

4.4 Relationships, families and intimacies The role of families, carers and intimacy in end of life care

What	Good practice tips in assessment and design of support and care that engages with the role of families, carers and intimacy in end of life care
Purpose	Students can identify the key issues to come up if a LGTB+ older person is at the end of life.
Target group	Teachers and trainers in vocational education and their students
Level	Level 2-3-4 in vocational education.
Execution	Extra support from the teacher might be necessary depending on the ability of the students to work independently
Sources	Guidance for improving end-of-life care for LGBT people

Introduction Care in health crises or old age

Heaphy et al's (2003) study of 266 LGBT+ people aged 50 to 80-plus found overwhelmingly that partners were the most likely providers of care in times of chronic illness; and partners and health professionals in the case of care in old age. Few expected family members to assume this responsibility. Friendships can be an unexpected source of care in this context. Few LGBT+ older people had actually made plans for care in health crises or old age. Forward planning and carers' support is therefore an important aspect of assessment and intervention.

Almack et al (2015) examined particular needs and preferences salient to sexual/gender orientation relating to end of life care (EoLC) as identified by LGBT+ older people. One of the areas they explored was LGBT+ older people's familial and friendship networks and the ways in which these personal networks may influence later life experiences towards and at end of life.

Having one's wishes respected after death was a particular concern. Almack et al's respondents gave many anecdotal stories of LGBT+ people they knew who had died and whose partners and/or friends had been excluded from the funerals by families of origin. For trans people, particular concerns are expressed about being buried by family of origin under their birth gender, despite knowledge of legal protection of one's acquired gender identity – concerns here are not only about being cared for and dying where one wishes, but to be buried as one wishes.

Trans people in particular were often estranged from family of origin or had conditional relationships (for example, a trans woman who wants to maintain contact with her daughters and grand-children is only able to do so if she reverts to being their 'Dad' and 'Granddad' in their company).

The NHS national end-of-life care programme (2012) produced guidance for improving end-of-life care for LGBT+ people (<http://www.nhs.uk/resources/publications/eolc-rts-lgbt.aspx>), and this identifies the importance of encouraging LGBT+ people to be confident in being open about their relationships and emotional needs during end-of-life care and bereavement. One way that social work can respond to the unique needs of older LGBT people during end-of-life care or bereavement is to acknowledge the impact of "historical disadvantage" on people's fears and expectations of health and social care practice (Fenge, 2014). Social work is in a unique position to support LGBT+ older individuals as it "brings a whole systems approach to dying", which includes community and cultural perspectives. Research has shown that many years of feeling different, coupled with complex emotions of shame and rejection, can have a big impact on LGBT+ older people's self-esteem. This may lead to mental health problems such as depression. Symptoms may include feeling sad or empty, losing interest in activities previously enjoyed, and having problems with sleeping or eating.

Activity

Students and learners should be encouraged to identify the key issues that may come up if an LGBT+ older person is at the end of life.

They can be asked to research what provisions are in place (legislation and policies and resources) that enable LGBT+ older people to plan and document who they want to be involved in their care and what guidance is available in their practice area.



Students asked to make a checklist of up to 6 key points from existing guidance that apply to their direct area of work.

Keep on learning

- Almack, K., Yip, A., Seymour, J., Seargent, A., Patterson, A., Makita, M. (2015) T The Last Outing: exploring end of life experiences and care needs in the lives of older LGBT people. University of Nottingham. Project Report.
- Weeks, J., Heaphy, B., Donovan, C. (2001) Same Sex Intimacies: Families of Choice and Other Life Experiments Psychology Press,