LGBT people and Dementia

National LGB&T Partnership

Tina Wathern & Rowena Mcarthy

What is different?

- Heteronormative services prioritise heterosexuality in normal daily living, both implicitly and explicitly, and LGB&T carers and those receiving care have to fit their experiences into a framework based on heterosexuality as the default position.

- Same is true of cisgendered services

- Carer and *patient* relationship with services is often impacted by the ‘coming out’ process

What do services tell us ?

- The recent ASCOF (Adult Social Care Outcome Framework) LGB&T companion document139 surveyed a number of service users and commissioners about the effectiveness of dementia care post-diagnosis and found that:
- Nearly three quarters (73%) of respondents said that the service they provide or commission does not collect data for LGB&T service users with dementia in relation to the effectiveness of post-diagnosis care,in sustaining independence and improving quality of life. A fifth said this was collected, and a further 7% were unsure.

- Respondents who gave further information had not considered monitoring sexual orientation or gender identity in this area.

What do we know?

- Older LGBT people are more likely to live alone and be single than their heterosexual peers.
- More likely to have a family of choice
- Lack of traditional models of support leads to an increased use of services
- Most older LGBT people in care settings choose not to ‘come out’
- Response is often based on a fear of prejudice or hostility which may be as a result of discrimination they have experienced.

- It is crucial for care facilities to understand the importance of how sexuality and gender affect the experience of LGBT service users and their carers as well and adapt this knowledge into their service procedures
- Responsibilities can become more difficult if there is a lack of recognition from care homes and other services that do not fully understand the nuances of sexuality and gender (Westwood, 2014).
- Traditional support groups may not be comfortable places.
- Language is often inappropriate- husband/wife etc

- It is important to remember that older gay men and lesbians grew up at a time when being homosexual was illegal, and for gay men being ‘found out’ resulted in a number of judicial consequences.

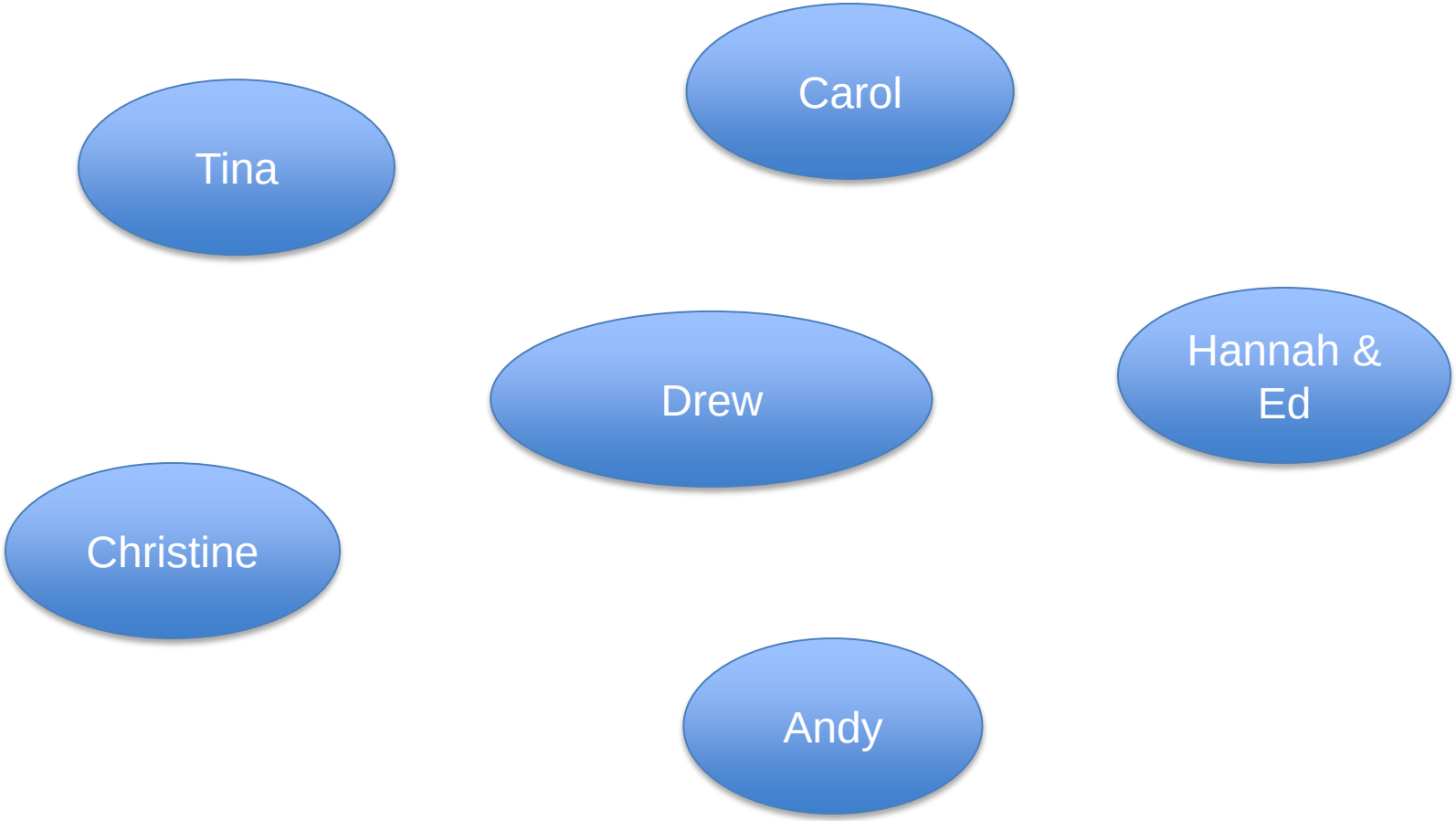
- Therefore, their sense of identity is shaped in the context of homosexuality being unnatural, and hiding themselves in a protective survival mechanism.

