death. Each section outlines relevant steps of the pathway, identifies issues to consider and links to the practitioner/staff roles. Case studies are used to highlight good practice. Each step outlines the key questions to ask about the individual's care, the practitioner's role in that care and best practice. Sections of this guide are reproduced in Annex B.

Recommendation four. Improving hospital forms

- **There is need to ensure that better, more inclusive data is captured on hospital forms.** Capturing inclusive data in this way helps to mitigate against patients having repetitive, potentially uncomfortable, conversations with staff and the need for an individual to continually 'out themselves' to different staff members.
- Extending the collection of demographic information to include both sexual orientation and gender identity, pronouns, and preferred name, together with 'who is important to them' helps to build a complete picture of the patient's needs and preferences.

Recommendation five. Promoting inclusivity

- 60% of respondents to a survey[8] said they would prefer health and social care services that were specifically for LGBT people, or which were run by LGBT people. However, many were wary of this approach leading to segregation. It is probably not practical or ideal to create a dedicated end of life service for LGBTQ+ patients, but there may be merit in UHS exploring this.
- Irrespective of the above suggestion, all materials that patients receive should aim to include diverse images of LGBTQ+ people or LGBTQ+ symbols such as the rainbow flag or other LGBTQ+ flags. This is likely to make LGBTQ+ individuals feel more comfortable about using palliative services.

Recommandation six. Working with LGBTQ+ community groups

- It is recommended that UHS work with local LGBTQ+ groups to understand more about the end of life care needs of local LGBTQ+ residents to facilitate an ongoing and open conversation. This would help to increase awareness within UHS and enable ongoing change. We would recommend creating a working end of life palliative group with representatives from the local community. The Trust could also consider:
    - Providing an LGBTQ+ befriender to support people who feel isolated, as they may feel more comfortable opening up to another LGBTQ+ person.
    - Identifying an external or internal 'go to' person who has knowledge and expertise in LGBT issues and needs for staff.
    - Establishing a 'go to' point within the Trust for staff and LGBTQ+ service users to approach with any questions in relation to LGBTQ+ issues and advertising this role publicly.

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[8] "Hiding who I am: The reality of end of life care for LGBT people"

- There may be benefit in producing a specific Palliative & End-of-Life Care guide for LGBTQ+ patients similar to: https://leedspalliativecare.org.uk/wp-content/uploads/2019/08/LGBT_End-of-Life-Leaflet.pdf

Recommendation seven. The importance of advance decisions

- An Advance Statement may be of particular interest to many LGBTQ+ people as it helps them to express their needs and preferences and assists care staff treating a patient to know how to care for them. An Advance Statement can cover things such as:
  - Is there a name different to your given name that you would like to be called?
  - What are your preferred pronouns?
  - Do you prefer wearing certain clothes?

- **We would recommend that UHS (as well as all LGBTQ+ voluntary organisations and all health and community services) promote Advance Statements to all patients receiving end of life care, but in particular to LGBTQ+ patients:**

  > *"Planning ahead is a way to express who you are and what's important to you now, in case you're later unable to make a decision for yourself. Recording your wishes gives you control over your future treatment and care and reassurance that the right decisions will be made. It can also be a good way to start conversations with."*

The spiritual needs of LGBTQ+

Although not one of our recommendations, the literature highlighted the need to ensure that Bereavement Support Services are made equally available to LGBTQ+ individuals and next of kin. LGBTQ+ people can have equally deep-rooted spirituality but may worry that they will be treated with hostility by church-affiliated providers of hospice care. Service providers must consider the role of recognised and unrecognised religious affiliations in delivering a holistic approach to end of life care which considers the whole person and what is important to them at the end of their live.

Annex A - Detailed literature conducted reviewed by Healthwatch

Reports, etc. with no publication date

(1) Terrence Higgins Trust

This is a useful guide to Advance decisions.

Terrence Higgins Trust (THT) are the UK's leading HIV and sexual health charity. They support people living with HIV and amplify their voices and help the people using their services to achieve good sexual health.

Their website includes advice around Advance decisions (living wills) and explains that an **advance decision** (sometimes known as a **living will** or **advance directive**) tells medical staff how you wish to be treated when you're no longer able to communicate your wishes to your medical team. This guidance is not specifically aimed at LGBTQ+ people.

(2) Marie Curie

(a) Marie Curie provide general advice and information for people who are nearing the end of their life, and their loved ones.

(b) Marie Curie, together with the Kings Fund, the Gay Men's Health charity (GMFA), and The University of Nottingham have produced a Leaflet for patients - Palliative and end of life care for LGBT people

This is a useful guide for LGBTQ+ patients but would benefit from being adapted to better meet the needs of the local populace.

This guide describes what palliative care is, and that support is available for both the patient and their family. It provides a series of case studies to bring to life important considerations and conversations. It does not provide practical advice, rather it gives links to other sources of information. It does however highlight important equality end of life considerations:

> *"When facing a life-limiting illness, it is important that the care and support you receive is shaped around who you are and your individual needs… this booklet can help you think about:*
> ○ *Why your sexual orientation or gender identity may be important in relation to your care needs, and preferences*
> ○ *The care you are entitled to receive.*

> ○ *What you should do if you think you have been discriminated against, because of your sexuality or gender identity*
> ○ *Where you can go for more help and information.*

> *"Sharing information about who is close to you, can not only help to make sure [your] needs are considered, but will also help health and social care professionals to know who you would like involved in discussions and decisions about your care. Sharing your gender identity may be important in relation to treatment preferences."*

The guide includes links to the Equality Act 2010, Equality and Diversity in the NHS, how to make a complaint about health and social care services, and to an NHS National End or Care Programme leaflet called "The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people" (published in 2012) which is aimed at staff, CCGs, Trusts, etc. (this report is discussed below).

Articles published in 2012

(1) NHS National End or Care Programme leaflet

This is a key document for staff, CCGs, Trusts, etc.

"The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people" (published in 2012)

This guide is now nine years old so some of its contents are not up-to-date or reflective of concepts such as gender fluidity and pronouns, and it is unclear if a scheduled review planned for 2014 took place.

