

End-of-Life Care for Gay, Lesbian, Bisexual and Transgender People: A Human Rights Issue

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Background

- GLBT people are socially and economically disadvantaged as a result of historical discrimination, social stigma and lack of legal recognition of relationships and gender identity (ACON, 2006).
- All Australian States/Territories have legislation relating to end-of-life decision-making and substitute judgment.
- However, reports to relevant legal and community services – plus a review of the literature - indicate that many GLBT people are denied their legal rights in the end-of-life care of their partners and other important people in their lives
- If advance care planning does not take place, GLBT people can be further disadvantaged at the end of their lives.

Legislation

- When an adult loses decision-making capacity, the law in most Australian states/territories specifies an “order of authority” of substitute decision-makers.
- In NSW, the Guardianship Act (1987) established a hierarchy of substitute decision-makers (Person Responsible) – the first readily available and culturally appropriate of:
 - The person’s guardian
 - Appointed by Tribunal; or
 - Appointed by the adult as an Enduring Guardian
 - Spouse (including same-sex or de facto spouse)
 - Non-professional carer
 - Close friend or relative of the person

Study Conducted in Northern Rivers Region of NSW in 2009

- Study conducted by ASLaRC with support from ACON
- Study design included:
 - an international literature review,
 - ethics approval – SCU HREC and ACON
 - development of GLBT-specific schedule of questions to guide community and service provider consultations, based on previous research by the ASLaRC Director
- Target Group: GLBT residents in North Coast NSW
- Sample Selection: Community and service provider forums were advertised through health and community service emails lists, by word-of-mouth, by a mainstream media release, promoted on Northern Rivers radio and through ACON's *Rainbow News*.

Issues Identified in the Literature

- Stigma and discrimination faced by gay and lesbian people prevents end-of-life care planning for fear of being outed, leading to ‘disenfranchised grief’ and loss of entitlements for same-sex partners;
- GLBT people need to engage with Advance Care Planning in order to protect their rights, counter discrimination and die with dignity;
- Barriers such as lack of knowledge and difficulties identifying alternative decision-makers mean there is a need for information resources on advance care planning;
- Discrimination faced by GLBT people in health care settings and fear of such discrimination leads to failure to or delays in GLBT people accessing health services, resulting in problems in end-of-life care;
- Difficulties in end-of-life care mean there is a need for advocacy.

Data Collection Issues

- The service provider forum was held but the community forum had to be cancelled due to rising floodwaters (a common occurrence in the Northern Rivers) and low response numbers.
- Anecdotal evidence from community members and service providers who spoke to the researcher about the proposed community forum, and its cancellation, was noted.

Participant Profile

- 12 Service Providers attended the forum and an additional seven provided information/comments during the course of the project (N = 19; 4 males, 15 females)
- Service Provider professional areas included:
 - Nursing; Home and community care
 - Palliative care; Residential aged care;
 - Allied health; Voluntary community care
 - Social work; Funeral Industry
- Three service providers had end-of-life care experience covering many years and multiple cases, incl. from the AIDS epidemic.
- Six GLBT Community Members provided individual comments during the project about their experiences with end-of-life care; (4 males, 2 females)

Major Findings - 1

- Lack of legitimacy of same-sex relationships, sexual and gender identity accorded by family, health professionals and society;
- Failure by family and health professionals to acknowledge the appropriate (and legally recognised) substitute decision-maker/ Person Responsible in end-of-life care for GLBT people.
- This exclusion caused additional grief and loss of dignity for both the patient and their partner.
- Several service provider participants did not know that same-sex partner was recognised as Person Responsible under the NSW legislation, with legal authority to make substitute health care decisions for their partner, if their partner lacked capacity

Major Findings - 2

- Levels of awareness/use of legal mechanisms for advance care planning varied considerably among clients of service providers.
- Important that GLBT people communicate their end-of-life care wishes to family and health care professionals before they become incapacitated. If not, they risk their wishes and those of their close friends/partners being overridden by blood relatives and health care workers. Advocates have an important role in ensuring that the wishes of the dying person are met.
- When same-sex and other important relationships are recognised by families/health care professionals, and advance care planning is well organised and communicated to significant people, it is possible for GLBT people to experience appropriate end-of-life care and to die with dignity.

Barriers to Advance Care Planning by GLBT People

- Not wanting to think about the end of life
 - Suggested as a reason for people not attending the community consultation, and for clients not completing an Advance Health Care Directive (AHCD).
- For gay men only, a denial of the realities of ageing and death
 - Many older gay men are socially isolated and alienated from the gay community because of its focus on youth and beauty; this can result in a lack of interest in, and even a denial of, the realities of ageing and death.
- Lack of time / low priority
 - *I'm not ready for this one yet. I'm in good health. I'll get there. It's procrastination.*
- Lack of knowledge
 - Not knowing what decisions to put in an AHCD; who to ask for help
- Not knowing who to appoint to significant decision-making roles
 - It is very personally confronting. Is it a new partner, or an old friend or family member? How do I tell the new partner if it's not him?

Recommendations

- **Systemic Change**
 - Legal and social recognition of same-sex relationships, and the diversity of sexual and gender identity would benefit GLBT end-of-life care; an end to discrimination may have a flow-on effect to service provision.
- **Information Resources Targeting GLBT People**
 - Legal mechanisms to assist people with end-of-life care planning are available now but are little known. GLBT-specific information resources are required, including for closeted rural and regional GLBT people and those still married.
- **Interventions to Prevent Social Isolation, Encourage Social Connection**
 - Assist GLBT people to develop friendships/partnerships that might be relied upon at critical times, such as the end of life.
- **Education of Service Providers**
 - Relevant agencies need to provide education about end-of-life decision-making, incl. changes to the Guardianship Act (1987) & who is PR.

Access to Current Resources

ASLaRC Website: <http://aslarc.scu.edu.au>

– Go along top menu line to Downloads

- Documents for use in both NSW and Qld community
- Documents for use in NSW residential care
- Some PowerPoint presentations (incl. this one soon) – feel free to use for educating staff, community
- Reports of research projects (incl. this one: End-of-Life Care for GLBT People: Phase 1)
- For Information/Resources in other States/Territories, go to Google, type in Austlii, browse!