



Supporting Lesbian, Gay, Bisexual and Trans people with **cancer**

A practical guide for cancer and other health professionals

1. Introduction

Quality of life and care are important aspects of cancer survivorship and there is now a greater focus on recovery, health and well being after treatment. While Lesbian, Gay, Bisexual and Trans (LGBT) people report many good experiences of care, there are some areas that still need attention. These case examples of practice are intended to support professionals to personalise care for LGBT people with cancer. The guidance aims to give practical advice where cancer professionals may feel unsure or embarrassed about what to say without fear of causing offence.



Supporting Lesbian, Gay, Bisexual and Trans people with cancer



2. What do we know about LGBT people's experiences of cancer services?

The Department of Health, Cancer Patient Experience Survey (2010) of 67,000 LGBT and heterosexual patients suggested that there are some differences relating to human rights, specifically, the respect and dignity with which LGBT cancer service users were treated. They reported less positive experiences than their heterosexual counterparts in regard to:

- **Doctors never talked in front of patient as if they were not there**
- **Never felt treated as a set of cancer symptoms rather than as a whole person**
- **Always treated with respect and dignity by hospital staff**
- **Hospital staff always did everything they could to control their pain**
- **Patient was given information about support/self help groups for people with cancer**
- **Doctors/nurses never deliberately did not tell patient things they wanted to know**

A YouGov survey of 1,600 LGBT and heterosexual people, which asked about awareness of cancer, found that:

- **Bisexual women are more likely to perceive barriers to help seeking;**
- **There is less awareness of lifestyle as a risk factor among older lesbian and bisexual women**
- **Awareness of lifestyle as a risk factor could be promoted among younger heterosexual and bisexual men**

This is supported by evidence from a Macmillan study which showed that LGBT patients and carers report persistent insensitivities regarding their domestic and family life and status of partners (BRAP, 2010).



3. Coming out about breast cancer in lesbians and bisexual women?

The study highlighted four key findings which have wider relevance for gay and bisexual men and trans people with cancer:

Involving partners and carers

“I think it’s really weird that cancer has made a lesbian relationship acceptable, that’s what it really felt like to me. In lots of places, we maybe came across people who wouldn’t have given us the time of day but they did because I’d got cancer. I suppose partly because it’s their job to but I guess in some ways, we have probably changed some attitudes along the way as well”

• **Ursula, cancer services user**

LGBT people wish to have their partners and carers involved in their care rather than them being ignored or disregarded. They want their partners and carers involvement to be welcomed and valued by cancer professionals. They appreciate it when their relationships are acknowledged, accepted and respected.

Coming out to health professionals

“If we’d had someone treating us that was maybe, was very relaxed about our sexuality, I think it might have just made it a bit easier to ask questions... you sort of worry about it sometimes and think, oh God, they are really uncomfortable with it” • Naomi, carer

Professionals can help to facilitate disclosure by using gender neutral terms (e.g. partner) and not using language that makes assumptions about the person with cancer (e.g. Mrs). They can enquire as to who has come along with the person with cancer. LGBT people appreciate it when assumptions are not made about them, their sexual orientation, relationships, living arrangements or support network, and when professionals ask about these important areas of their life.



Access to support

“I didn’t access any support groups, in all the discussions, all that was really being talked about was their relationships with their husbands and how that had been affected. I already felt quite excluded, so I never tried to access anything”

• **Lucy, cancer services user**

Professionals can recognise that LGBT service users may feel isolated when using cancer support services and can strive to ensure that activities and discussions are inclusive. They may also consider developing services specifically for LGBT people, such as, a support group as some LGBT appreciate meeting other LGBT people and carers with cancer.



Access to information

“I found myself having to think about the information that’s there that fits with you and your life. You need to go back a few steps and work things out for yourself. It’s trying to find out about things that would be very difficult to explain to a straight person. The information is there but it doesn’t always say your name”

• **Sophie, cancer services user**

Written materials on cancer may assume heterosexuality. Professionals may want to review their information and publicity materials to see if LGBT people and their experiences are reflected in them. Professionals may want to consider developing materials aimed at the LGBT communities, possibly, through working with LGBT and BME LGBT organisations. LGBT people appreciate it when cancer services demonstrate they are LGBT-friendly through displaying LGBT materials in the waiting area or on their website.