The guide's purpose is definitive and summarised below. **These principles should lie at the heart of end of life care provided for LGBTQ+ people by UHS.**

> *"This practical implementation document aims to address end of life care needs in relation to lesbian, gay, bisexual or transgender (LGBT) people, in order to improve quality of care. It has been developed following consultation with stakeholders at a series of discussion groups held around the country.* ***It aims to provide a practical guide for everyone working with LGBT people, and for LGBT people themselves****, whether giving or receiving end of life care. This guide is an invitation to:*
>
> - *Encourage LGBT people to be confident in being open about their relationships and needs*

> - *Guide organisations and people within them to have an LGBT friendly culture and Highlight constructive key messages for everyone to act on."*
>
> *"… care should be the same high quality for all and able to take account of any difference, irrespective of the person's diagnosis and setting in which they are being cared for. The key approach is one of inclusivity, therefore LGBT people and their families and carers should have access to high quality end of life care that takes account of their needs and preferences, regardless of their individual circumstances."*
>
> *"It is intended the guide will raise awareness to support practitioners and staff to develop their understanding of the unique issues faced by LGBT people, and their families and carers within our community, and how these issues impact on end of life care"*
>
> *"The following core principles will help to achieve the delivery of high quality end of life care: care is person-centred and integrated; treat individuals with dignity and respect; communicate appropriately with compassion; identify and respect people's preferences and provide care after death."*

The guide goes onto clarify that next of kin has no legal or clear definition, and that this is not limited to those who are related by blood or marriage but is in fact anyone whom the patient nominates.

The guide also highlights specific considerations for bisexual people who may be 'excluded' from the LGBTQ+ community or face greater heteronormative bias, **and trans people,** notably that the Gender Recognition Act (2004) provides transgender people with enhanced privacy rights which means anyone who has learnt about a person's transitioned status in an 'official capacity' (such as health and social care workers) is not able to disclose this information without the person's express permission. To share this information without permission would be a criminal offence.

The guide follows the six steps of the end of life care pathway, beginning with initiating discussions as the end of life approaches and concluding with care after death. **Each step outlines the key questions to ask about the individual's care, the practitioner's role in that care and case studies highlighting best practice.**

Stage one is reproduced below as it is perhaps the most important, focusing on the discussions which take place as the end of life approaches and the role of the care giver and how the information which is gathered from the patient and their 'important people' at this stage can ensure quality of care throughout the patient's journey (all six stages are reproduced in Annex B):

Stage one: discussions which take place as the end of life approaches

Top tips

Note: These apply here but will also apply throughout all the stages of the pathway.

- Be open to different possibilities of relationships and avoid assumptions
- Identify who is important in the individual's personal network, essential for any future decisions that might need to made in their best interests
- Consider if communication is sensitive to differences and feels comfortable. How would this question feel to you if you were asked it?
- Be open and flexible when gathering information about someone's life history, ensure clear understanding before determining needs
- Consider living arrangements, the individual may live alone and may or may not have a partner
- Avoid euphemisms/slang terms as they can be easily misunderstood
- Be aware of over imposing 'political correctness' as this could be a barrier to communication due to fear of getting it wrong
- Communicate and offer information in an accessible and sensitive way in response to an individual's needs and preferences (9)
- Ensure language is inclusive but not over-complicated, for example 'tell me who is important to you in your life'
- Be prepared to educate and support those working with you in having these difficult conversations.

Your role

- Recognise when someone's condition has deteriorated
- Ask yourself the question 'Would I be surprised if this person were to die in the next 6-12 months?'
- Discuss with multi-disciplinary team colleagues and select appropriate time to begin discussions
- Recognise that LGBT people may be more likely to live alone, therefore may be socially isolated and having these discussions for the first time
- Recognise the barriers that might have prevented an individual and their family from accessing services and thus having such discussions
- Recognise the potential for prejudice and acknowledge the individual may have fears about this, and the negative impact it could have on communication
- Be aware that coming out can be really difficult and may feel as if it could jeopardise the quality of care given
- Be aware that older LGBT people in particular may have historical and experiential reasons for not identifying themselves
- Recognise the full strength of friendships and their significance in a person's support network
- An approach that conveys empathy, honesty and non-judgement and incorporates self-awareness is important
- Listening skills are paramount
- Ensure practitioners and staff have access to communication skills training to support open and honest discussions
- Provide relevant information as needed about a person's condition, services available and finances as appropriate
- Consider cultural and spiritual aspects for the individual and their family.

Articles published in 2016

(1) Compassion in Dying (London)

This is a useful guide to help LGBTQ+ patients plan ahead

“Planning ahead for the LGBT community” (produced 14 October 2016, in conjunction with Opening Doors and Stonewall)

Compassion in Dying help people prepare for the end of life: how to talk about it, plan for it, and record wishes. Stonewall supports all lesbian, gay, bi and trans people, here and abroad. Opening Doors London is the biggest project providing information and support services with and for older Lesbian, Gay, Bisexual and Trans people in the UK.

This comprehensive guidance includes the following statements:

> *“Most people have some form of opinion about how they would like to be treated at the end of their lives, regardless of their identity or background. For LGBT people in particular, your identity might have an impact on the treatment and care you would like to receive.”*
>
> *“Planning ahead is a way to express who you are and what’s important to you now, in case you’re later unable to make a decision for yourself. Recording your wishes gives you control over your future treatment and care and reassurance that the right decisions will be made. It can also be a good way to start conversations with those close to you about what you want in the future.”*

The guides touch on the concept of next of kin and explains that immediate family members do not have an automatic right to take decisions on someone else’s behalf. It also explains how to award someone else legal power:

> *“Many people think that those close to them can make decisions about their care or treatment if they are unwell, but this isn’t always the case. Even though these people must be consulted when a decision is made, they won’t have the final say.”*

The guide explains individual rights under the Mental Capacity Act 2005 which may be of particular importance to LGBTQ+ people in terms of the principle of capacity and nominating someone to act on their behalf.

It also includes information on the differences between a Lasting Power of Attorney, an Advance Decision and an Advance Statement, providing case studies to bring them to life, and 'top tips' for people to consider.

An Advance Statement may be of particular interest to some LGBTQ+ people as it helps any staff treating an individual to know how to care for them. An Advance Statement can cover things such as:
- Is there a name different to your given name that you would like to be called?
- What are your preferred pronouns?
- Do you prefer wearing certain clothes?

The guide stresses the importance of discussing things with a GP, but it is important to recognise that not all LGBTQ+ people have good relationships with their GPs, possibly trans individuals more so.

