

“Hiding who I am”

The reality of end of life care for LGBT people

In partnership with



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Care and support
through terminal illness



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Foreword



Visibility of LGBT people and their needs has grown substantially over the last decade – a change which is helping combat the invisibility and isolation which impacts so negatively on this community. However, in the past many LGBT people in the north of Ireland have often felt stigmatised, and lived with the anxiety of potential exclusion, violence and even criminalisation. The legacy from that time has meant that now, accessing care as an openly LGBT person can be daunting. For many LGBT people who have faced discrimination in accessing care or invisibility of their specific health needs – coming out to health professionals can create anxiety and fear, even when they have a terminal illness.

Discrimination has no place in the north's health and social care services. On becoming Minister of Health I was pleased to be in a position to remove the lifetime ban on blood donation by men who have had sex with men. While this decision was based on scientific evidence I am aware of the symbolic importance of this policy change for the LGBT community and for everyone who wants our society to be more equal, diverse and inclusive.

Removing discrimination and stigmatisation is even more important when a person is at the end of their life. At this most sensitive of times, it is of vital importance that people can be their authentic selves and can share time with the people who mean the most to them.

Bereavement will always be difficult for those who have lost loved ones. However, prejudice and discrimination can negatively impact not only those survivors whose ability to say goodbye in a respectful and dignified manner has been marred but also for those who spend their last days feeling isolated, marginalised and alone.

Health and social care services in the north have made great strides in recognising and meeting the needs of our diverse community, and are committed to respecting personal differences, as are providers of palliative and end of life care like Marie Curie and other hospice services. However, as this report demonstrates, many LGBT people are still concerned about how they will be treated by health and social care staff because of their sexual orientation or gender.

While many health and social care workers truly believe that they treat everyone the same, the lived reality is that, sometimes, for people to be treated equally, service providers must

be mindful of patient differences and how these may need to be factored into current services. There is still a lot of work to be done to ensure that LGBT people are treated equally at the end of life.

I am very pleased to be able to endorse this report and Marie Curie's commitment to improving palliative and end of life care to LGBT people and their family and friends. I will work to ensure that the hospice and palliative care sector as a whole exemplifies care for our LGBT community and can help champion services with health and social care colleagues across the north.

Everyone, regardless of who they are, has a right to the best quality of care at the end of their lives and I am committed to making this a reality.



Michelle O'Neill MLA

Minister for Health

Introduction

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 been ranked as the best country in the world for the quality of palliative care on offer here. However, access to this care is patchy. One in four people who need palliative care in Northern Ireland miss out each year.

LGBT people experience significant barriers to getting palliative care when they need it. This report explores why.

It shows that 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.

These fears are not unwarranted. This report highlights real barriers that LGBT people have experienced in trying to access high-quality palliative and end of life care. These range from outright discrimination, such as a doctor who would not treat a lesbian woman without a chaperone, to more commonplace, but no less damaging issues, such as the experience of having to come out to each new healthcare professional encountered.

The end of someone’s life is a time of significant vulnerability, both for the person who is dying and the people

they choose to have around them. 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.

Not all the stories in this report are of bad care. There are some examples where people get it right. But these tend to be in the minority. As is often the case in palliative and end of life care, the question is how to take pockets of good practice and make them universal across the health and social care system. This must happen sooner rather than later – as our population ages and the overall need for palliative care grows, there will also be rising expectations among LGBT people of person-centred care that acknowledges and supports them in their last months, weeks and days.

Marie Curie is dedicated to making sure that LGBT people who have a terminal illness experience the best palliative and end of life care possible, alongside the people they choose to have around them.

This means a commitment going forward to deliver person-centred care of the highest quality for LGBT people. We want everyone who receives our care to feel safe and have the best possible experience. Palliative care is for everyone.

Some of the names of the case studies used in this report have been changed to protect the identities of those sharing their personal stories.

What is palliative care?

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 people usually have an advanced, progressive condition, this isn't always the case.

Palliative care treats or manages pain and other physical symptoms. It also helps with any psychological, social or spiritual needs.

It can be delivered alongside particular treatments, such as chemotherapy or radiotherapy. Palliative care helps people with advanced or terminal illnesses have the best possible quality of life. This also includes 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 illness¹.

What is end of life care?

End of life care is an important part of palliative care for people who are nearing the end of their life. It's for people who are considered to be in the last year of life, but this time frame can be difficult to predict.

End of life care helps people live as well as possible and to die with dignity, and can include additional support, such as help with legal matters. End of life care continues for as long as it is needed².

What is person-centred care?

Person-centred care is a concept used by health and social care organisations in Northern Ireland and around the UK. Instead of offering a limited definition, the Health Foundation has adopted a framework comprising of four principles of person-centred care :

1. Affording people dignity, compassion and respect;
2. Offering coordinated care, support or treatment;
3. Offering personalised care, support or treatment;
4. Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life:

“I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me³.”

Who do we mean by LGBT people?

