"If you don't have children or a partner, no family you're close to, who is there?": advance care planning for older LGBT people

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Some of the research I've led or been involved in addressing concerns of older LGBT people in the UK

2010 -12 worked with the National End of Life Care Programme (NEOLCP) to start to address the invisibility of older LGBT people within end of life care provision

2013-15 **Almack, K**, Seymour, J, Yip, A and Sargeant, A
The Last Outing: Exploring the End of Life Care needs and experiences in the lives of older LGBT people (funded by Marie Curie Research Programme)

2014 **Almack, K** and Simpson, P
Attitudes, knowledge and practices in care homes towards LGBT residents (funded by the NEOLCP)

2015-16 Hafford-Letchfield, T., **Almack, K.,** Willis, P. and Simpson, P.
Developing an LGBTI inclusive environment for older people living in care homes. (with Research Partner, Anchor Housing Trust, funded by Comic Relief))

2014-16: Harding, R., Daveson, B., **Almack, K.**
ACCESSCare: Advanced Cancer Care Equality Strategy for Sexual minorities (funded by Marie Curie Research Programme)

2017 – 19 Harding, R., Bristowe, K., King, M, Almack, K.
ACCESSCare II - bereavement outcomes for LGB and heterosexual bereaved partners: a population based cross sectional mixed methods study (funded by Marie Curie Research Programme)

Reason for action

- National reviews in England reveal that:

  "sexual orientation and gender identity are perhaps the most likely areas for inequality and discrimination to occur in end of life care" (2008)

  "may experience poorer quality care at the end of their lives because providers do not always understand or fully consider their needs" (2016)

- Equality legislation now protects LGBT people against discrimination in the delivery of services
- We need more evidence about the needs and experiences of the oldest generations of LGBT people to inform the delivery of end of life care

2008: The English End of Life Strategy equality impact assessment
2016: Care Quality Commission review of inequalities at EOL: A different ending: addressing inequalities in end of life care

The end of life care needs of lesbian, gay, bisexual and transgender people are in many ways similar to those of heterosexual people.

However: care providers should recognise that there are also unique needs and considerations

Advance care planning (ACP)

provides the basis for delivering person-centred end of life care in line with the wishes and preferences of the individual

enables a record of the individual's wishes and preferences, which guides the person's care when they have lost mental capacity and provides crucial support for families and carers

offers ongoing opportunities to enhance the choice and control an individual has over their treatment and care needs / preferences

Using ACP can be particularly important for LGBT people – especially if there are concerns relating to chosen caregivers being contested or overridden by members from a family of origin or healthcare professionals

Aspects of Advance Care Planning

- Opening the conversation
- Explore your options
- Identify your wishes and preferences
- Refusing specific treatment, if you wish to
- Ask/nominate someone to speak for you
- Appoint someone to make decisions for you using a Lasting Power of Attorney (two types: health and welfare; property and financial affairs)
- Let people know your wishes.

Exploring the end of life care needs and experiences in the lives of older LGBT people

Mixed-methods study:

- 237 completed surveys
- 60 in-depth interviews
- L,G,B and/or T people aged 60 and over or under 60 but in a partnership with an L,G,B and/or T person aged 60 and older.

Age range 37 – 93 years

Gender	%
Female	49.8
Male	46.8
Alternate identity (e.g. ‘pangender’, ‘transgender’, ‘trans man’, ‘dual gender life’)	3.4

Sexual Orientation	%
Heterosexual/straight	3
Gay	43
Bisexual	10
Lesbian	37
Other (e.g. ‘queer’, ‘dyke’, ‘asexual’ and ‘not the marrying kind’)	7

Gender Identity
17% of respondents have a different gender to that assigned at birth

Findings from The Last Outing project

- Motivations to complete advance care plans include some issues similar to those reported for the general population such as not placing burdens on others but also **distinct issues such as providing protection for partners and significant others who might otherwise not be recognised**.
- 82% agreed that it was particularly important for LGBT people to make and record plans for future care
- 40% said that they had talked/informed their partners or friends about their preferences for future care and treatment.
- Only 18.5% of the respondents had written down and recorded their preferences for future care and treatment. These figures are broadly reflective of the general population.
- One important point made was that LGBT people needed access to advice and advisors to make plans, who would understand something about the diversity of LGBT lives.