A series of links to additional sources of information is also provided:

(2) Marie Curie

This a key report.

Marie Curie have produced a report "Hiding who I am: The reality of end of life care for LGBT people" in partnership with the Kings Fund and The University of Nottingham, published June 2016.

The report draws on interviews with LGBT people living with a terminal illness, and their partners, conducted by the University of Nottingham (The Last Outing) and King's College London (ACCESSCare). It includes examples of indirect and direct discrimination, including a dying lady whose doctor refused to see her without a chaperone because she was a lesbian.

This begins with an opening statement:

> *"… this report and others show that LGBT people still worry about experiencing discrimination from health and social care staff and often do also experience it."*
>
> *"Many health and social care professionals say that they treat everyone the same. This is well-intentioned. However, as this report shows, sometimes for everyone to be equal, differences need to be acknowledged and given space to be celebrated."*

And within the body of the report:

> *"People approaching the end of life are among the most vulnerable in our communities. This vulnerability can be made worse if people fear that services might not understand their needs related to their sexual orientation or*

> *gender identity. These fears are based on real experiences. Older LGBT people have lived through times when identifying openly as lesbian, gay, bisexual or trans could mean, for example, being arrested, being defined as mentally ill and in need of treatment, or losing one's job, family or children."*
>
> *"… many older LGBT people have significant fears about palliative and end of life care services. They are concerned that service providers and health and social care professionals will be indifferent to their sexuality and gender identity, or, at worst, actively hostile. They worry that palliative and end of life care services are simply 'not for them', or that they will receive worse treatment than their straight peers."*
>
> *"Service providers and health and social care professionals can do significant and long-lasting damage to people by being insensitive or actively hostile to people's sexuality or gender identity at this time."*

In terms of next of kin, LGBTQ+ people are more likely to be estranged from their birth families, and be child-free, though many LGBT people will have alternative family structures in place and people at the end of life may choose to be surrounded by close friends and support groups which represent constructed support networks alongside biological ones. These factors are likely to lower the chances of stable, ongoing informal care for some LGBT people. In addition, informal care without adequate support from health and social care professionals can put immense strain on people. **The report reaffirms that confusion over who can be named as next of kin and a lack of legal clarity can result in partners or close friends of LGBT patients being overlooked**. This issue is difficult for hospitals and staff who may need to try to work out who is the person closest to them.

The report describes some of the additional difficulties trans people face may face when accessing general NHS services, citing a "*lack of understanding and lack of cultural competency around trans issues*" in the NHS. For this group there are further concerns about being recognised as their birth gender or a gender they do not identify with when they can no longer advocate for themselves, and in some cases, being treated after death as a gender which their family feel is appropriate but may not align with their wishes

The report touches on religious considerations at end of life. LGBTQ+ people can have equally deep-rooted spirituality but may worry that they will be treated with hostility by church-affiliated providers of hospice care. This underpins the fact that service providers must consider the role of recognised and unrecognised religious affiliations in delivering a holistic approach to end of life care which considers the whole person and what is important to them at the end of their live.

The report highlights the need for staff to avoid making assumptions about sexuality and gender:

> *"health and social care professionals wrongly understand sexuality purely as who someone has sex with, and not an aspect of someone's identity that plays a large role in determining who they love, who is important to them, who is a part of their family, and the way they need to be cared for at the end of life."*

> *"Some health and social care professionals may deliberately avoid conversations about sexuality and gender identity, or assume heterosexuality, because they feel a patient's sexuality has nothing to do with the care they deliver. Fifty seven per cent of health and social care professionals surveyed by Stonewall for the Unhealthy Attitudes project said that a person's sexuality had nothing to do with their healthcare."*

The report highlights the importance of advance planning for LGBTQ+ individuals citing that it enables patients to express preferences about the care they would like to receive, and who they would like to advocate for them on their behalf should they become unable to make or communicate their own decisions.

The report identifies the needs of partners who may be experiencing grief but whose support needs may get overlooked. In this context, the report also highlights the impacts on support networks and those who fulfil informal carer roles. Stonewall states that 95% of older gay people say they would prefer to live in their own home for as long as possible. However, some people fear providers of care could still discriminate against them placing extra strains on informal carers. This is underpinned by research led by King's College London which concluded that Health Care Professionals must make changes to their practice to improve care for terminally ill LGBTQ+ people.[9]

The report describes what LGBTQ+ people want:

- 60% said they would prefer health and social care **services that were specifically for LGBTQ+ people**, while 63% said they would like to be able to access health and social care services run by LGBT people. However, many were wary of segregation.

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[9] HCPs must address discrimination to improve LGBT care (mariecurie.org.uk)

- They said that including **images of LGBTQ+ people or LGBTQ+ symbols** such as the rainbow flag in promotional materials would make them more comfortable using palliative care services.
- Promote **inclusive language** which may help people feel they can disclose their sexuality or gender without any fear. This can be as straightforward as asking questions like “who are the most important people in your life?” and what someone’s preferred name is to alleviate any pressure on gender identity.
- **Forms need to fill in should also use inclusive language** and serve as an opportunity to start conversations between patients and health and social care professionals.
- By **giving patients an option to self-identify as LGBT**, this can start a helpful conversation with those involved in their care to discuss what is important to them at the end of life, and who they would like to be involved in their care.
- **Advance care planning** can become increasingly important for LGBT people at the end of their life.
- **healthcare professionals should be encouraged to have open discussions about who is important to patients**. Staff should be supported to explore any existing relationship dynamics which may affect a patient’s last wishes and preferences and help identify who needs support during bereavement by having honest and open discussions with the patient
- **encourage the professionals involved in care to signpost support for carers earlier,** to ease the pressure on those providing care to a loved one

(3) Dying Matters

Dying Matters have produced a resource on end of life care for LGBT people. The publication, “Being Accepted Being Me: Understanding the end of life care needs for older LGBT people” 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. It has been jointly produced and written by Kathryn Almack of the University of Nottingham and NCPC (the parent charity of Dying Matters). It can be seen as a complement to the Marie Curie resource, “Hiding who I am: The reality of end of life care for LGBT people” Unfortunately, this resource needs to be purchased in order to access it, and so it’s contents have not been reviewed.