4. Case studies of LGBT people with cancer

In the next section a series of case studies are provided together with some of the key issues professionals may want to consider in their practice with LGBT people with cancer.

Case study 1: **Raksha**

Raksha is a 38 year old lesbian who is recovering from a cervical cone biopsy she had 4 weeks ago. She asks you whether she can continue to have sex with her girlfriend. What advice do you give her?

Discussion points

The issues in this case study relate to comfort around talking about sexual behaviours with lesbian and bisexual (LB) women and knowing that women may engage in a range of sexual practices (as heterosexual women may also do). Societal views about the sexual behaviour of LB women often characterise them as being over-sexualised or it is assumed they do not have sex at all. It is often assumed they do not engage in penetrative sex. Some women may use sex toys or fingers and you may advise her not to have penetrative sex in the first months after surgery. Further, LGBT people come from all cultural, linguistic and religious communities.



Case study 2: **Sam**

Sam is a 42 year old transman (female to male person) with breast cancer. He has become increasingly isolated during the course of his treatment and has come to you for information about support groups. He feels that his masculinity has been threatened by the disease. What do you say/do?

Discussion points

There is little or no research or resources in the UK about cancer among trans people. Cases of breast cancer have been reported in FTM trans people; moreover, it is recommended that they have breast screening if they have not had surgery. FTM's who do not take hormones or have not had surgery have the same risks as other women. As a transman, it is unlikely that Sam would have access to support which acknowledges his gender identity and his cancer diagnosis. There may be a local service or online group for trans people that Sam could be signposted to for support. Sam may be unaware that men can also develop breast cancer. Gender reassignment is a protected characteristic under the 2010 Equality Act and trans people are protected from direct and indirect discrimination.



Case study 3: **Rasheed**

Rasheed is a 50 year old man with anal cancer. You are on your first visit to his home and you are accompanying the district nurse, who has visited Rasheed several times recently. As you are getting out of the car, she says she is not sure whether he is a gay man and she wonders whether she should ask him. What do you say?

Discussion points

You could say that some LGBT people are comfortable in coming out (including gay men from Black and Minority Ethnic communities) and want their sexual orientation acknowledged as part of holistic care. Research suggests that LGBT people are more satisfied with the care they receive if they are able to come out to health care providers, they see their identity as relevant to the care they receive and want to talk about their relationships.

It is important to recognise, however, that for some LGBT people (even if they are out in all other aspects of their lives) do not want to come out in health care because they fear that their sexual orientation will be the only aspect of themselves that elicits attention. For Rasheed, it may be that he would face particular challenges in disclosing his sexuality as a LGBT person from a BME community (and this is also the case among LGBT people from white communities).

You could ask open questions which don't assume heterosexuality and use gender neutral terminology. Make it clear that you are open - minded and will not label him. Remember: it is the organisation's responsibility to come out as LGBT friendly, rather than the individual LGBT person who is facing a life threatening condition.



Case study 4: **Jack**

Jack is a 74 year old bisexual man with cancer. Although he has been living with his male partner, Andrew (who is 69), for the past 15 years, he has never divorced his wife. He has three children who he rarely sees and who live 200 miles away. He does not have a will nor has he made provision for his funeral. The house is in Jack's name and Andrew has only a small pension. What advice would you give him about advance care planning?

Discussion points

A lesbian, gay man or bisexual person in a same sex relationship has the same right as a spouse or cohabitee of the opposite sex to take over a deceased partner's tenancy. It would be important to make the landlord aware of Andrew's rights. It is not uncommon for biological families to ignore the wishes of the same sex partner and to exclude them from decisions about funeral arrangements and the disposal of assets. This is sometimes known as disenfranchised grief where there is inadequate social support for the bereaved person.

Jack may want to seek advice on the legal options available to him including making a will. Age UK have produced a free guide about planning for later life as older LGBT person.