The abbreviation LGBT covers a diverse group, with very different experiences and needs. Understanding the distinctions between people who identify as LGBT is vital to understanding their end of life experiences.

For the purposes of the report we will use the following definitions:

LGBT: lesbian, gay, bisexual, trans.

Lesbian: A woman whose sexual and emotional attraction is towards women.

Gay: A man whose sexual and emotional attraction is towards men.

Bisexual: Bisexuality generally refers to having attraction to more than one gender. It is a broad umbrella term which may include the following groups and more:

- People who see themselves as attracted to both men and women.
- People who are mostly attracted to one gender but recognise that this is not exclusive.
- People who experience their sexual identities as fluid and changeable over time.
- People who see their attraction as 'regardless of gender' (other aspects of people are more important in determining who they are attracted to).
- People who dispute the idea that there are only two genders and that people are attracted to one, the other, or both⁴.

Trans: A simple definition of a trans person is someone whose gender is different from the gender they were assigned at birth. Trans people can be men or women or a non-binary person whose experience of gender is neither fully male nor female eg. genderfluid, genderless. Trans people may change their name, be addressed by different pronouns or change the way they dress. Some trans people, though not all, may undergo a medical transition, however, this is not a requirement of being trans⁵.

Gender identity: The sense of being male, female, non-binary, agender, genderfluid, genderqueer and others. For some people, gender identity is in accord with physical anatomy; this is known as being cisgender. For trans people, however, gender identity may differ from physical anatomy or expected social roles. It is important to note that gender identity, biological sex, and sexual orientation are separate and that one cannot assume how someone identifies in one category based on how they identify in another category⁶.

Families of choice: In this report, we also refer to the families of choice of people who are LGBT and the important role they can play throughout care. For the purposes of this report, we are defining these as chosen, rather than fixed, relationships and ties of intimacy, care and support⁷.

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, regardless of sexual orientation, gender, relationship or family status, everyone's needs and preferences at the end of life will be unique. While we are discussing LGBT people's needs and experiences in this report, it is important to recognise that not all LGBT people will have the same needs and experiences at the end of their lives.



What do we know about the experiences of LGBT people at the end of life?

Research on access to palliative care for LGBT people

Marie Curie is committed to ensuring that everyone with a terminal illness is able to access high-quality palliative care, regardless of where they live, their diagnosis, or their personal circumstances. In 2014, the charity commissioned the London School of Economics and Political Science (LSE) to undertake research into who was missing out on palliative care in the UK and why.

The report by the LSE, *Equity in provision of palliative care in the UK* (April 2015)⁸, found a startling lack of evidence about LGBT people's experiences of palliative and end of life care.

The LSE identified just one systematic review, from 2012, which highlighted 12 relevant papers⁹. Most of these papers focused on the experience of gay men and lesbian women with cancer, leaving some significant gaps around:

- **the experiences of LGBT people living with and dying from diseases other than cancer.**

Different diseases can result in a range of experiences for people at the end of their life; for example, the experiences of someone with motor

neurone disease can be extremely different from someone affected by dementia.

- **the issues faced by bisexual and trans people at the end of life**

Bisexual people and trans people face different kinds of prejudice and discrimination to gay men and lesbian women, and this may sometimes come from within the LGBT community itself.

More recently, a 2016 systematic review¹⁰, looking at evidence around the bereavement experience of partners of LGBT people, identified 13 relevant studies. All of them highlighted additional barriers faced by bereaved LGBT people, beyond the universal pain experienced after losing a partner.

UK policy context

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.

Northern Ireland

In Northern Ireland, much like in Great Britain, there is a paucity of data around the level of need for palliative care amongst LGBT people and the amount of LGBT people missing out on palliative care altogether.

The previous end of life care strategy, *Living Matters, Dying Matters*¹⁹ did not specifically reference palliative care needs for LGBT people. However addressing the health inequalities of older people who identify as LGBT is a priority for the Public Health Agency. As a component of its overall plan to address health inequalities, and in consultation with the LGBT sector organisations, the Public Health Agency identified the need for a set of guidelines to help those involved in the development and delivery of care for older people, to ensure that their services to the LGBT population are welcoming, safe and inclusive. The guidelines, See Me, Hear Me, Know Me, were published in March 2014.

The Regional Palliative Care Programme ('Palliative Care in Partnership') was established in 2016 and has amalgamated existing work under the Living Matters, Dying Matters Strategy and the Transforming Your Palliative and End of Life Care

Programme to progress and enable the delivery of quality palliative and end of life care policy, guidance and initiatives across Northern Ireland.

Under the regional programme, work has already been carried out to review the language used in palliative care tools and guidance, in line with the See Me, Hear Me, Know Me guidelines to support the needs of older LGBT people.

England

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.

