



# Sexual and gender diversity: Implications for palliative care

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## Introduction

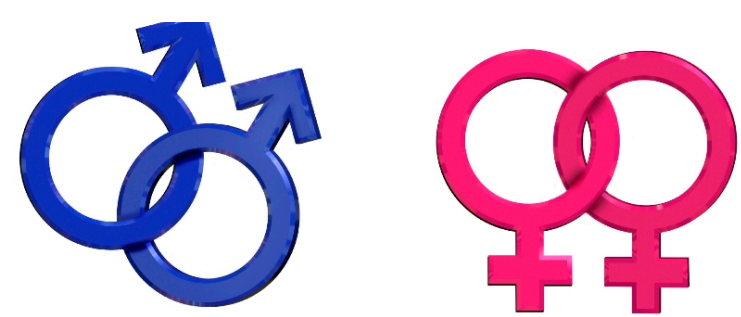
CareSearch is an online resource for those providing palliative care and those receiving palliative care, however, when looking to provide evidence-based information about people with palliative care needs it is apparent that no approach is 'one size fits all'.

The palliative care sector acknowledges that some individuals are marginalised and have very different needs that can impact their care at the end-of-life, but has not always had access to specific information and resources.

A population health approach identifies groups that may have specific needs in ensuring equitable care, and for some gay, lesbian, bisexual and transgender (GLBT) individuals who have specific health considerations.

## Disparities in health outcomes

Unequal access to the services and lifestyle choices (such as marriage) that their heterosexual counterparts take for granted can result in adverse health outcomes and compromised quality of life for some GLBT individuals. These include higher reported rates of alcohol consumption, suicidal behaviour and mental disorders, smoking, substance abuse and obesity. [1] An understanding of these risk factors is required in relation to care.



## Implications for end-of-life care

Due to fear of discrimination, not all GLBT individuals are open about their sexuality when seeking healthcare. For some, non-disclosure to health professionals and reluctance to access preventative screening can impact on diagnostics and timely treatment. [2]

Palliative care providers might not understand the degree to which life experiences influence the behaviours and decisions of patients and how GLBT individuals' experiences, such as hostility, violence or rejection, can impact on end-of-life care.

## Advance Care Planning (ACP)

Same-sex partners are not always afforded the legal protection offered by marriage and may have no or limited rights when it comes to being involved in the end-of-life care of a partner.

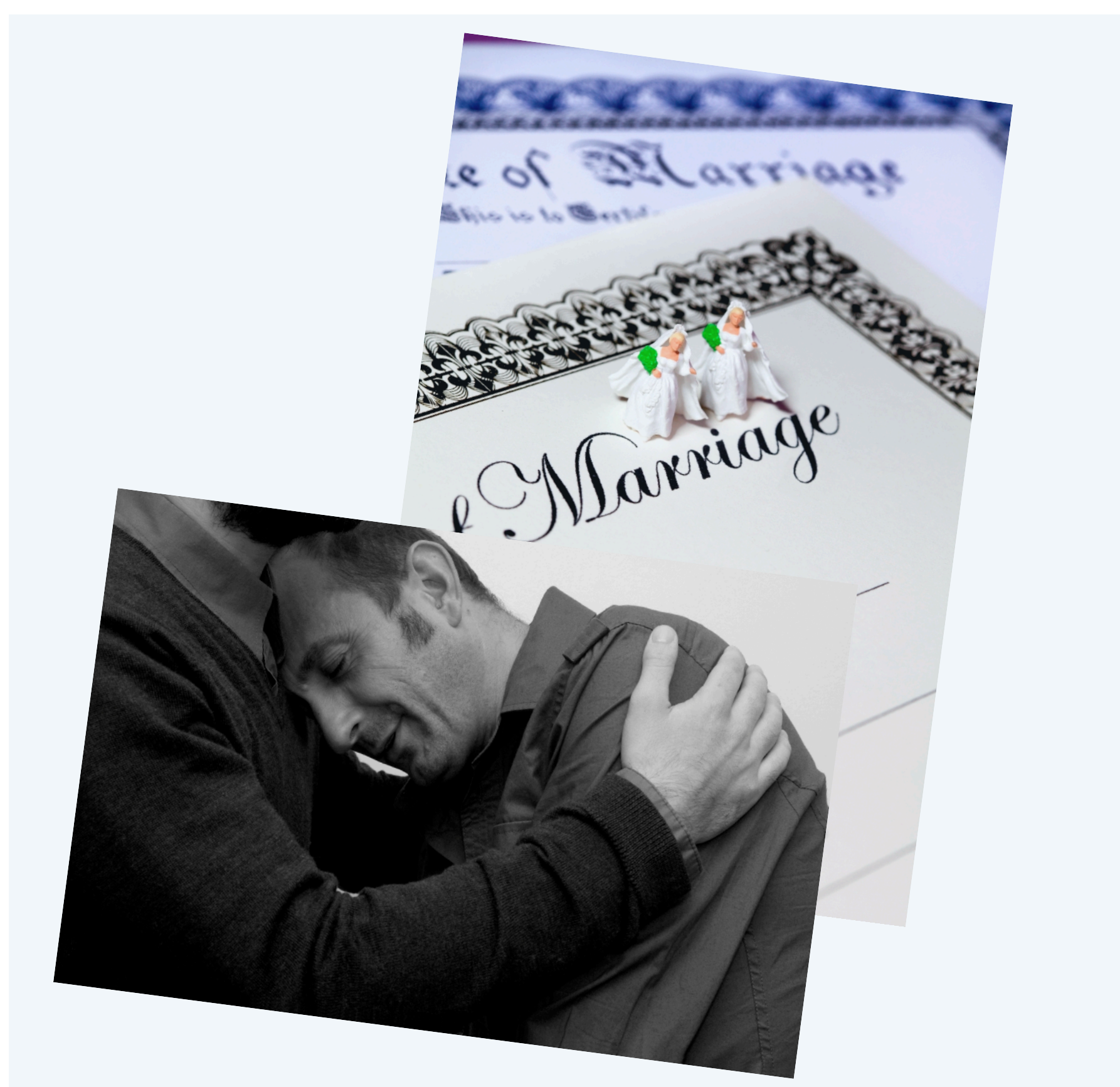
Individuals can use ACP to document their wishes and help ensure partners are not excluded. One reason GLBT individuals gave for ACP was fear of family interference in decision making and fear that their wishes would not be respected, with examples cited of health professionals restricting access to a dying same-sex partner. [3]