Articles published in 2018

(1) Marie Curie

This is a useful resource for staff, hospitals, and health care settings

Marie Curie have produced information for staff and health organisations including "Marie Curie nurse Tracey's blog - Supporting LGBTQ+ people at the end of life (4 July 2018). **In this, Tracey identifies six learning points for staff:**

- Remember that respect and wellbeing go hand in hand
- Using the right language matters
- It's okay to check, so you get it right
- You never know what someone may have experienced in past
- It's everyone's right to choose how much to share
- Get trained up

(2) Care committed to me - Delivering high quality, personalised palliative and end of life care for Gypsies and Travellers, LGBT people and people experiencing homelessness.

This publication provides useful learning from other organisations who have taken steps to become more inclusive

This provides a resource for commissioners, service providers and health, care, and support staff.[10]

The following organisations worked together as the Tackling Inequalities in End of Life Care for Minority Groups VCSE project group to produce this report: 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 report provides various case studies that support the delivery of more inclusive services. Four of these are described below, along with key learning points:

(i) Royal Trinity Hospice

- The hospice extended their collection demographic information to include, both sexual orientation and gender identity, helping to build a complete picture of their patients. This information means the hospice can better understand staff and patient needs.

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[10] care_committed_to_me_web.pdf (hospiceuk.org) https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/care_committed_to_me_web.pdf?sfvrsn=0

- They reviewed their internal policies and procedures to ensure they are actively inclusive of LGBTQ+ people and take account of any specific needs.
- The hospice invited in LGBTQ+ organisations and individuals to provide staff awareness training, increasing staff ability to proactively deliver more inclusive services and ensure LGBTQ+ service users can develop personalised care plans and feel listened to when determining the right care for them.
- This internal work has helped the hospice with becoming a Stonewall Diversity Champion.
- The hospice recognised that to be inclusive they needed to be visible with that inclusivity which has led to the inclusion of rainbow pins for staff and rainbow stickers being placed within the hospice.
- The hospice has engaged with the local community with a dedicated group meeting regularly. This 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 LGBTQ+ people and communities.
- The hospice now has a reputation for being inclusive. Through their engagement with local LGBTQ+ communities, further barriers to inclusion have been identified, enabling Trinity to embed LGBTQ+ inclusion within their work rather than see it as a one-off action, helping LGBTQ+ 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 LGBTQ+ people but over time staff have understood that LGBTQ+ 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 LGBTQ+ patients without those patients worrying whether their sexual orientation or gender identity will be a barrier for them.

(ii) Saint Francis Hospice

The hospice developed a training module which provides health and social care professionals with an opportunity to explore the impact of sexual orientation and gender identity on palliative and end of life care

Top tips:

- 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. 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.
- A whole system approach is needed to be able to respond to the unique needs of LGBT people.

(iii) Wigan and Leigh Hospice

Top tips

- Deliver education on both LGB and Trans issues
- Provide accessible and relevant materials available for staff and patients
- Provide a safe space commitment to ensure all staff and patients feel safe and supported
- Increase knowledge of LGBTQ+ populations in hospice through better monitoring
- Make LGBTQ+ inclusion visible throughout the hospice
- Create long-term relationships and embedding best practice.

(iv) The London Hospices LGBTQ+ Network

The 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 LGBTQ+ people and better support for LGBTQ+ hospice staff and volunteers.

Top tips

- Don't think about special services for LGBTQ+ people, but more about how to make existing services accessible and inclusive.
- Lessons learned from considering LGBTQ+ 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.

Articles published in 2019

Marie Curie

Marie Curie have produced a guide for the public called planning ahead (latest edition published July 2019). This is not specifically aimed at LGBTQ+ people. It states:

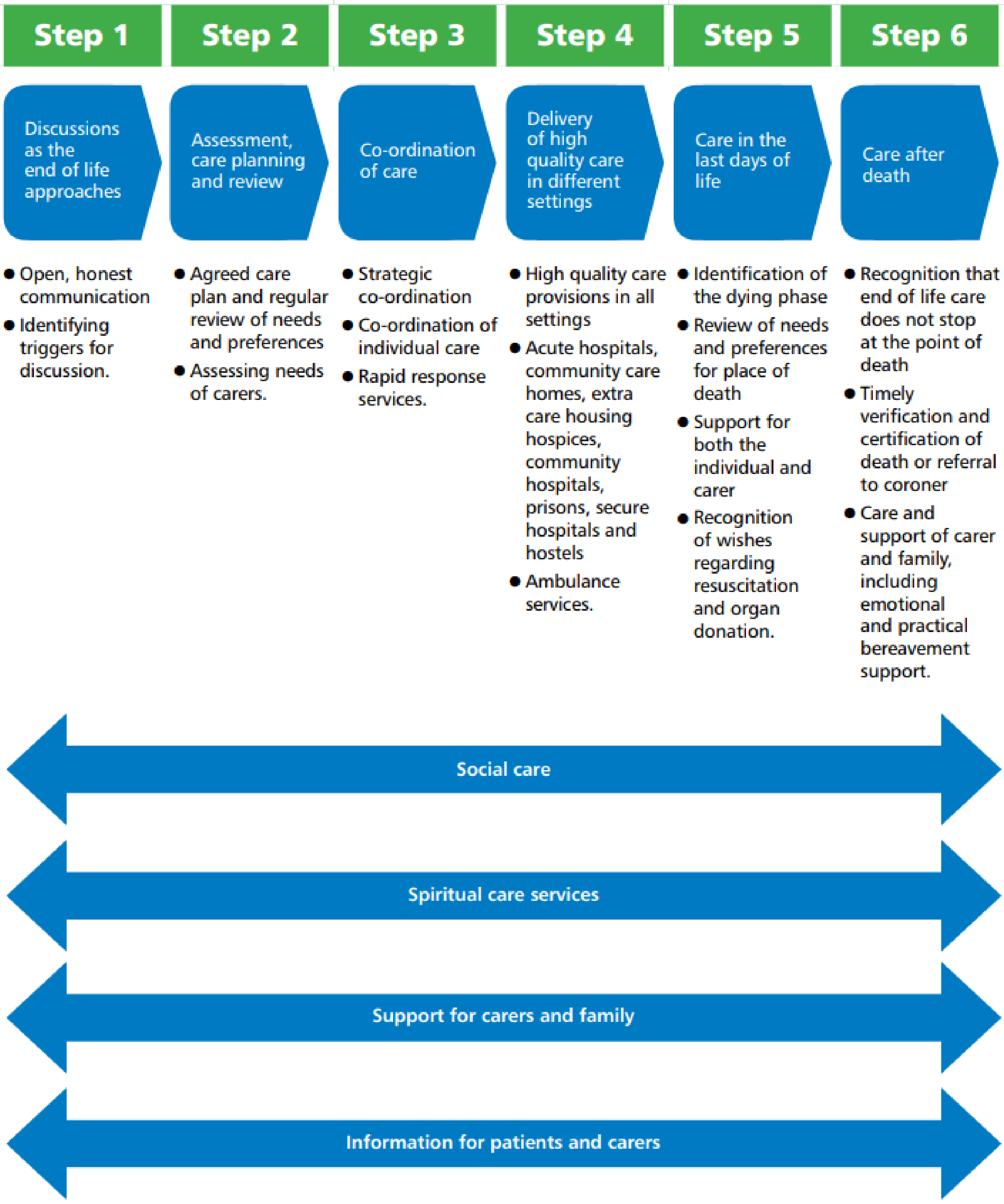
> *"You may not feel like planning ahead when you're ill, but thinking about the future now and making your wishes known will help you feel more in control. It can also help those close to you handle your affairs if you aren't able to. This booklet has information about some of the things you might want to think about, like deciding where and how you want to be cared for or making a Will."*