Scotland

In Scotland, there have been strong commitments from the Scottish Government. Most recently, the *Equality Impact Assessment for the Strategic Framework for Action on Palliative and End of Life Care*¹⁵ shows an acknowledgement that more needs to be done for LGBT people at the end of life:

- The Scottish Strategic Framework for Action on Palliative and End of Life Care¹⁶ makes a specific reference to the difficulties facing LGBT communities in accessing palliative care and commits to ensuring that everyone who needs palliative care has access to it by 2021.
- The Equality Impact Assessment of the framework¹⁷ also sets out that there is a need for “further and specific research required” on the “population, and the palliative care needs, of patients who are lesbian, gay, bisexual, transgender or intersex” (LGBTI).
- The impact assessment also calls for a “specific and focused education of health and care professionals to enhance their awareness of the concerns of people who are LGBTI about the possibility of discrimination, heterosexist assumptions and to recognise the importance of partners in decision making in respect of palliative and end of life care”.

Wales

In Wales, the *Together for Health – Deliver End of Life Care*¹⁸ delivery plan has no reference to the needs of LGBT people at the end of life.

This strategy is due to be refreshed in 2016.

Addressing the research gap

Marie Curie runs the largest palliative care research programme in the UK. In 2010, we recognised that there was a gap in research on the experiences of LGBT people at the end of life.

In response, we funded research by the University of Nottingham, *The Last Outing*²⁰, to look in detail at the particular needs of LGBT people at the end of life. It also explored older LGBT people’s familial and friendship networks and how these personal networks may influence experiences towards and at the end of life. This project was the first of its kind across the UK²¹.

In May 2014, Marie Curie also funded a joint project led by King’s College London, with the University of Nottingham and the Gay Men’s Health Charity (GMFA), to improve demand for and supply of palliative care for LGB and/or T people who are in the later stages of a life-limiting illness.

The ACCESSCare²² project involves in-depth interviews with LGBT people who are in the later stages of a life-limiting illness, their informal caregivers (partners, friends or relatives), and bereaved caregivers of people who died a predictable death from a progressive illness or condition.

The interviews will be used to inform resources for LGB and/or T communities and organisations as well as for the training of healthcare professionals.

Colleagues at the University of Nottingham and King's College London have agreed to share some of their findings and provided case studies for this report.

How many people are affected?

The Integrated Household Survey 2015²³ estimates that about 1.6% of the population in Northern Ireland is lesbian, gay or bisexual, though the Treasury estimates that 6% of the UK population identifies as lesbian, gay or bisexual. Understanding the proportion of the population who identify as trans is more difficult. The Gender Identity Research and Education Society (GIREs) estimates the overall percentage of 'gender variant' people in the UK is 1%.

In 2014 in Northern Ireland, 286,000 people were estimated to be over the age of 65²⁴. This means there are around 17,160 LGB people and 2,860 trans people over the age of 65 (some trans people might, however, also identify as either lesbian, gay or bisexual).

Around 15,000 people die annually in Northern Ireland at present. This means that just around 900 LGB people and around 150 trans people die each year.

However, we know that annual deaths are set to increase by 28% in Northern Ireland by 2037²⁵, the highest rate in the UK, and demand for high-quality palliative care services for LGBT people will grow alongside that of the wider population.

In fact, the research suggests that LGBT people have a higher incidence of life-limiting and life-threatening disease than people who are not LGBT. The risk of smoking and alcohol abuse is higher among LGBT people, and is attributed to stress from homophobia, discrimination and marginalisation.

However, findings from The Rainbow Project report *The Health of Ageing LGBT People* suggest that older LGBT people are not confident in care providers' abilities to meet their needs. In this report 79.4% of respondents felt that healthcare professionals need more awareness of the needs and issues faced by LGBT people²⁶.

What are the issues?

Looking at the existing policy and research papers as well as case studies from *The Last Outing* and ACCESSCare, we identified a number of key issues 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 three in five older gay people are not confident that social care and 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 and social care staff often make 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)
- significantly more likely to 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 on how being single influences access 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.



1. Anticipating discrimination

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.

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 or bisexual may have vastly different 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 to and relationships with a range of services, including health and social care.

According to a recent study by the UK Parliamentary Women and Equalities Committee on Transgender Equality, trans people face significant difficulties when accessing general NHS services, citing a "lack of understanding and lack of cultural competency around trans issues" in the NHS³³.

This group can face different barriers to those experienced by other LGBT groups, such as a lack of understanding over the process and implications of being trans and how this may affect their daily lives and the care they receive.

In some cases, this group can be revealed by their physicality, which presents different issues for both patients and staff in how to identify specific needs and support, such as different levels of privacy and how to refer to the person in both public and private settings.

Changes in legislation and attitudes

The UK has made considerable progress in ensuring equality for LGBT people, with the Civil Partnership Act 2004, Gender Recognition Act 2004, and Marriage (Same-Sex Couples) Act 2013 in England and Wales. However, the latter Act has not restored the marriages of trans people whose marriages were forcibly annulled as a precondition of seeking a gender recognition certificate. Scotland similarly legalised same-sex marriage in 2014.

Following a referendum allowing for a constitutional amendment, the Republic of Ireland also legalised same-sex marriage in 2015. Northern

Ireland has not legalised same-sex marriage and remains the only part of the British and Irish isles which has not legislated for same-sex marriage.