International evidence available highlights concerns that LGBT people's partners, ex-partners and friends are sometimes not fully recognised as having a legitimate role in end-of-life decision-making by biological family members and healthcare providers.

While there is an absence of legal clarity about who is 'next of kin', in practice the default position reflects heteronormative norms; it is still often assumed to refer to people related by blood or (heterosexual) marriage.

Key people in the lives of LGBT people were not consistently included and even actively excluded as important, in a range of health and care settings.

I had a bad set to in hospital with nurses about getting listened. For example, I was acting on her behalf, as her partner, but they would not listen to me, only to her direct family and this caused serious problems for us in relation to information about her on-going care and treatment. (Anonymous survey respondent)

When I was in hospital, I remember Irene being asked to step outside while the surgeon had the final consultation with me, the day that I was admitted, and we weren't at that point brave enough to say no I want her here. (Rachel, lesbian, 71)

Staff almost always presume we are father and son and have to be corrected. Some staff appear not to know what a 'civil partnership' is!! In the early years of being a carer I was often simply ignored. (Anonymous survey respondent)

One issue identified by a number of participants was about not knowing who to nominate in decision-making roles due to their personal networks comprising people of the same age or ongoing social isolation

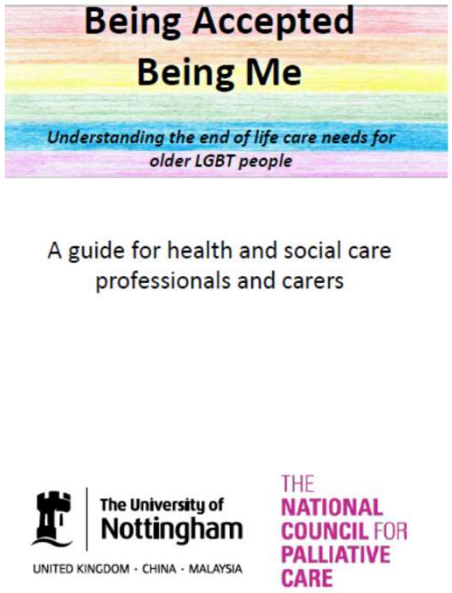
I've got a will, but I haven't appointed a lasting power of attorney. I should but I don't have anybody obvious and close to me to ask, there must be lots of people in that position. It strikes me as somewhere I could be very isolated and frightened indeed (Grace, trans woman, 68).

So I'm involved in promoting and publicising advance planning to others through Dying Matters but I haven't done it myself. Because you need someone on hand and who is able to respond. And if you don't have children or a partner, no family you're close to, who is there? My friends are all as old as me! (Martin, gay man, 73)

I'm fortunate to be very well-off; I have no concerns on that front, I can afford the best care. But in terms of planning ahead … who can I appoint? I think it correlates a lot with being gay and not having had a kind of traditional family life. I worry if someone is in a position to make decisions on my behalf, they need to accept who I am. I will start talking to my niece more, and her daughter too, I forget her name but she's a nice girl … (Matthew, gay man, 71).

Other important considerations

- *I don't want anyone putting me in a dress or cutting my hair or putting make-up on me*
- *I would like the company of other LGBT people, preferably women only (gay or straight) environments*
- *I want my partner to have a say about what happens to me, it is important to me that she is not dismissed or pushed out by my biological family*
- *I wish to end my life including my funeral as a woman. I want to be buried as a woman but I have a feeling my daughter would like to bury a father who is designated male*



Some useful resources – both available online or email me for a hard copy of ‘Being Accepted Being Me’

Thank you for listening

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