The guide includes information on choosing where to be cared for; planning your care in advance; setting up Power of Attorney; making a will and planning your funeral.

Annex B – Extracts taken from the NHS National End or Care Programme leaflet

"The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people"

The six steps of the end of life care pathway, beginning with initiating discussions as end of life approaches and concluding with care after death. A guide for staff, Trusts and CCGs



Step 1

Discussions as the end of life approaches

- Open, honest communication
- Identifying triggers for discussion.

Step 2

Assessment, care planning and review

- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers.

Step 3

Co-ordination of care

- Strategic co-ordination
- Co-ordination of individual care
- Rapid response services.

Step 4

Delivery of high quality care in different settings

- High quality care provisions in all settings
- Acute hospitals, community care homes, extra care housing hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services.

Step 5

Care in the last days of life

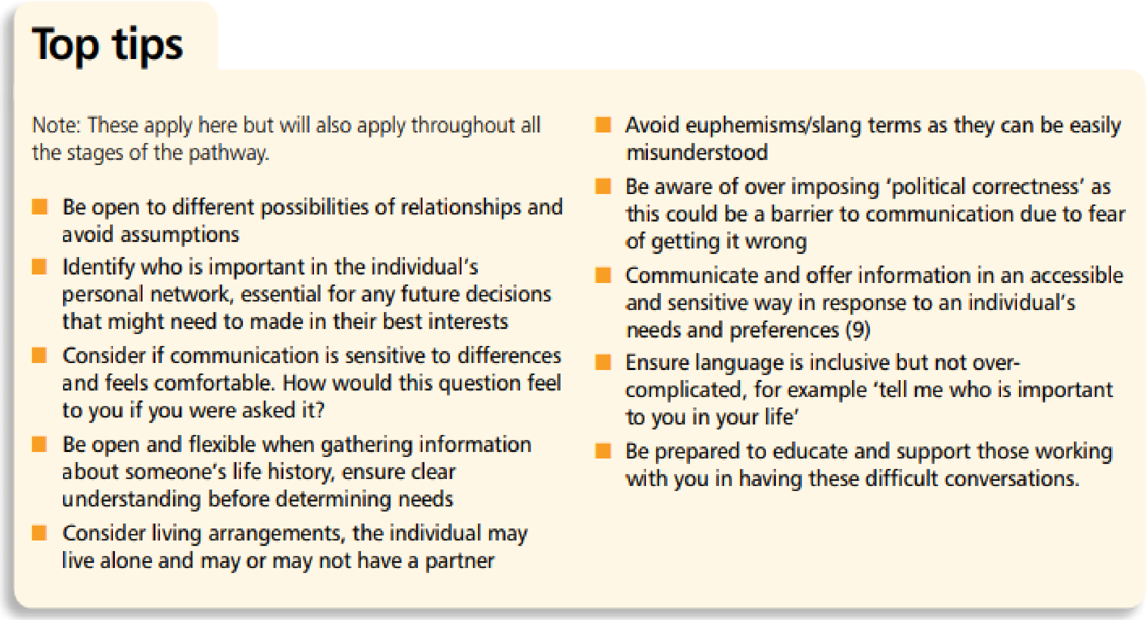
- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both the individual and carer
- Recognition of wishes regarding resuscitation and organ donation.

Step 6

Care after death

- Recognition that end of life care does not stop at the point of death
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support.

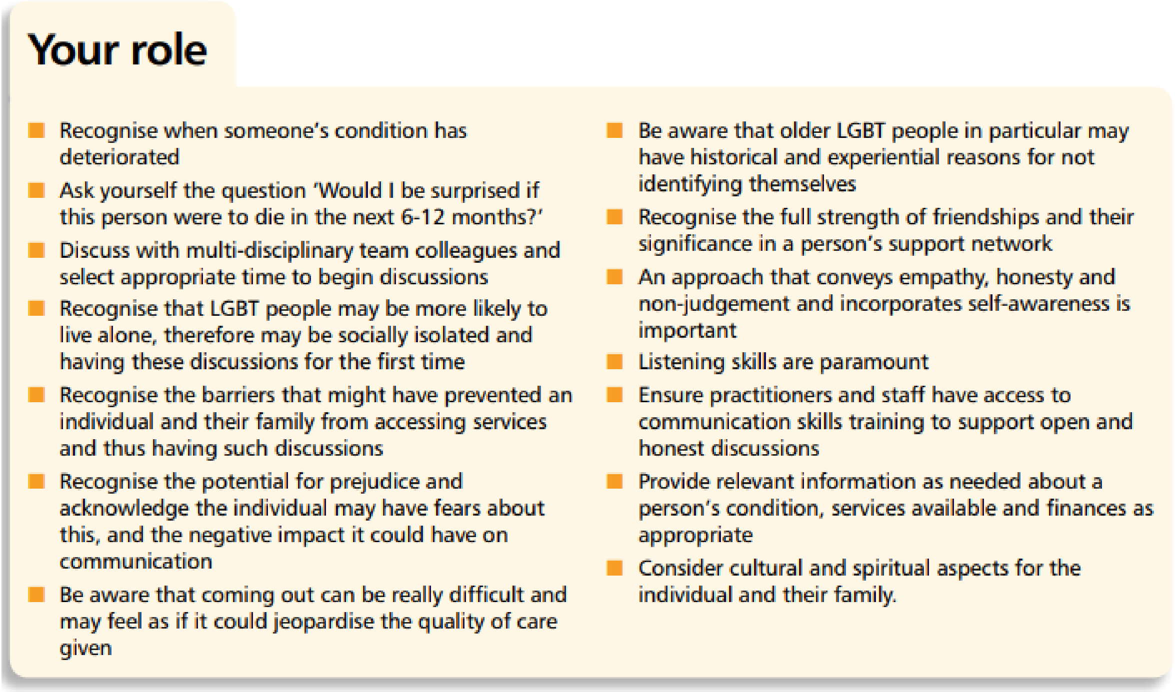
Stage one: discussions which take place as the end of life approaches