Attitudes have also changed. In 2016, 70% of people in Northern Ireland indicated their support for same-sex marriage in a poll conducted by Ipsos MORI³⁴. Research conducted by the Equality Commission for Northern Ireland found that only 15% of people in Northern Ireland consider themselves to have negative attitudes towards lesbian, gay and bisexual people and 22% consider themselves to have negative attitudes towards transgender people³⁵.

The reality of discrimination

Despite legislative shifts and changes in attitudes, LGBT people are still highly likely to experience violence or abuse because of their sexuality or gender identity.

Research conducted by The Rainbow Project in 2009³⁶ found that 21% of gay and bisexual men and 18% of lesbian, gay and bisexual women had been the victim of a homophobic crime or incident in the three preceding years and the charity Galop estimates that three quarters of trans people are the target of transphobic abuse each year³⁷.

Two thirds of the people surveyed by The Rainbow Project had not reported their experiences to the police and 14% of people did not report because they didn't think the police would do anything about it³⁸. The British Crime Survey found that 57% of all hate crimes are not reported to the police³⁹.

In health and social care services, discrimination against LGBT people is not only a matter for patients but also for LGBT staff who may experience discrimination from colleagues and patients alike. However, the greatest impact on access to health and social care services for LGBT people lay in the invisibility of sexual orientation and the barriers this creates.

Research published by The Rainbow Project in March 2016 found that:

- 20% of LGBT people wouldn't know where to access support or advice in relation to their mental health and wellbeing.
- 30% of respondents did not seek help when they experienced depression.
- 40% of respondents had never accessed a sexual health check up.
- Two thirds of respondents had not seen sexual health services promoted in their area⁴⁰.
- When asked why they had not accessed sexual health services, respondents indicated that this was a result of; concerns about experiencing discrimination, previous negative personal experiences and a reluctance to discuss issues with the local family GP⁴¹.

A recent thematic review by the Care Quality Commission found that some people's experience of discrimination in their day-to-day life means they are concerned that they may not be treated with dignity and respect by health and care services at the end of life, or that their partners may not be involved in the way they wish⁴².

Research from the University of Nottingham also identified that LGBT people who are comfortable with their sexuality and gender identity, and are not generally worried about being discriminated against, may nevertheless worry about being discriminated against when they are at the end of their life and more vulnerable.

What is the impact of anticipated discrimination?

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 discrimination⁴³, 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 identity, or to demonstrate affection 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 services⁴⁴. The benefits of early access to palliative care are well-established, particularly for people with terminal cancer, where earlier involvement of palliative care services can:

- improve quality and length of life^{45, 46}
- result in fewer hospital admissions and reduce the likelihood of dying in hospital⁴⁷
- help family carers to have lower levels of anxiety and depression⁴⁸

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 depression⁴⁹.

What people say they need

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

that were specifically for LGBT 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. They said that including images of LGBT people or LGBT symbols such as the rainbow flag in promotional materials would make them more comfortable using palliative care services. This echoes the findings of the *Open to all?* report, which had a key recommendation for providers on the inclusion of LGBT imagery in promotional materials.

Under-representation or invisibility of LGBT people in the language and images used in service leaflets or posters can add to LGBT people feeling unacknowledged or invisible.

If LGBT people are not confident about services or staff, they may not seek support and/or may not feel able to be open about themselves and the people who are important to them – factors that are crucial to dying well.

Sheila has a diagnosis of cervical cancer and was receiving palliative care when we interviewed her. Overall she felt her treatment had been exemplary and she had nothing but praise for staff:

“I’d expect nothing less. And my partner Fran and I have spent our lives fighting discrimination, working in the voluntary sector. Fran is a very strong woman, she’ll take no nonsense. So we felt

confident approaching services and being out as a couple.

When there were incidents where that didn’t happen, well, I suppose we were a bit taken aback. There were two main incidents that I remember and actually I didn’t challenge either of them at the time. I’ve spent my life challenging homophobia! But when you are as weak as a kitten it is hard.

One of the staff was talking me through what I was to expect of the cancer treatment. She looked very uncomfortable, when Fran was with me and I introduced her as my partner, and she couldn’t help referring to her as my friend.

I said, no, she’s my partner. And she just couldn’t kind of get that, but I wasn’t in the right frame of mind to challenge her there and then.

Then another time, Fran had gone for a drink and the doctor with me was asking intimate questions; I know she needed to, but anyway some of her questions weren’t relevant. I said I was lesbian and she’d seen Fran leave, so I said that woman with me, she’s my partner.

Well, this doctor, a female doctor, stood outside the door saying, ‘I need a chaperone’. I’m lying there, really ill and thinking: what? Why does she need a chaperone? And she must have called out about a dozen times, louder and louder, I need a

chaperone! And it got louder and louder. And then eventually one of the nurses came up to her and said, '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 quite difficult and you've struggled, it's hard to think about the future (with those sorts of worries)."