- LGBT older people are rarely acknowledged by service providers and commissioner

What is a family of choice?

- Often includes ex partners and their new partners
- Can be intergenerational
- May not include blood relations
- Next of kin or contact person?
- Peer group- HIV impact

A family of choice



Dementia roundtable…what did people say? What are people worried about

- *Reduced inhibition sometimes caused by dementia was a concern, "a fear of losing control over what people do and say*

- *"People 'disappear' in residential care- their identity ceases to exist – not many people are 'out' in care."*

(National LGB&T partnership- 2015)

Out Loud: A narrative for LGBT people in health and social care

“I Statements”

(LGB&T partnership, National Voices 2016)

Dignity and Respect

“I am seen as a whole person with a wide collection of identities and needs”

“My relationships are acknowledged and respected by health care providers”

For LGB&T people with dementia, part of treating people with dignity is recognition of the person’s identity as LGB and/or T as part of their life and ensuring that conversations of the past include their relationships and identity where appropriate

Equality

“Health care providers do not make assumptions or judgements about my body, identity or relationships”

“People providing my care act in a professional and non-discriminatory way”

Many health and social care professionals often do not think sexual orientation and gender identity is relevant to any health care need, which reinforces the invisibility of people’s identity and means that the specific needs of LGB&T people are overlooked

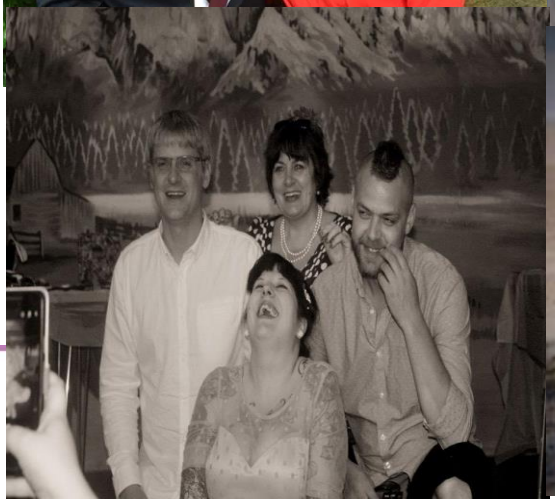
What would my memory book look like?











- K’s story

Recommendations

- *Service providers should invest in training materials and specialist LGB&T training* – that includes an overview of LGB&T terms, historical context and legislation changes.

- *Important to ensure that in order to make a lasting change* any project aiming to empower LGB&T people with dementia is driven by LGB&T people with dementia.

- *The Joint Strategic Needs Assessment* should explicitly consider the needs of the local LGB&T community in relation to care and support

- *Health and Wellbeing Boards and local authorities* should work closely with CCGs to promote the integration of health and social care which recognises the particular needs of LGB&T people.
- *Commissioners should use equality impact assessments* which include sexual orientation and gender identity when planning for the needs of people with dementia.
- *Commissioners and providers need to consider identifying appropriate support groups* – An LGB&T person living with dementia will talk about memories and people that are influenced by their experiences as an LGB&T person. They may feel unable to express this and connecting them with other LGB&T people and support groups may help support their identity and confidence.

- For further information, please contact:
  LGBTPartnership@lgf.org.uk

  nationallgbtpartnership.org