Top tips

Note: These apply here but will also apply throughout all the stages of the pathway.

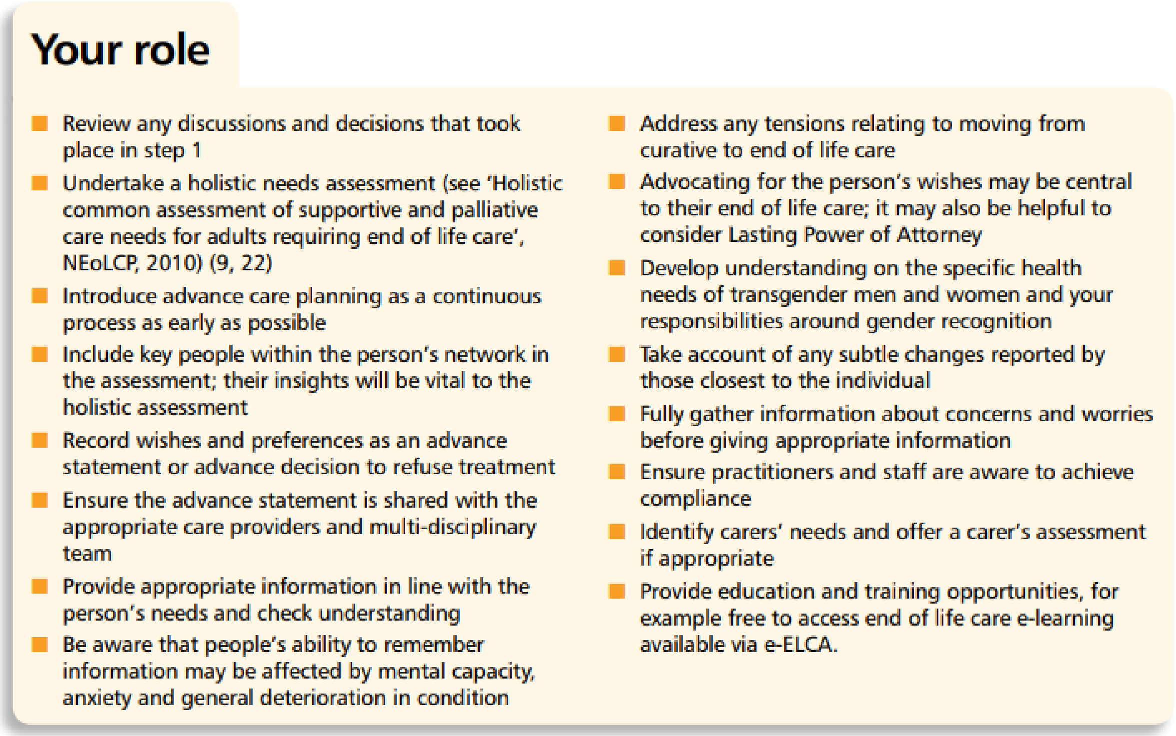
- Be open to different possibilities of relationships and avoid assumptions
- Identify who is important in the individual's personal network, essential for any future decisions that might need to made in their best interests
- Consider if communication is sensitive to differences and feels comfortable. How would this question feel to you if you were asked it?
- Be open and flexible when gathering information about someone's life history, ensure clear understanding before determining needs
- Consider living arrangements, the individual may live alone and may or may not have a partner
- Avoid euphemisms/slang terms as they can be easily misunderstood
- Be aware of over imposing 'political correctness' as this could be a barrier to communication due to fear of getting it wrong
- Communicate and offer information in an accessible and sensitive way in response to an individual's needs and preferences (9)
- Ensure language is inclusive but not over-complicated, for example 'tell me who is important to you in your life'
- Be prepared to educate and support those working with you in having these difficult conversations.



Your role

- Recognise when someone's condition has deteriorated
- Ask yourself the question 'Would I be surprised if this person were to die in the next 6-12 months?'
- Discuss with multi-disciplinary team colleagues and select appropriate time to begin discussions
- Recognise that LGBT people may be more likely to live alone, therefore may be socially isolated and having these discussions for the first time
- Recognise the barriers that might have prevented an individual and their family from accessing services and thus having such discussions
- Recognise the potential for prejudice and acknowledge the individual may have fears about this, and the negative impact it could have on communication
- Be aware that coming out can be really difficult and may feel as if it could jeopardise the quality of care given
- Be aware that older LGBT people in particular may have historical and experiential reasons for not identifying themselves
- Recognise the full strength of friendships and their significance in a person's support network
- An approach that conveys empathy, honesty and non-judgement and incorporates self-awareness is important
- Listening skills are paramount
- Ensure practitioners and staff have access to communication skills training to support open and honest discussions
- Provide relevant information as needed about a person's condition, services available and finances as appropriate
- Consider cultural and spiritual aspects for the individual and their family.