– Sandra, lesbian, 60

"It's the humiliation of the personal care because there is a care thing that goes from social worker to care team. And I've been fearful that girls are going to walk in here who hadn't been pre-warned about it...when I hadn't had the genital surgery...And I feel hurt because I'm aware that in the background some sort of process is happening without my knowledge, without my acceptance. I haven't been involved in a discussion...But then would it have done any good if I had been involved in the discussion? Because it might cause more anxiety,

being part of the process...

Does that make sense?...Yes, so it's not a win-win; it's a lose-lose. And either way you become anxious."

– Louise, 51, trans woman living with COPD

"It was very worrying, trying to find the right place for my partner to be in. I went to a couple of places. I went to a Methodist foundation. First of all, I'm not religious at all. I just didn't feel comfortable. I didn't feel able to say, 'I'm looking for a place for my partner.'" – Trisha, aged 61, bereaved partner of lesbian woman living with dementia

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 the end of their life as any other patient. Gay men in particular may be concerned that they will be treated with hostility by church-affiliated providers of hospice care⁵⁰.

Like heterosexual people, LGBT people can have deeply rooted faith (residual or active) and belief structures, as well as established religious affiliations. This area is under-researched, but 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 lives.

“It was one of the hospice chaplains that still brings back some warmth to the memory; she walked into the room, introduced herself and just sat with Diane. She did not want to know if she had any affiliations religiously, and then for some reason just said, ‘I can sing something if you would like’. Diane nodded. This lady then sang Diane’s favourite piece of religious music, John Rutter’s ‘The Lord Bless You and Keep You’.

“It was already in her memory book for her thanksgiving service. She held her hand and just sang... The upshot was she saw the person which included recognising our relationship. Holistic care is about the whole person; it does not have to be a man or woman with a collar on, it can be anyone who can understand that we are at our closest to faith and/or our own spirituality when facing death. It’s made so much harder by the failure of those who provide care to recognise our humanity, regardless of the gender of the person we have dedicated our lives to.” – Carol, 57, partner of Diane who had breast cancer

3. Assumptions about identity and family structure

Health and social care professionals often assume that LGB people using services are heterosexual. Trans people similarly report that they are often referred to by the pronouns of their birth gender, asked insensitive questions about being trans, or even ‘outed’ as trans in front of other patients and staff.

A study conducted in 2006 found that practitioner and staff attitudes towards sexual identities influences the quality of care offered and received, and that heterosexual assumption may exist throughout care⁵¹.

The reality of assumptions about identity

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 healthcare⁵².

Health and social care professionals may hold this attitude because they misunderstand the importance of sexuality and gender identity to patients.

In some cases this is because health and social care professionals 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.

We found this attitude common when we undertook a survey of our own hospice staff and volunteers in order to understand attitudes around the importance of considering a patient's sexuality alongside their end of life care needs*.

The survey was developed using a similar model to one used to interview care home staff on their attitudes and performance in addressing the needs of LGBT people at the end of life⁵³.

Just over 70% of respondents said they agreed or strongly agreed that it was easy to assume that individuals accompanying patients are related by blood or marriage. Many respondents volunteered that they felt patients should be treated the same, regardless of sexuality or gender.

What is the impact of assumptions about identity?

The assumption of heterosexuality or the use of birth gender pronouns by health and social care professionals does not necessarily indicate disapproval of LGBT people.

It does, however, lead to challenging situations where LGBT people must make a decision about whether to disclose their true identity and risk misunderstanding or discrimination, or to continue under the assumption that has been made about them, excluding parts of their lives which they feel may expose them.

One research paper defined three strategies that LGBT people adopt in response to these kinds of situations: active disclosure (ie verbally correcting the mistake), passive disclosure (correcting the mistake through behaviour), and passive 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 who is most important to the person approaching the end of life⁵⁴.

This can result in professionals discrediting the role of same-sex partners and partners of trans people⁵⁵, or making assumptions about who the closest person to the patient is.

These assumptions can sometimes mean that partners or loved ones are excluded from important decisions about future treatment or care, despite research by the University of Nottingham showing that LGBT people want significant others in their lives to be acknowledged and involved in their care⁵⁶.

Many of the respondents to *The Last Outing* had anecdotal stories of a friend to whom this had happened – such as a trans person being buried under their birth name, against their wishes – and it fuelled their own wariness of health and social care services at the end of life⁵⁷.

For LGBT people, the possibility that a health and social care professional may react badly to being corrected and that this may have an impact on the care they receive is always possible. Respondents to *The Last Outing* survey cited a large number of anecdotal cases where friends had their sexuality or gender identity ignored at the end of life.

As Stonewall notes, there is often a well-meaning intention behind this response, with many health and social care professionals saying they treat everyone the same, regardless of their sexual orientation⁵⁸.

