

Palliative Care for Lesbian, Gay, Bisexual, Transgender People and People with Intersex Characteristics (LGBTI)

Position Statement

This is a joint position statement from Palliative Care Australia (PCA) and the National LGBTI Health Alliance

***Palliative Care Australia** is the peak national body for palliative care. We represent all those who work towards high quality palliative care for all Australians. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to, and promote the need for, palliative care.*

***The National LGBTI Health Alliance** is the national peak health organisation in Australia for organisations and individuals that provide health-related programs, services and research focused on lesbian, gay, bisexual, transgender, and intersex people and other sexuality and gender diverse (LGBTI) people and communities.*

PCA and the National LGBTI Health Alliance believe:

- Quality palliative care should be available to all people with life-limiting conditions. This includes people who are lesbian, gay, bisexual, of transgender experience and people with intersex characteristics (LGBTI).
- Palliative care for LGBTI people with life-limiting conditions, their self-designated family¹ and carer(s), should be accessible, inclusive and affirm their right to dignity and respect.
- Many LGBTI people have experienced discrimination, stigma, rejection, criminalisation, exclusion, medical abuses, persecution and isolation.² Palliative care services must provide a safe environment where LGBTI people with life-limiting conditions can live and die with equity, respect and dignity, and without fear of prejudice and discrimination. Their self-designated family and chosen carer(s) should be treated with the same level of dignity and respect.
- There is significant diversity amongst people who are lesbian, gay, bisexual, of transgender experience and people with intersex characteristics. Australian research shows that most people in these populations do not consider these terms their “identity”; this means they can

¹ Not limited by blood relative and is defined by the patient

² Australian Government, Department of Health and Ageing *National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy* Commonwealth of Australia, 2012 p.4

be easy to miss if we expect them to use specific terms about themselves instead of recognising the diverse ways people might describe themselves and their life experiences.

- It is the individual's right to withhold or disclose their sexual orientation, gender identity or intersex status, as this may have significant ramifications. Therefore, confidentiality and discretion are paramount.
- It is important that LGBTI people are supported in choosing their end of life pathway. Their self-designated family and chosen carer(s) should be supported in enabling these choices as they can often fall secondary to biological relatives through assumed rights.

PCA and the National LGBTI Health Alliance call for:

- Person-directed care for all people with life-limiting conditions. Person-directed care means that people with life-limiting conditions:
 - make their own decisions on their own behalf in consultation with professionals or have their personal wishes represented by an appointed substitute decision-maker in the event they lose capacity to make decisions;
 - receive helpful communication from health professionals that assists them to understand their illness and prognosis, the respective benefits and burdens and likely outcomes of various treatment options, and the availability of care and other services and supports that could assist to achieve their goals of care.
- Recognition of partner(s) regardless of sexual orientation, gender identity or intersex status as the legal next of kin.³
- Acknowledgment that family includes biological family as well as the self-designated family. This recognises that many LGBTI people have been ostracised or abandoned by their biological relatives, and that strong networks of friends and loved ones are as intrinsic and equally valid in the life of an LGBTI person with life-limiting conditions.
- Palliative care providers to be supported to deliver LGBTI-inclusive services and have the opportunities for appropriate accreditation and training for whole-of-service approaches to LGBTI people. There are many approaches to achieving this across Australia and information can be found at Silver Rainbow, the national LGBTI Ageing and Aged Care Project of the Alliance at www.lgbtihealth.org.au.
- Efficient case management through the collaboration of health professionals, the person with the life-limiting condition, their partner (if any), their self-designated family and carer(s) using a person-directed approach.
- Effective procedures to address discrimination and breaches of confidentiality by staff and other service users.
- Increased palliative care research in addressing the diverse needs of the community, in particular for each population within L,G,B,T,I.
- Protection from medical abuse, such as denial or cessation of hormones, unnecessary physical examinations or coerced 'normalising' interventions.
- Nationally consistent and inclusive advance care planning legislation to reduce jurisdictional confusion and provide greater certainty for health professionals, patients, carers, self-designated family and loved ones.

Background

Although there have been increasing levels of social acceptance and legislative improvements, LGBTI people continue to experience prejudice and discrimination in healthcare settings and often feel compelled to hide their sexuality, gender identity (including their history of having lived in another gender previously) or intersex status for fear of negative responses. Despite Federal legislative

³ PCA recommends services familiarise themselves with the relevant legislation in their state or territory

protection, women and men of trans experience, people with non-binary genders⁴, and people with intersex characteristics are still regarded or treated as psychologically abnormal in many areas of healthcare today. They also continue to experience higher levels of abuse and poorer mental health compared with the broader population.⁵ In later life, LGBTI people are more likely to be single, living alone and less likely to have close relationships with their biological family than the broader population.⁶ Services consequently need to be proactive in providing support and in some cases advocate for the LGBTI person in a care environment.

Care that focuses on the needs of the person and all aspects of their well-being is an essential part of palliative care. It is important to note the diversity amongst LGBTI people, and tailor care to each individual as a result. While LGBTI people are not a homogenous group, this population group shares many common experiences of exclusion, discrimination and stigma.⁷

As a result of these experiences, many LGBTI people have hesitations and feel uncertainty towards services such as palliative care and may delay seeking treatment in the expectation that they will be subject to discrimination or receive reduced quality of care. A diagnosis of a life-limiting condition is distressing enough without the additional concerns of isolation, inequality and discrimination from care providers. It is essential that healthcare staff treat LGBTI people in a respectful, person-directed manner, maintaining their physical, social, cultural, spiritual and emotional wellbeing. Recognising the importance of all partners particularly in their roles as primary carer/s is essential in providing holistic care. In addition it is important to recognise the person's self-designated family and that there may be a need to protect the person from biological relatives who they do not consider to be family.

By providing services with professional development opportunities, staff can have more confidence in caring for LGBTI people appropriately. Opportunities for continuous professional development in relation to diverse groups should be available to all services providing palliative care.

It is important that services create a safe and inclusive environment for LGBTI people so that they can feel comfortable and safe to provide personal information should they choose to do so, including the disclosure of their sexual orientation, relationship status, gender identity (including their gender experience, history, and/or gender-associated expression) or intersex status. The person's LGBTI experience or characteristics do not necessarily dictate who they are, or how they primarily understand themselves, and care should be individualised to the specific individual to reflect this. Systems should be in place to ensure the privacy of the LGBTI person, their self-designated family and carer(s), and a collective staff responsibility to eradicate discrimination must be encouraged.

⁴ Non-binary gender refers to a gender identity that isn't exclusively male or female.

⁵ Leonard, William., et al. *Private Lives 2: The Second National Survey of the Health and Wellbeing of GLBT Australians* La Trobe University, Melbourne 2012 p. 13

⁶ Stonewall UK [Lesbian, Gay and Bisexual People in Later Life](http://www.stonewall.org.uk/documents/lgb_in_later_life_final.pdf) London, UK. Stonewall UK, October 2010 http://www.stonewall.org.uk/documents/lgb_in_later_life_final.pdf. Accessed on 2 February 2015.

⁷ Australian Government, Department of Health and Ageing *National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy* Commonwealth of Australia, 2012 p.4