

Lesbian, gay, bisexual or transgender people

A DIFFERENT ENDING: ADDRESSING INEQUALITIES IN END OF LIFE CARE



Although lesbian, gay, bisexual and transgender (LGBT) people experience a higher incidence of life-limiting illness, the experience of LGBT people at the end of life has often been overlooked.^{1,2} Evidence shows that discrimination continues to have an adverse impact on people's access, needs and experience of services.

Lack of awareness

We found limited evidence of services proactively engaging with LGBT people or specifically considering their needs, although LGBT people were represented in forums or consultations in some areas. Services and commissioners often told us there were low numbers of LGBT people in their area, but as there was little formal monitoring of sexual orientation or gender identity it was not clear how this was known. This suggests that services and commissioners are not prioritising this group and may not understand how to meet the diverse needs of LGBT people.

Commissioners and providers also said that sexual orientation was not a barrier to identifying people who were approaching the end of life, or to people accessing end of life care. However, this was not always supported by the experiences of people we spoke to, which again suggests a limited understanding and awareness of the factors that may prevent LGBT people from receiving good quality, personalised end of life care.

Attitudes of staff

The attitude of providers and health and care staff has a significant impact on the experience of LGBT people. People we spoke to told us about their fear of discrimination, which led to some older people hiding their sexual orientation or gender identity, while some same sex couples could feel inhibited and unable to comfort their partner physically in a hospital environment. LGBT people sometimes felt that staff made assumptions about their preferences so they were less able to make choices.

In settings such as nursing or care homes or communal areas of supported living, LGBT people may feel even more excluded. This may be because other residents have negative attitudes towards them as they grew up in times when there were significant prejudicial attitudes towards LGBT people. There may be more subtle forms of exclusion, such as feeling they do not have common experiences to talk about with their peer group.

1 Harding R, Epiphanious R, Chidgey-Clark J, Needs, experiences and preferences of sexual minorities for end-of-life care and palliative care: a systematic review. *Journal of Palliative Medicine*, 2012, 15:602-611

2 Almack K, Moss B and Smith T, *Research and policy about end of life care for LGBT people: identifying implications for social work services*, in Fish J and Karban K, eds, *Social Work and Lesbian, Gay, Bisexual and Trans Health Inequalities: International Perspectives*. Bristol: Policy Press, 2015, p173-186.

People often had both positive and negative experiences of health and care services previously, which shaped their perspective on the care they were likely to receive at the end of life. As a result, some people were concerned that they may not be treated with dignity and respect by health and care services, or that their partners may not be involved in the way they wish.

Open communication

Evidence suggests that health and care staff should acknowledge people's sexual orientation and gender identity, and ask about people's sexual orientation and gender identity as part of planning treatment and care at the end of life. This will enable LGBT people to discuss their needs and concerns.^{2,3}

However, whether people want to talk to health and care staff about their sexual orientation and gender identity is an individual choice. Some people may not want to or may not consider it to be relevant to their end of life care. One person told us about the experience of a friend who was a transvestite, and was denied the end of life care he wished for as he was being treated as a man although he lived as a woman. He felt unable to discuss this with staff and felt it was safer to be treated as a man. His partner

had always known him living as a woman and also found it very distressing, but the staff were unaware of this.

LGBT people that we spoke to felt that their partners were sometimes not involved in their care in the same way that a heterosexual partner would be. We were told about instances where same sex partners, or other important people who were close to the person, were not given information and were not treated in the same way as heterosexual partners, sometimes even being asked to leave during a consultation. This suggests a limited understanding of who may be important to a person, which does not reflect the reality of diverse families as well as important relationships outside of a family structure. Wider family relationships are also a big consideration.

However, for some LGBT people end of life care they received was good. Some people felt respected, and sexual orientation or gender identity were not felt to be an issue. This was often the case in hospices but also in other health and care services, as described in the case study on page 3. The attitude of health and care staff, and their ability to communicate in a sensitive way that provides the opportunity to understand individual wishes and preferences, is key.

3 Harding R, Epiphaniou R, Chidgey-Clark J, Needs, experiences and preferences of sexual minorities for end-of-life care and palliative care: a systematic review. *Journal of Palliative Medicine*, 15:602-611, 2012

4 Almack K, **The Last Outing: exploring end of life experiences and care needs in the lives of older lesbian, gay, bisexual and trans people**, research in progress, 2015

THE IMPACT OF POOR COMMUNICATION

A trans woman, who has not undergone gender reassignment surgery but whose expression and identity is female, recalled how on one visit to a hospital both a doctor and subsequently a nurse referred to her as 'mister'. When she challenged this, the doctor "stomped off and virtually refused to treat me."

On a different occasion a ward secretary came along and drew the curtains and explained that she was having trouble matching up her file since they did not seem to have her full medical records. The ward secretary went on to say that the closest records they have are for a person of 'this name'. She confirmed that that used to be her, and the secretary said that's fine I can combine the notes now. She recalls thinking that that was really enlightened, and concluded that "a little bit of thought works wonders".

When her diagnosis was unfavourable and she was forced to consider issues surrounding her mortality – she worried that at the end of her life, in order to be reconciled with other members of her family, she would have to concede to being buried as a man, in order to spare the feelings of her child in particular from whom she had been estranged for a time.

From Kathryn Almack, The Last Outing⁴

THE IMPACT OF GOOD COMMUNICATION

K and E were together for 48 years and despite E never wanting to reveal his sexuality, K was very open with medical staff about their relationship when E was ill. Once E became terminally ill, K told E that he couldn't hide their relationship anymore. K felt no discrimination from anyone or that E was treated any differently because of their relationship or his sexuality, other than one doctor who he felt didn't approve, though this was never explicitly expressed. K felt that nursing staff he came across were more 'intrigued' by their relationship if anything, and actually found them an interesting couple. E received care from a local hospice and K described also being supported as E's partner by the hospice staff.

**National Council for Palliative Care
interview**

CQC ENCOURAGES:

- Commissioners, providers and health and care staff to consider the needs of LGBT people in planning and delivering end of life care services.
- Health and care staff to communicate openly and sensitively about sexual orientation and gender identity as a routine part of their delivering good quality, personalised end of life care.
- Commissioners and providers to collect data on sexual orientation and gender identity as part of an equalities approach to monitoring end of life care outcomes.

How to contact us


Call us on > 03000 616161

Email us at > enquiries@cqc.org.uk

Look at our website > www.cqc.org.uk

Write to us at >

Care Quality Commission
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

 Follow us on Twitter >
@CareQualityComm

Please contact us if you would like this report in another language or format.



CQC-324-052016

See our other reports on the thematic review:

OVERVIEW REPORT

GOOD PRACTICE CASE STUDIES

PEOPLE'S EXPERIENCE BRIEFINGS:

- People with conditions other than cancer
- Older people
- People with dementia
- People from Black and minority ethnic (BME) groups
- People with a learning disability
- People with a mental health condition
- People who are homeless
- People who are in secure or detained settings
- Gypsies and Travellers