However, there is conclusive evidence that sexual and gender identity do have a major impact on people's health needs⁵⁹. The Rainbow Project notes that LGBT people in Northern Ireland are more likely to experience depression and other forms of mental ill health⁶⁰, and research from Cambridge University shows that LGB people are more likely to experience all kinds of mental illness⁶¹.

What people say they need

One of the key ways this can be improved is by promoting inclusive language which may help people feel they can disclose their sexuality or gender without any fear that they are correcting assumptions or going against 'what is normal'.

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. Any forms patients 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.

* Marie Curie currently has nine hospices located throughout the UK, with around 994 members of staff. Throughout the nine hospices, Marie Curie cares for around 8,500 people per year (Marie Curie, November 2015). The survey was circulated to all hospice staff and hospice volunteers. There were 153 responses to the survey which was conducted during April 2016.

“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 children?’... which is not an offence. It’s a simple question. But it creates that tiny little bit of distance...which is saying, I’m heterosexual and I wonder what your experience of heterosexuality is...And it’s perfectly fair, it doesn’t offend me or anything like that. But it says I’m different. Basically it’s ...speaking in ways that assume that you already share that sexuality, rather than coming at the topic with an open mind that you might be gay.’” – Andrew, 67, gay man living with lung cancer

“I think there needs to be more of a realisation that people are gay because there is an assumption that everyone is straight. You know, I’m forever being called Mrs somebody or other. Just to think about it before they assume. And my partner would not be amused by me saying this but she’s older than me, so we’ve got nearly 19 years of an age gap; I think a lot of people do assume she’s my mother, actually.” – Lynda, lesbian, 64

“I’ve been in resus where I didn’t know if I was going to survive the event or not... where it has ten bays with ten patients, just with curtains. And you can hear every conversation... Some doctors have said to me, ‘How long have you been transgendered for?’ and everybody has heard.” – Louise, 51, trans woman living with COPD

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. These families can often be referred to as ‘families of choice’, or ‘lavender families’⁶².

The involvement of these families can sometimes present challenges for health and social care staff as this support group and more traditional biological support groups may not agree over the care of the LGBT patient.

One Marie Curie member of staff noted the particular difficulties this can cause in establishing who is best placed to provide care and support and how to manage conflicts between the various support groups:

“Visiting rotas needed to be sorted as blood relatives weren’t accepting of their loved one.” – Marie Curie staff member

The complexities of these relationships can put extra strain on the patient at an already vulnerable time and it is important that LGBT people are able to access the care and support they need from those they wish to be closest to them.

LGBT people can also feel concerned that their loved ones will not be respected and recognised as next of kin. Age Concern in Wales found that older LGBT people often worry that the person they might regard as next of kin, or who is most able to express their needs and desires could be disregarded by care professionals, particularly if a person from the family of origin appears and attempts to take over⁶³.

For trans people, there are further concerns about being recognised as their birth gender or a gender they don’t 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.

Next of kin definition

The Royal Free London NHS Foundation Trust states that despite widespread use of the phrase, who is next of kin to a hospital patient is not actually defined in law. It notes that the policy in most NHS trusts is to

ask patients to nominate who is next of kin formally, on their admission to hospital. However, if patients are unable to say, the hospital will try to work out who is the person closest to them. The advice also highlights that in practice, hospitals have generally used spouses and close blood relatives to define next of kin and that this has been more common with same-sex partners⁶⁴.

The Last Outing revealed 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 as the person most capable of acting on their loved ones’ behalf.

A Nursing Times article in 2012 based on the publication of *The Route to Success in End of Life Care - Achieving Quality for Lesbian, Gay, Bisexual and Transgender People* found that there were significant challenges presented to healthcare staff around assumptions of next of kin, particularly for LGBT patients at the end of life. The article highlights that key to delivering high-quality person-centred end of life care, is understanding complexities around family dynamics, which may need to consider the basis of the relationship the patient has with their blood relatives and whether they are accepting of their status as LGBT⁶⁵.

What people say they need

Advance care planning can become increasingly important for LGBT people at the end of their life.

Advance care planning is about thinking ahead and talking to the people involved in a patient's care, such as their family, friends, doctors and nurses, and other services involved in the delivery or provision of care.

In end of life care planning, it is a key process that allows 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 decisions⁶⁶.

Survey and interview respondents to *The Last Outing* report that advance care planning is important for LGBT people. Eighty-two per cent agreed that it was particularly important for LGBT people to make and record plans for future care, however only 18.5% of the respondents had written down and recorded their preferences for future care and treatment⁶⁷.

In the survey of Marie Curie hospice staff, members of staff highlighted that LGBT people may have specific needs at the end of life around "future care planning to allow transfer of assets etc/will writing".

Some motivations for LGBT people to complete advance care plans include issues similar to those reported for the general public, such as not placing burdens on others, but there were also distinct issues highlighted in the research such as providing protection for partners and significant others who might otherwise not be recognised.

