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Our NHS is committed to respecting

providers of palliative care like Marie Curie and other hospice services.

But this report and others show that LGBT people still worry about experiencing discrimination from

do also experience it.

Many health and social care

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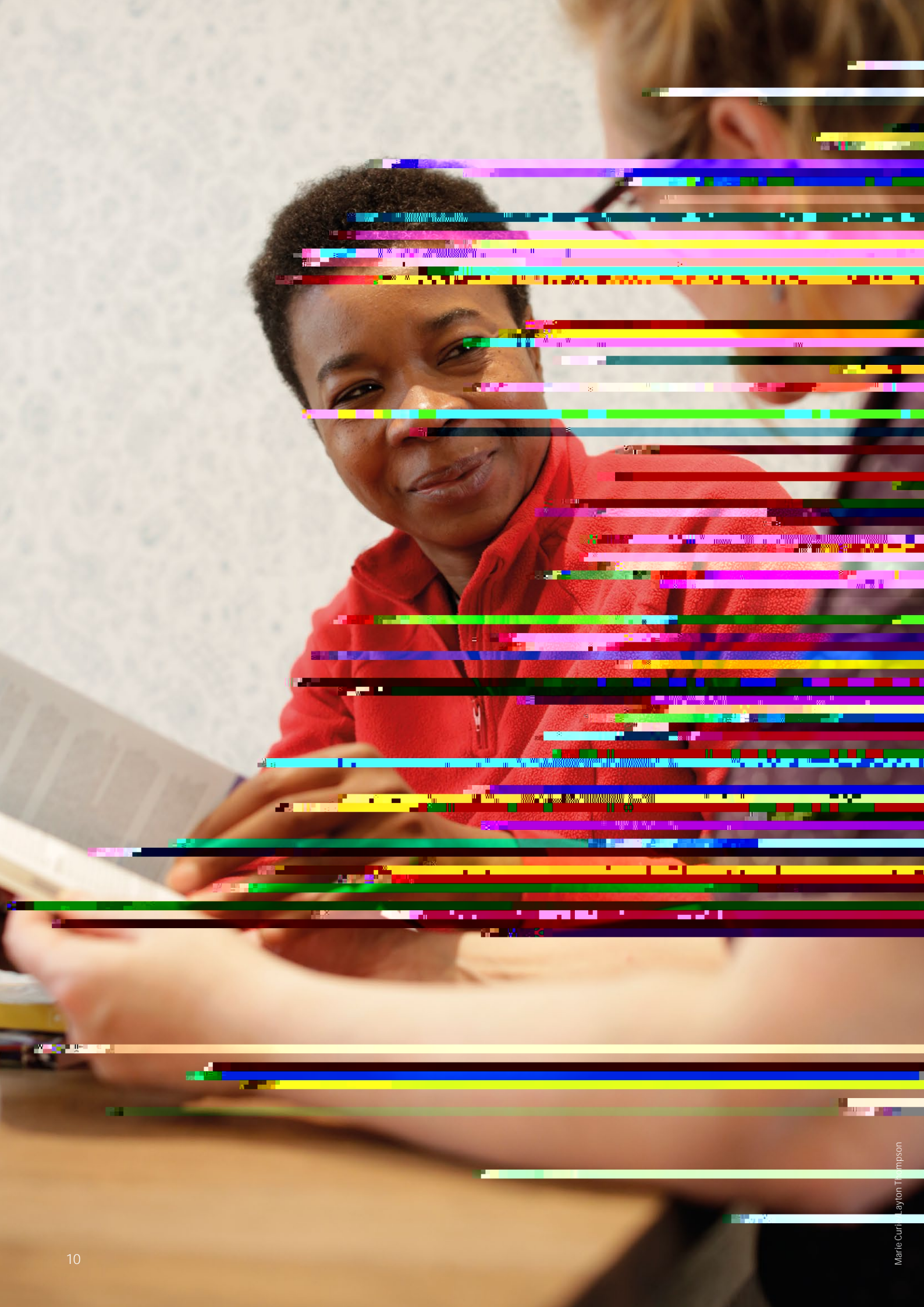
Everyone should have the right to high-quality palliative care when they have a terminal illness, regardless of their condition, where they live, or their personal circumstances. The UK has

Palliative care is for people living with a terminal illness where a cure is no longer possible. It's also for people who have a complex illness and need their symptoms controlled. Although these



Other abbreviations: As well as the widely used abbreviation LGBT, there are other abbreviations, acronyms and groups used by both academics and thought leaders, as well as LGBT people themselves. These include but are not limited to: LGBTQQIAA (Lesbian, Gay, Bi, Trans, Queer, Questioning, Intersex, Asexual, Allies), LGBTQI (Lesbian, Gay, Bi, Trans, Queer, Questioning, Intersex) and GSRD/M (Gender, Sexuality and Romantic/ Relationship Diversity/Minority – a non-hierarchical term that also includes relationship diversities such as non-monogamy and polyamory).