There is an Age UK factsheet for trans people:
http://www.ageuk.org.uk/documents/en-gb/factsheets/fs16_transgender_issues_in_later_life_october_2010_fcs.pdf



Case study 5: **Matt**

Matt is a 45 year old gay man with prostate cancer. He lives on his own in an inner city with a small LGBT population. He has a group of 3 younger men, some of whom are ex-partners, who pop in to see him regularly. He has recently been told that he has six months left to live. You plan to talk to him about his wishes about end of life care and who will be his 'next of kin'. How do you approach this?

Discussion points

It is common for LGBT people to have a network of friends, ex-partners and some biological family members in their close circle. Decisions about medical treatment may then need to involve more than one person as 'next of kin'.

The incidence of prostate cancer in gay and bisexual men is the same as in heterosexual men although the psycho-social affects may differ.



Case study 6: **Jane**

Jane is 68 and her partner recently died of cancer. She retired early to take care of her partner although previously she had a busy social life taking part in a number of social groups including a walking group and the University of the Third Age. She lives in a small terraced house and does not get on with her neighbours. She has stopped going out and she often does not get dressed until late morning. What do you say/do?

Discussion points

Jane appears to be grieving, perhaps depressed, and isolated. She has lost contact with her social networks and may need support to make new contacts or re-establish old ones. She may need help to find a new focus in her life after focusing all her energies on looking after her partner. For example, getting involved in activities she previously enjoyed or developing new interests. She may need bereavement counselling.

Please see resource on setting up a support group for lesbian/ bisexual women with breast cancer.

London Friend provides a LGBT bereavement helpline.
<http://www.londonfriend.org.uk/bereavementhelpline/>

My deepest thanks go to the lesbian and bisexual women who took part in the Coming Out about Breast Cancer study: without them these stories would not have been told.

5. Research evidence

Almack, K (2012) End of life care: the experiences and needs of lesbian, gay and bisexual and trans (LGBT) elders. Funded through Marie Curie Cancer Care Research Programme. University of Nottingham.

BRAP (2010) Walking into the unknown: Discrimination in cancer services. London: Macmillan.

Department of Health (2010) Cancer Patient Experience Survey. London: Department of Health.

Fish, J. (2010) Coming out about breast cancer in lesbian and bisexual women. Leicester: De Montfort University.

Gunstone, B. (2010) Cancer awareness: The impact of Sexual Orientation. London: YouGov.

6. Resources

Cancer Research UK (2008) Policy statement: Health inequalities in cancer and LGBT communities. Available from **http://info.cancerresearchuk.org/publicpolicy/ourpolicypositions/healthcancerinequalities_policy/health-and-cancer-inequalities**

Dhami, K. (2011) Lesbian and Bisexual women with breast cancer: Policy briefing for health and social care professionals. Breast Cancer Care: London. (ESRC Knowledge Exchange Programme RES-192-22-011). **<http://www.breastcancercare.org.uk/campaigning-volunteering/policy/breast-cancer-inequalities/lesbian-bisexual-women-breast-cancer>**

Setting up a breast cancer support group, Sherbourne Health, Canada
http://www.sherbourne.on.ca/PDFs/MUV_TipSheet1.pdf

7. Acknowledgements to steering group

Ellen Boyle and Dee O'Brien, Older Lesbian Network; Natasha Burgess, Cancer Research UK; Jackie Foley and Marguerite McLaughlin, Metro Centre, London; Carol Gibbons, User and Involvement Projects Manager, Macmillan; Vanessa Gordon-Dseagu, University College, London; Perlita Harris, Goldsmiths University of London, Jane Hatfield, Director of Research, and Kiran Dhami, Policy Officer, Breast Cancer Care; Rev. Caroline Redfearn, Metropolitan Community Church; Michail Sanidas, South West Strategic Health Authority; Ruth Turner, London Lesbian & Gay Switchboard.

Thanks also to:

Carol Gibbons, Karen Chesters, Marilyn Mead-Brown, Fiona Taylor and Tony Hemsley, Macmillan Cancer Support.

This project is funded through Government Research Council, ESRC Knowledge Exchange Programme RES-192-22-011.

The guide forms part of the work of the Department of Health, National Cancer Equalities Initiative. It was produced by Dr Julie Fish and Dr Perlita Harris.



Supporting Lesbian, Gay, Bisexual and Trans people with cancer



**WE ARE
MACMILLAN.
CANCER SUPPORT**