"We're not in a formal partnership at the moment. For a variety of reasons that's not happening in the near future. Of course being in a formal partnership and being able to wave your papers is the easiest and quickest way of being recognised as next of kin, and we've got to work on that, but I suspect that straight couples don't actually have to wave their marriage lines." – Carol, 70, partner of lesbian woman living with bowel cancer and lung disease

"We went to some considerable lengths and some considerable cost to ensure that we had a level of legal protection to be recognised as each other's next of kin, the one to make decisions if that need arose. I mean, fortunately we never really had to test that but it was reassuring for us, having heard horror stories about people's partners being denied access to their bedside.

So it's a little bit of protection for each other really when having to deal with each other's biological families who might potentially have a different opinion - probably because of their own grief and upset and what have you. Obviously, since we've had our civil partnership, that gives us a whole layer of protection over and above that anyway."
– Lydia, lesbian, age 46

5. Unsupported grief and bereavement

LGBT relationships may not be openly acknowledged or accepted. If a relationship isn't recognised as existing, grief may also not be recognised in the usual way. In that situation, LGBT people may feel under more pressure to hide their grief, and may not be identified as needing support. This is sometimes referred to as disenfranchised grief⁶⁸.

The Last Outing found that having their wishes respected after death was particularly important for LGB people at the end of life. It highlighted the importance of their loved ones being supported and involved in the process after death. Many of the respondents to the survey were able to give examples of stories of LGB people who had died and their partners or close friends had been excluded from funerals or any similar arrangements.

For example, Jeremy and his partner David had not disclosed their relationship to anyone. Jeremy said David had been very clear they could not be open about their relationship. When David died, his family made the funeral arrangements in which Jeremy had no say⁶⁹:

"I knew he wanted a burial and he wanted to be buried next to his mother. He ended up being cremated [which] was totally against his religion ... I couldn't stop them but it was like strangers organising his funeral; I was his family... But he never wanted it to be known that he

was gay. And I respected that. [If] he wasn't out, I wasn't out either. I couldn't talk to my family ... they thought David was just a friend. I was a right mess. I had nobody to turn to."

What is the impact of unsupported bereavement?

People in same-sex relationships may struggle both to have their grief recognised, and to recognise their own grief, particularly if their relationship was not validated by others both publicly and privately⁷⁰.

Disenfranchised grief can reduce the level of support available to the bereaved partner or loved ones and can make it harder to access the usual sources of support during an already isolating time⁷¹.

The loss of a partner for anyone who is LGBT can also sometimes lead to a loss of identity if they had defined themselves as LGBT purely through their existing relationship. The loss of the relationship can sometimes lead to people feeling that their LGBT identity is once again hidden due to a lack of support for the relationship and support through the grieving process⁷².

What people say they need

It is crucial that healthcare professionals and those working with patients and their loved ones encourage 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.

“I do think there is a difference, you 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 layer about somebody’s sexuality, I think that makes it even more complicated for people because they’re not sure how to respond.”

– Melanie, 54, bereaved partner of a lesbian woman who died of ovarian cancer

“That’s why when Leo died it was such a huge blow, because we were one person really and [we] were totally involved together, and that was the sort of real whammy of the bereavement, because once he’d gone there was nobody else.”

– Ken, gay man, 70

6. Increased pressure on LGBT carers

Although LGBT people are likely to have a higher reliance on formal care services due to a lack of distinct support networks⁶⁷, the pressure on carers of LGBT people can be greater due to a reluctance to access these services.

LGBT people can sometimes feel more comfortable staying in their own homes or a desired place of care because of a fear of discrimination from health and social care services or a worry that other services aren’t suited to their needs. However, this can mean that informal carers may have to provide higher levels of care for longer and try and provide care which may be more suited to being provided by a trained professional.

Another concern expressed by LGBT people at the end of life is that they may have to hide their true identity if they choose to receive formal care at home. In their guide for care and support staff working with lesbian, gay, bisexual and trans people, Stonewall states that 95% of older gay people say they would prefer to live in their own home for as long as possible and they are nearly twice as likely as older heterosexual people to rely on a range of external services for support⁵⁹. However, some people fear these providers could still discriminate against them.

How many people are affected?

The Commissioner for Older People highlights that there are 214,000 carers in Northern Ireland.⁷³ In this

context, a carer can be anyone who provides unpaid care and support to a family member or friend who is ill, disabled or in need of care⁷⁴. Currently, there is no formal research which shows how many people in the UK are providing care or end of life care to someone who is LGBT.

What is the impact of pressure on LGBT carers?

Carers of LGBT people can feel under increased pressure to care for longer without support. This is because LGBT people are more likely to access services later due to a fear of discrimination or lack of acceptance and understanding of their relationships and personal circumstances⁷⁵.

In their support for carers, the LGBT Foundation highlights that as an LGBT carer looking after a partner, there may be pressure to ‘come out’ about the nature of the relationship with the various professionals involved in their care⁷⁶. For people who choose not to disclose their sexuality or gender identity in a place where they had previously felt comfortable to do so, this can have negative effects on their wellbeing, and would prevent the best possible experience at the end of a loved one’s life.