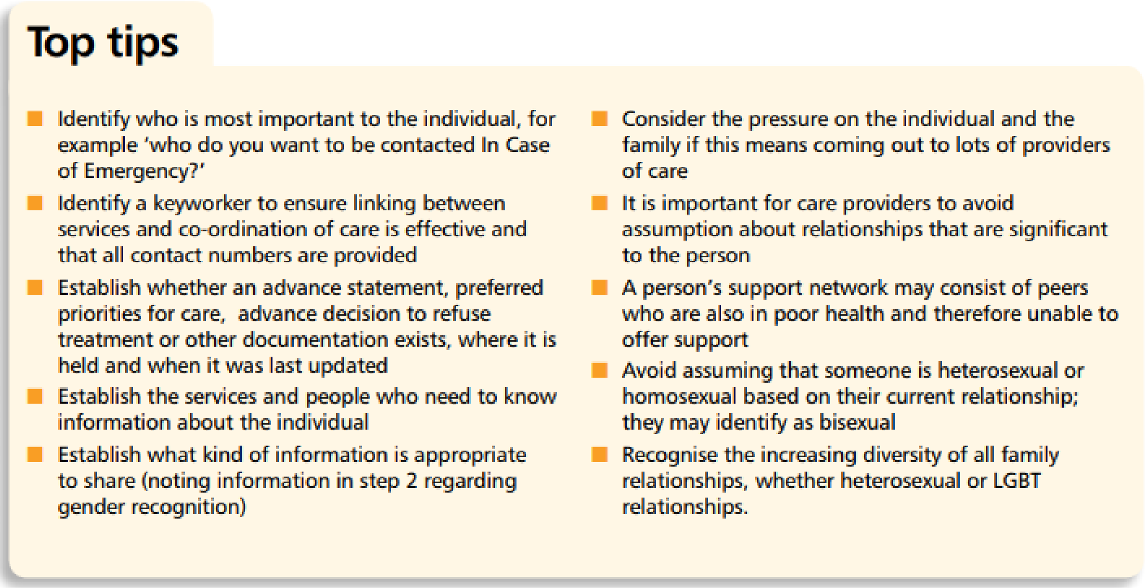
Stage two is the assessment, care planning and review:



Your role

- Review any discussions and decisions that took place in step 1
- Undertake a holistic needs assessment (see 'Holistic common assessment of supportive and palliative care needs for adults requiring end of life care', NEoLCP, 2010) (9, 22)
- Introduce advance care planning as a continuous process as early as possible
- Include key people within the person's network in the assessment; their insights will be vital to the holistic assessment
- Record wishes and preferences as an advance statement or advance decision to refuse treatment
- Ensure the advance statement is shared with the appropriate care providers and multi-disciplinary team
- Provide appropriate information in line with the person's needs and check understanding
- Be aware that people's ability to remember information may be affected by mental capacity, anxiety and general deterioration in condition
- Address any tensions relating to moving from curative to end of life care
- Advocating for the person's wishes may be central to their end of life care; it may also be helpful to consider Lasting Power of Attorney
- Develop understanding on the specific health needs of transgender men and women and your responsibilities around gender recognition
- Take account of any subtle changes reported by those closest to the individual
- Fully gather information about concerns and worries before giving appropriate information
- Ensure practitioners and staff are aware to achieve compliance
- Identify carers' needs and offer a carer's assessment if appropriate
- Provide education and training opportunities, for example free to access end of life care e-learning available via e-ELCA.

Stage three is coordination of care:



Top tips

- Identify who is most important to the individual, for example 'who do you want to be contacted In Case of Emergency?'
- Identify a keyworker to ensure linking between services and co-ordination of care is effective and that all contact numbers are provided
- Establish whether an advance statement, preferred priorities for care, advance decision to refuse treatment or other documentation exists, where it is held and when it was last updated
- Establish the services and people who need to know information about the individual
- Establish what kind of information is appropriate to share (noting information in step 2 regarding gender recognition)
- Consider the pressure on the individual and the family if this means coming out to lots of providers of care
- It is important for care providers to avoid assumption about relationships that are significant to the person
- A person's support network may consist of peers who are also in poor health and therefore unable to offer support
- Avoid assuming that someone is heterosexual or homosexual based on their current relationship; they may identify as bisexual
- Recognise the increasing diversity of all family relationships, whether heterosexual or LGBT relationships.

Your role

- Ensure that wishes and preferences are clear and can be understood
- Ensure communication systems are in place and clear with all service providers and identify the key contacts across all organisations
- Check whether the person is on the Supportive Care Register or an electronic palliative care co-ordination system (EPaCCS)
- Provide access to 24/7 advice, support and urgent care including medicines and equipment in the event of a crisis, day or night (9)
- Refer to specialist palliative care, appropriate to a person's needs and preferences (9)
- Inform out of hours services of any anticipated needs and provide the individual and their family with essential contacts
- Facilitate/utilise anticipatory prescribing as appropriate
- Offer support for social, practical and emotional needs, appropriate to preferences, to maximise independence and social participation (9); this could include finding out about LGBT services in the local area
- Be aware of the complexity of relationships and the difficulty in explaining them to carers or having to do so multiple times
- Be aware that the person and their family may have encountered homophobia/biphobia/transphobia or expect to do so when meeting care providers for the first time
- Be aware a person may 'depersonalise' their home, for example take down photographs, to ensure feeling safe from discrimination and hostility when encountering a variety of care providers
- Be aware there may be a need to provide support for people to lead their lives as they choose; this could include contact with other LGBT people
- Promote acceptance of all relationships and provide learning opportunities for colleagues about equality and diversity, which includes issues relating to LGBT people.

Stage four relates to quality of care in different settings

Top tips

- Ensure the environment and organisational literature conveys images that support a range of family situations, portraying a variety of relationships, including same-sex relationships
- Review organisational mission statement and core values to ensure these are inclusive and person-centred
- Practitioners and staff may need support to bring about change
- Collaborate with other providers to share good practice and identify models of practice
- Identify a measured response to environmental changes, it may be that acknowledgement of difference is more appropriate than high profile messages
- Positively challenge poor practice and embed awareness with education and training to ensure a learning culture is promoted
- Be aware that individuals and their families can encounter multiple providers of care at the end of life
- Promote open and honest communication
- Involve LGBT people in reviewing end of life care services.

Your role

- Develop or be aware of a policy for end of life care in your care setting
- Ensure all staff are aware of and understand the core principles of end of life care and values
- Promote or participate in end of life care training, including communication skills, assessment and care planning, advance care planning, symptom management and ensuring comfort and well-being
- Ensure due consideration is given to the environment in which end of life care is delivered
- Engage LGBT people and organisations in the process on continuous service improvement
- Develop links with other care providers to develop practice.