## CareSearch and population health

In conjunction with the National Advisory Group, CareSearch identified certain groups who require specific consumer and health professional information, which was subsequently provided to build awareness of care issues and resources. These groups included those who are of atypical gender. As with any page developed for the website, feedback was received from consumers and health professionals and was formally peer reviewed by an academic with an interest in both palliative care and sexual health.

CareSearch provides information relating to GLBT individuals that is summarised for health professionals in the *Clinical Practice* section (specific populations) and for consumers in the *For Patients and Families* section (groups with specific needs).

CareSearch also provides information pages on many of the themes covered here such as ageing, caring and ACP, which are relevant issues for many individuals regardless of sexual orientation. As with anyone's care, however, ACP needs to be contextual and holistic.



## Results

CareSearch has summarised the evidence in relation to GLBT individuals, focusing on issues they may face and how this may impact end-of-life care. The literature review highlighted a lack of research and resources in this field, although several studies are now underway.

During a one year period (2010/2011), web statistics showed that the information was regularly accessed and viewed as follows:

- the consumer pages on 873 occasions
- the health professional and/or further reading pages on 2,141 occasions
- the PubMed Topic Search was accessed 641 times

## Care issues

When a member of a GLBT couple is dying at home, it may mean having to 'come out' to health professionals regarding living arrangements that had previously been kept private. [4]

Large numbers of gay, lesbian, bisexual and transgender midlife individuals are also providing significant support, care and advocacy for older parents and for each other. [5]

Homophobia is a serious issue in ageing and disability with fear of discrimination acting as a deterrent in utilisation of mainstream services. This is reinforced by invisibility in policy, such as lack of available supported accommodation for elderly same-sex couples. Aged care staff are unprepared for a future that will see an estimated doubling of the GLBT population in coming decades in line with the ageing population. [6]

You can find further relevant information via PubMed Topic Searches. Try combining searches on 'gay, lesbian, bisexual and transgender' with ones on 'aged' or 'aged care facilities' or on 'carers', 'supporting carers' or 'carer interventions'.



## Conclusion

It is vital that the palliative care community have access to relevant evidence-based information and resources to support the care of any individual, but especially those who may have inequitable access and specific needs. CareSearch has provided information and resources to support the provision of quality care for gay, lesbian, bisexual and transgender individuals.

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## References

- [1] Gay and Lesbian Medical Association (2001) Healthy people 2010: The companion document for Lesbian, Gay, Bisexual and Transgender (GLBT) Health.
- [2] Van Dam M, Koh A and Dibble S (2001) Lesbian Disclosure to Health Care providers and Delay of Care. *Journal of the Gay and Lesbian Medical Association*. 5 (1):11-19.
- [3] Hash K and Netting E (2007) Long-Term Planning and Decision-Making Among Midlife and Older Gay Men and Lesbians *Journal of Social Work in End-Of-Life & Palliative Care*, 3 (2) :59 – 77.
- [4] Price E (2010) Coming out to care: gay and lesbian carers' experiences of dementia services *Health and Social Care in the Community* 18(2) :160–168.
- [5] Department of Health and Human Services' (2003) Gay, Lesbian, Bisexual and Transgender Reference Group: Lesbian, Bisexual and Transgender Health and Wellbeing Needs Assessment. Blanch Consulting. Tasmania.
- [6] Tolley C and Ranzijn R (2006) Predictors of heteronormativity in residential aged care facilities *Australasian Journal on Ageing*, 25 (4) :209–214.