What people say they need

A positive step which could be made to avoid this is to encourage the professionals involved in care to signpost support for carers earlier, to ease the pressure on those providing care to a loved one.

It is also important for staff to take a person-centred approach to care, understanding the relationship between the care receiver and provider, and the best way to recognise that relationship.

This can be something as simple as asking questions which do not make presumptions about the relationship of the carer to the person they are caring for, and asking the carer whether they feel they have enough support.

Attitudes towards end of life care for LGBT people at Marie Curie

Despite a lack of comprehensive research on the end of life experiences of LGBT people, the case studies and in-depth interviews carried out by the ACCESSCare project and *The Last Outing* show that further analysis is needed on care for LGBT people at the end of their life, and in particular the performance of care settings.

To understand more about our own services and how Marie Curie is performing in relation to end of life care for LGBT people, we conducted a survey of our nine hospices to gain a wider understanding of how LGBT issues are perceived in this setting, and how supported staff felt in addressing these.

The results of the survey showed that Marie Curie staff have positive attitudes to LGBT people across the board, and an acceptance and respect for their personal choices. However, staff may not recognise that LGBT people at the end of life may have specific needs, particularly around existing fears of discrimination.

“I genuinely haven’t heard any homophobic comments from members of staff or in fact anything judgemental or negative said, which is a lovely thing. But because I haven’t heard it, that doesn’t mean the issue still isn’t one which is very real for some people. As a straight woman my experience and

sensitivities are different and I might not have picked up on things.”

The survey also showed that there was some confusion around the process of recording LGBT status and whether this was good practice or unnecessary, as well as a lack of clarity over procedures in place to deal with any negativity from other service users.

“I feel able to ask about this but am unsure if it is an integral part of the current set up/admission process.”

The survey results showed examples of good care, with hospice staff ensuring they take a person-centred approach to care.

“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.”

The survey also confirmed that issues surrounding correct identification of next of kin and dealing with complex family relationships can be challenging for staff and this may be an area where more support can be offered in future.



“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.”

Questions were asked about staff 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 hospice staff, and what the existing demand is for improving this.

Of the 153 respondents to the survey, 65% agreed there was a need for more training on this subject to support staff.

“My preference would be to access training that is already available from external agencies - in the morning, externally-led generic training about LGBT issues, then in the afternoon have internally-led end of life specific training.”

“Wouldn’t it be wonderful if this was no longer an issue of acceptance but of being able to fully address the specific needs of members of the LGBT community? I recognise I need training to fully be aware of the individual needs.”

Conclusions

What does good care for LGBT people look like?

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 an individual and whether or not their partner is accepted as such.

Some other comments from the existing research on what good care looks like included:

“My priority is there should be a decent service for everybody and that is a service which respects diversity as part of the day job.”

“I want my sexual orientation to be fully accepted, not just tolerated.”

“I’d like carers who accept my anatomical differences as a trans person.”

“That they welcome a same sex partner but don’t need to comment on it, that they are respectful and open and honest with me. That they’re friendly, I suppose, and interested in what I’m doing and have a sense of humour about everything.”

We want everyone to be able to identify with the below statements:

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

“I feel confident that services providing my end of life care will take a person-centred approach.”

“I can recognise from materials and literature that end of life care providers equally represent me and my needs.”

“I feel confident that those I wish to be around me at the end of my life will be there.”

“I feel comfortable receiving care in a place of my choice without the fear of discrimination or judgement.”

“I feel supported to complete an advance care plan and confident my wishes will be respected.”

“The people closest to me are identified and supported in an appropriate way, both while I am alive and after my death.”

“I am consulted on decisions about my care and what is best for me.”

“I know where to go to find out about my options for end of life care.”

“I feel confident that those closest to me will be supported after my death.”

Our commitment

To achieve this, Marie Curie is committed to:

- ensuring that literature and materials on 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
- supporting staff through further training to understand that LGBT people may have specific concerns 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
- helping staff to understand internal policies and practices relating to negative or discriminatory attitudes from either hospice users or staff
- 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 services at end of life and of advance care planning
- supporting the rights of LGBT carers
- gathering examples of local excellence in end of life care for LGBT people

- raising the issue of good end of life care for LGBT people with parliamentarians and other key policy stakeholders.

We will continue to conduct an annual survey of Marie Curie hospice staff to understand how awareness is growing around LGBT people’s specific end of life care needs and measure our success in supporting staff so they can deliver high-quality, person-centred care.

Recommendations

We would also encourage other service providers to commit to the following actions:

- Undertake training for staff on the specific concerns or needs of LGBT people at the end of life, including in the context of home care services
- Work with other national and local charities to help promote the importance of LGBT appropriate services at end of life
- Ensure that literature and materials about end of life care services represents all diverse groups, including LGBT
- Share examples of local excellence in end of life care for LGBT people.
- Work with local LGBT groups to understand more about end of life care needs and facilitate a national conversation about these
- Specifically explore issues relating to LGBT communities and access to palliative care when considering national implementation strategies.

Final words

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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