Marie Curie recognises that,



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.

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.

In May 2016, the Care Quality Commission (CQC) published a

In England, there have been numerous policy reports noting the barriers that LGBT people experience at the end of life, and urging action:

- In 2008, the *English End of Life Care Strategy Quality Impact Assessment*¹¹ noted that, in terms of access to quality palliative and end of life care, LGBT people were at the most risk of experiencing discrimination.
- In 2011, the National Council for Palliative Care produced *Open to All? Meeting the Needs of Lesbian, Gay, Bisexual and Transgender People Nearing the End of Life*¹², a report based on a survey of service providers and users. It found that LGBT people were concerned that palliative and end of life care services were not open to them and they might experience discrimination.
- In 2012, the National End of Life Care Programme published *The Route to Success in End of Life Care – Achieving Quality for Lesbian, Gay, Bisexual and Transgender People*, a guide for providers and practitioners of palliative and end of life care¹³.

Around 572,000 people die annually



Looking at the existing policy and research papers as well as case studies from *The Last Outing* and ACCESSCare,

experienced by LGBT people at the end of life:

1. Anticipating discrimination:

People access palliative care services late or not at all, either because they anticipate stigma or discrimination or they think the service is not for them²⁷. Stonewall reports that

support services will be able to understand and meet their needs²⁸.

2. Complexities of religion and LGBT end of life care:

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.

3. Assumptions about identity and family structure:

Health assumptions about people's sexuality or gender identity that have an impact on their experience of palliative and end of life care. Evidence suggests that some clinicians do discriminate on the basis of sexual orientation²⁹.

4. Varied support networks:

LGBT 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. LGBT

people can also feel concerned that their loved ones will not be respected and recognised as next of kin.

5. Unsupported grief and bereavement:

Partners feel isolated or unsupported during bereavement because of their sexuality.

6. Increased pressure on LGBT carers:

There is increased pressure on informal carers, because people are accessing palliative and end of life care services late or not at all.

LGBT people may also experience barriers to palliative care because they are:

- three times more likely to be single
- less likely to have children
- far more likely to be estranged from their birth families (though many LGBT people will have alternative family structures in place)
- experience damaging mental health problems³⁰

These factors are likely to lower the chances of stable, ongoing informal care for some LGBT people. Informal care, particularly from a partner, plays a vital role in ensuring someone gets access to palliative care.

However, further research is needed

to health and social care services at the end of life, and on how adaptable hospice and palliative care services are to alternative family structures.

to and relationships with a whole range of services, including health guide wtisgeo th

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,

need of treatment, or losing one's job, family or children.

Lesbian, gay, bisexual and trans people do not all experience the same kinds of discrimination. The NHS England guide on ensuring the route to success in end of life care for LGBT people notes that people who identify as trans

experiences and issues to those who identify as gay or lesbian³¹.

There is also a notable lack of understanding and knowledge about bisexual people's relationships. This could lead to an even greater gap in addressing the needs of this community and creating services which are able to support their particular life experiences.

Bisexual men and women can also often encounter discrimination within lesbian and gay support networks and communities³² which will clearly have an impact on their approach

Attitudes have also changed. In 2015, 60% of British people said they supported same-sex marriage, up from 47% in 2007³⁴. In 1983, 50% of

In 2010, research for the Equality and Human Rights Commission suggested that some older LGB people were delaying access to social care services for as long as possible out of fear of discrimination⁴², but said this was an area that needed further research.

Interviews for the ACCESSCare project also revealed evidence of anxiety about care delivered in the home; in particular, individuals faced constant fear associated with disclosure of their identity, and how that would be responded to.

For LGBT people this situation – as well as every contact with a new health and social care professional – represents another coming out, which brings with it anxiety about the reaction of the health and social care professional and whether this will impact on the care they receive. This kind of anxiety in itself has a negative impact on the experience of care at the end of life insofar as it diminishes the wellbeing of the dying person and their family and friends.

We know this kind of anxiety is not limited to care at home. Some respondents to *The Last Outing* survey also said that health and social care settings like hospices, care homes, and hospitals do not represent safe spaces to disclose important aspects of their

towards their partner at a time when they may feel more vulnerable.