Stage five is about are in the last days of life

Top tips

- Ensure that communication continues to be open now the person is dying
- Clarify the level of information that people want as this may have changed as the person deteriorates
- Recognise discussions about wishes and preferences may have already taken place, but some may not have had the opportunity
- Check if any wishes have changed and ensure care is still tailored to needs; place of death may be part of this but ensure plans are realistic
- Recognise support needs of friends/carers/family; consider how relationships are being affected by the dying process
- Support those working with the individual and their family, especially in the recognition of dying and communication skills
- Identify and address any spiritual and religious needs (9)
- Identify who the person wants present at the bedside and facilitate where possible
- Be aware there may be conflicts of interest between people involved, such as those closest to the person and members of their family of origin
- Be open to specific requests; the individual may want a wide group of friends with them or particular items of significance.

Your role

- Use a validated integrated care pathway for care in the last few days, such as the Liverpool Care Pathway
- Be aware that using a care pathway does not hasten or postpone death; occasionally a person's condition may improve and the pathway can be discontinued
- Ensure anticipatory prescribing is in place in advance of need
- Identify any concerns friends and family may have and provide information appropriately, sensitively and honestly so they know what to expect in the last few days
- Ensure where possible that a person's preferences and wishes are met
- Be aware that the person's partner may be their main carer and feel loss of the partnership; support them in restoring that part of the relationship if possible
- Ensure that care is inclusive and offers support to all involved, regardless of tensions
- Ensure practitioners and staff remain impartial if there is family conflict but recognise difficulties and support all concerned.

Stage six is about Care after death

Your role

- Care for the body of a person in a dignified and culturally sensitive way (9)
- Respect individual relationships, faiths and beliefs and take steps to meet their requirements
- Be aware of verification and certification of death policies and develop them if not in place
- Ensure key people closest to the deceased are involved in care immediately after death, if they wish to be
- Provide information to the relevant people about the next steps and ensure the correct person receives the death certificate
- Offer information on bereavement support or consider need for referral as appropriate and in accordance with their preferences (9)
- Ask for specialist advice to discuss bereavement needs assessment if necessary (17)
- Offer practitioners and staff the opportunity for debriefing after a death
- Provide a comfortable environment for practitioners and staff to discuss and share their concerns.

Annex C – list of all publications reviewed

- Dying Matters have produced a resource on end of life care for LGBT people. The publication, "Being Accepted Being Me: Understanding the end of life care needs for older LGBT people" (Dying Matters, August 2016)

- LGBT people face discrimination as they die (Marie Curie, October 2016) Nearly three-quarters (74%) of lesbian, gay, bisexual and trans (LGBT) people are not confident they'll get suitable end of life care.

- The National LGBT Cancer Network (USA) offers LGBT cultural competence training to healthcare systems across the country. https://cancer-network.org/cancer-information/cancer-and-the-lgbt-community/lgbt-palliative-care/ (no publication date)

- Stonewall – information on issues affecting LGBTQ+ people and a useful glossary of terms (no publication date)

- The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people (NHS National End of Life Care Programme, June 2012)

- Marie Curie nurse Tracey's blog – Supporting LGBTQ+ people at the end of life (4 July 2018).

- Marie Curie have produced a guide for the public called planning ahead (latest edition published July 2019).

- Marie Curie resource, "Hiding who I am: The reality of end of life care for LGBT people" (June 2016)

- Marie Curie report Improving care for lesbian, gay, bisexual and trans* people at the end of life (2015 – a project aimed at improving care for sexual and gender minorities at the end of life is achieving high levels of community engagement).

- Marie Curie, together with the Kings Fund, the Gay Men's Health charity (GMFA), and The University of Nottingham have published a Leaflet for patients – Palliative and end of life care for LGBT people (no publication date).

- Marie Curie "Caring for LGBTQ+ people at the end of life" https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/equality-diversity/lgbt-end-life (February 2019)

- Compassion in Dying (London) "Planning ahead for the LGBT community" (produced 14 October 2016, in conjunction with Opening Doors and Stonewall)

- National Voices, “A Narrative for Person-Centred Coordinated Care”, https://www. england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf (2013)

- Terrence Higgins Trust (THT) website includes advice around Advance decisions (living wills) (no publication date)

- Interviews with LGBT people living with a terminal illness, and their partners, by the University of Nottingham (The Last Outing) and King’s College London (ACCESSCare).

- Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study - Katherine Bristowe, Matthew Hodson, Bee Wee, Kathryn Almack, Katherine Johnson, Barbara A Daveson, Jonathan Koffman, Linda McEnhill, Richard Harding, 2018 (sagepub.com)

- Leeds Palliative Care: Palliative & End-of-Life Care for LGBT People (2019) - A guide for lesbian, gay, bisexual and/or trans people facing advanced illness. https://leedspalliativecare.org.uk/wp-content/uploads/2019/08/LGBT_End-of-Life-Leaflet.pdf

- Palliative and End-of-Life Care for Lesbian, Gay, Bisexual, and Transgender (LGBT) Cancer Patients and Their Caregivers (2018)

- Research led by King’s College London concludes that HCPs must make changes to their practice to improve care for terminally ill LGBT people. HCPs must address discrimination to improve LGBT care (mariecurie.org.uk) (2017)

- Hospice UK: Care committed to me: Delivering high quality, personalised palliative and end of life care for Gypsies and Travellers, LGBT people and people experiencing homelessness.

Other identified resources not reviewed for this piece of work

- Book: LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice Paperback

- YouTube lectures: Kings College London; Hospice UK

- Hospice and Palliative Care for Older Lesbian, Gay, Bisexual and Transgender Adults: The Effect of History, Discrimination, Health Disparities and Legal Issues on Addressing Service Needs (USA, 2015)

- The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: A systematic review, thematic synthesis and modelling of the literature (USA, 2016)

- Healthcare and End-of-Life Needs of Lesbian, Gay, Bisexual, and Transgender (LGBT) Older Adults: A Scoping Review (USA, 2017)

- Dying in Long-Term Care: Perspectives from Sexual and Gender Minority Older Adults about Their Fears and Hopes for End of Life (USA, 2020)

- LGBTQ+ Inclusive Palliative Care in the Context of COVID-19: Pragmatic Recommendations for Clinicians (USA, 2020)

- Barriers to palliative care in sexual and gender minority patients with cancer: A scoping review of the literature (USA, 2021)

How to contact Healthwatch

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