



Care and support
through terminal illness

Marie Curie Briefing

The reality of end of life care for lesbian, gay, bisexual and transgender (LGBT) people

Many LGBT people are missing out on the care they need as they approach the end of life.

Marie Curie cares for over 8,000 people living with a terminal illness, their families and carers across Scotland through our hospices, community nursing services and support services. We treat people with all terminal conditions, whether that is terminal cancer, dementia and frailty, Motor Neurone Disease, Multiple Sclerosis, chronic obstructive pulmonary disease or heart failure. Every day matters when you're living with a terminal illness and we want to help people make the most of the time that they have left.

Key points

- LGBT people can often feel apprehensive using health and social care services, including end of life care, because of experiencing discrimination in the past.
- Often health and social care professionals will aim to treat everyone the same – however this misses some of the particular needs and wishes patients might have at the end of life.
- LGBT people are more likely to feel worried that their loved ones will not be acknowledged as important, and will not be properly supported after their death, due to assumptions that they are hetero-sexual.
- LGBT people often miss out on having those closest to them around them when they are dying and involved in the process after their death.
- People who care for LGBT people with a terminal illness can often be under more pressure because of a reluctance to access services.
- Advance Care Planning for LGBT people is important as a way to provide protection for loved ones who might not be recognised otherwise.
- Hetero-normative behaviour can make it more difficult for people who are LGBT to disclose their true identity.
- Seeking spiritual and religious support is important for LGBT people however it is not always easy to access.
- Having their wishes respected after death was a particular concern for people who are LGBT.

LGBT people accessing palliative and end of life care in Scotland?

Scotland is rated the best country in Europe for LGBT equality in the Rainbow Index. However, there is still a lack of data around the level of need for palliative care amongst LGBT people in Scotland and the amount of LGBT people missing out on palliative care altogether.

Nearly one in four people in Scotland miss out on the palliative care that they need, this will include LGBT people. Our report *Hiding who I am: The reality of end of life care for LGBT people* shows that lesbian, gay, bisexual and transgender (LGBT) people are likely to experience a number of barriers to accessing the high quality care they need when living with a terminal illness and at the end of life.

We need to make sure that the Scottish Government's commitment, that everyone who needs palliative care has access to it by 2021, is realised.

Our research

Marie Curie funded research from the University of Nottingham and King's College London to explore access to palliative care for LGBT people. Building on this research, our report examines some of the barriers LGBT people face in accessing high quality end of life care.

As part of the report, we surveyed our own hospice staff to understand more about the experiences of LGBT patients using our services and how staff perceive the quality of LGBT end of life care.

Our survey found that:

- There is a desire from our staff to develop professionally and learn more about how to provide person centred care which considers all aspects of someone's life.
- Staff were unsure whether the hospice admissions process allowed for people to identify as LGBT, and the best way to begin conversations with them about this if so. Many staff felt this was important in helping people to feel comfortable discussing what was personally important to them.
- The materials used in the hospices do not always show a diverse range of people who may use the service, which can leave people feeling that our services are not for them.

Although the UK has come far in ensuring equality for LGBT people, the effects of previous discrimination and fear of stigma can leave a lasting impression and can often mean that LGBT people delay accessing services they may need, including those at the end of life.

In addition, when LGBT people do decide to access services, they can face many barriers to feeling like they can reveal their true identity, such as assumptions that they are straight and the gender they were given at birth. This can make the process of using health and social care services seem overwhelming to LGBT people and particularly at the end of life when they are at their most vulnerable.

Recommendations

In Marie Curie, we will:

- Ensure that literature and materials in our services represents all diverse groups, including LGBT.
- Review 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.
- Support staff through further training to understand that LGBT people may have specific concerns or needs at the end of life.
- Highlight the importance of patient-centred care which looks to establish which people and factors are important to the patient.
- Help staff to understand internal policies and practices relating to negative or discriminatory attitudes from either hospice users or staff.
- Work with other local and national charities to help promote the importance of LGBT-appropriate services at end of life of advance care planning.
- Support the rights of LGBT carers.
- Gather examples of local excellence in end of life care for LGBT people.
- Raise the issue of good end of life care for LGBT people with parliamentarians and other key policy stakeholders.

Marie Curie would like to see:

- Palliative care is now the responsibility of the new health and social care partnerships and this must be an early priority for integration joint boards:
 - The partnerships should carry out work to identify palliative care needs in all communities in their localities.
 - The partnership must also put in place plans and services to meet unmet need, including LGBT people, as well as measure progress toward the Scottish Government's 2021 target.
- More research on the level of need for palliative care amongst LGBT people in Scotland and the amount of LGBT people missing out on palliative care altogether.
- Specific exploration of issues relating to LGBT communities and access to palliative care.
- Training for health and social care staff on the specific concerns or needs of LGBT people at the end of life, including in the context of home care services.
- Partnership working between national and local charities, and statutory organisations to help promote the importance of LGBT appropriate services at the end of life.
- Literature and materials about end of life care services representing all diverse groups, including LGBT.
- Cross-sector sharing of 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.

Research Notes

About The Last Outing

This was a two year UK-wide study (2012 - 2014), funded by Marie Curie Research Programme. It explored end of life experiences and care needs of older (60 and over) Lesbian, Gay, Bisexual and Transgender (LGBT) people. The project report was completed March 2015. The study incorporated a survey of (237) LGBT people and 60 in-depth interviews, a sub-sample of the survey respondents.

About ACCESSCare

The project led by Dr Richard Harding, and funded by Marie Curie Research Programme, aims to improve demand for and supply of palliative care for people who identify as lesbian, gay, bisexual and/or trans* (LGB and/or T) and are in the later stages of a life-limiting illness.

The project involved in-depth qualitative interviews with people who identify as LGB and/or T and are in the later stages of a life-limiting illness, their informal caregivers (partners, friends or relatives) as well as with bereaved caregivers of people who died a predictable death from a progressive illness or condition.

The findings from the previous literature and the qualitative interviews will be used to shape the mass media resources for the LGB and/or T communities, as well as the training for health care professionals.

Marie Curie across Scotland

We have two hospices in Scotland, in Edinburgh and Glasgow, and our Marie Curie nursing service cares for people in the community in 31 local authority areas. We also have a national information and support service, which includes a telephone helpline (0800 090 2309), an online community forum and a range of online materials, information and leaflets.

The Marie Curie Helper Service, currently available in Dumfries & Galloway, Fife, Grampian and Lothian, provides one-to-one emotional support, companionship and information about relevant local services to people living with terminal illnesses, and their families and carers through the use of volunteer helpers. We have plans to roll-out the Helper Service across the rest of Scotland.

Further information:

Richard Meade

Head of Policy & Public Affairs
richard.meade@mariecurie.org.uk

Marie Curie

14 Links Place
Edinburgh EH6 7EB

Susan Lowes

Policy & Public Affairs Manager
susan.lowes@mariecurie.org.uk

0131 561 3904/02

@MarieCurieSCO



Care and support
through terminal illness