The research suggests that these factors are leading LGBT people to delay access to services⁴³ of early access to palliative care are well-established, particularly for people with terminal cancer, where earlier involvement of palliative care

- improve quality and length of life^{44, 45}
- result in fewer hospital admissions and reduce the likelihood of dying in hospital⁴⁶
- help family carers to have lower levels of anxiety and depression⁴⁷

If LGBT people are delaying or refusing access to health and social care support at home at the end of life, it may also mean that they are relying heavily on family and friends to provide informal care. While care provided by family and friends is a vital part of palliative and end of life care, informal care without adequate support from health and social care professionals can put immense strain on people. Eighty-two per cent of carers say that caring has a negative impact on their health and 55% say their caring role has contributed to depression⁴⁸.

Sixty per cent of survey respondents to *The Last Outing* survey said they would prefer health and social care services

*'What do you need a chaperone for?'
She answered, 'Because she's
a lesbian!'*

*I can't tell you how furious I was,
but I was just simply too ill to
deal with it."*

*"I couldn't imagine going back into
that way of living and hiding who I
am. My worst nightmare would be
being in an old people's home. I bet
it's everyone's worst nightmare.
The thought of going back into the
closet really, into a heterosexual
environment, would be awful at the
end of your life. If your past has been*

*it's hard to think about the future
(with those sorts of worries)."*
– Sandra, lesbian, 60

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 the end of their life as any other patient. Gay men in particular may be concerned that they will be treated

providers of hospice care⁴⁹.

Like heterosexual people, LGBT people can have deeply rooted faith (residual or active) and belief structures, as well

This area is under-researched, but service providers must consider the role of recognised and unrecognised

holistic approach to end of life care

non-disclosure, where people neither revealed their sexuality nor claimed a heterosexual identity.

While passive non-disclosure might mean that people avoid stigma and discrimination, it also means that there may be a lack of recognition by health and social care professionals of

“Sometimes, when we were talking to people and Sharon said ‘my partner’ people might say ‘what’s his name?’ and some thought I was her sister but then were apologetic when I told them.” – Norma, 54

‘They don’t ask you about your sexuality, they ask about your heterosexuality: ‘Do you have





It is crucial that healthcare professionals and those working with patients and their loved ones encourage discussions about who is

be supported to explore any existing relationship dynamics which may

preferences and help identify who needs support during bereavement by having honest and open discussions with the patient.

can't be as open. But then having experienced the death of my father years ago, it's death that people struggle with, and if you then add a







"I always talk in terms of 'those who are important to you' as opposed to 'family' so I am open to that being whoever it is. The key for me is asking the patient."

next of kin and dealing with complex family relationships can be challenging

"One person struggled to feel that his partnership was acknowledged and accepted. Another was not allowed by the deceased's family to take up his role. Another kept up the pretence of being a carer until after his partner had died."

training in the survey, to understand whether there was appropriate training in place on end of life care for LGBT people, for care providers and


demand is for improving this.

Research shows that LGBT people approaching the end of life have a clear idea of what good care looks like for them. Two of the most important indicators are whether or not they are receiving care centred around them as



"I feel comfortable disclosing my sexuality/gender to those providing my care and know that they will support me in this decision."

providing my end of life care will take



To achieve this, Marie Curie is committed to:

- ensuring that literature and materials in our services represents all diverse groups, including LGBT
- reviewing the language used throughout hospice services to ensure more inclusive terms such as 'partner'
- further developing internal monitoring systems to understand the demographic of people accessing hospice services, including LGBT people
- training to understand that LGBT or needs at the end of life
- highlighting the importance of patient-centred care which looks to establish which people and what factors are important to the patient
- policies and practices relating to negative or discriminatory attitudes
- working with local and national LGBT groups to raise awareness of high-quality end of life care
- working with other national and local charities to help promote the importance of LGBT-appropriate

LGBT people, like everyone else, have the right to be treated with dignity and respect and spend their last months, weeks, and days with the people that they love.

The hospice and palliative care sector has always been committed to caring for people and understanding their needs, but on the issue of care for LGBT people, there is a danger that the sector is lagging behind the rest of the health and social care system.

We know that with attitudes to LGBT people changing and the number of people dying annually growing that there will be substantial demand for person-centred palliative care.

Providers of palliative care must start making these changes now, so that LGBT people not only see hospice and palliative care services as 'for them', but places where they and their families of choice are actively welcomed.


Marie Curie is committed to seeing this change happen in our own services and to work in partnership with other providers to see a greater focus across the UK on the care and support LGBT people need at the end of their lives.



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