



Proud to Care: LGBT and Dementia

**A Guide for Health and
Social Care Providers**

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Introduction

LGBT Health and Wellbeing has developed this toolkit to support health and social care staff to reflect on and develop their practice in working with lesbian, gay, bisexual and transgender (LGBT) people with dementia.

Around 5-7% of the population are LGBT. That means that 5-7% (about 1 in 16) of the people your service works with are likely to be LGBT. However, in many health and care settings, LGBT people's identities are often hidden, and this is perhaps even more likely in dementia care, where people may become less able to communicate what is important to them. This resource will help you consider why LGBT people may not be visible, the potential consequences for LGBT people you support, and ways to develop inclusive practice.

Being LGBT and having dementia can present additional difficulties and in the past this has not been widely talked about.

This resource looks at the specific experiences that LGBT people affected by dementia may have and how best practice can be developed.

We know that those working in care are committed to ensuring that every person living with dementia, or caring for someone who is, is treated as an individual and that their care is person-centred. However, we also recognise that many people – including staff - may feel uncomfortable talking about minority sexual orientation and / or gender identity. This tool aims to support opening up those conversations so that all staff can help make people's experiences of their services the best it can be.

We hope this toolkit can both raise awareness of LGBT experiences in dementia care and help health and social care services continue to develop best practice.

The toolkit uses Scotland's **Health and Social Care Standards, 'My support, my life'**¹, which came into effect in April 2018, as a basis to help you think about best practice in relation to LGBT inclusion.

The toolkit assumes knowledge of dementia, as it is aimed at dementia services. More information about dementia can be found on Alzheimer Scotland's website: www.alzscot.org

¹ <https://hub.careinspectorate.com/media/2544/sg-health-and-social-care-standards.pdf>

How the toolkit was developed?

This toolkit has been produced as part of LGBT Health and Wellbeing's two-year national LGBT Dementia Project. In the early stages of the project we undertook wide ranging desk research to look at others' work on this topic, nationally and internationally. We then spoke with a range of stakeholders, including people affected by dementia who identify as LGBT and health and social care staff.

The toolkit was produced with the input of a steering group including a range of representatives from care providers working across Scotland, Alzheimer Scotland, Scottish Care, and the Care Inspectorate.



It is a tool for everyone working in dementia care and carer support services to understand the unique experiences that LGBT people often experience and how best to respond to these to ensure that services are fully inclusive and affirmative. It draws on best practice.

How to use this toolkit

The toolkit is aimed at giving providers a starting point to think about how well they are supporting LGBT people and if there is anything they are doing particularly well or would like to change.

The Toolkit has 8 sections. Each section helps you to start to think about some of the issues, rather than giving you the "rights and wrongs". They provide a context for looking at the issues LGBT people may face, and give guidance on ways to reflect on policies and practice.

- You may wish to establish an internal group to look at your LGBT-inclusive practice using the toolkit. Your group may also want to look at and use some of the training resources we have produced, as well as taking forward the completion of the Self-Audit Tool.

As you read through the toolkit there will be a number of links to external resources.

- The toolkit has been developed through learning gained from delivery of community discussion events, one-to-one meetings and discussions with those taking part in the training we delivered as part of the LGBT Dementia Project.

We hope this toolkit will enable you to:

- Think about the experiences that LGBT people may have had, and how this influences the way that they may view care and support services.
- Promote the way that your service works towards creating an affirmative space that feels safe to LGBT people and recognises diversity.
- Identify what values, ethos and culture need to be fostered to enable LGBT people to fully engage with your service.
- Be confident that your service is meeting the Health and Social Care Standards in your work with LGBT people.

A note about language

LGBT people are not all the same. They have different identities, and a vast range of circumstances, preferences and ways of expressing their identity. They are a diverse community.

One aspect of this diversity is the terms people use to describe themselves. We have included a glossary of ways that people may describe their identity at the end of this toolkit (Appendix 1) to help those new to the diversity of this language.

Throughout this toolkit we have referred to the LGBT community and to LGBT people. However, we recognise that not everyone fits into a neat box to describe their sexual orientation or gender identity. Our use of the term LGBT is not to the exclusion of how people may individually or collectively wish to identify.

1- LGBT people and dementia

The needs of LGBT people living with dementia are often poorly recognised and researched. This is due partly to assumptions that all older people are heterosexual ('straight'). There is also often a general ageist assumption that older people become asexual.

Older LGBT adults are however in fact significantly more likely to require support, and to reside in care homes, than heterosexual people. This is because they are more likely to be single, to live alone and not to have children. For example, a quarter of gay and bisexual men and half of lesbian and bisexual women have children, compared to 90% of heterosexual women and men.

The limited knowledge and understanding of how LGBT people are affected by dementia is also due to the 'invisibility' of older LGBT people in dementia services and carer support services.

We know that often LGBT people may be unwilling to express their identity within support services and care settings. Often this is due to previous experiences of discrimination or fear of being "outed"². Both these barriers may make it less likely that LGBT people access support, or delay accessing support.

In Scotland today unfortunately, significant numbers of LGBT people continue to face prejudice and discrimination and many report having poor experiences of health and social

Some of the ways LGBT people's experience of dementia may be different include, for example:

- Older LGBT people have lived through times when there was great prejudice. It may not have been safe for them to be open about their sexuality or gender identity. So when someone develops dementia and starts to need support, they or their partner/carer may fear prejudice from professionals getting involved in their life. They may not feel safe to be open about their identity and their life story. They may be unwilling to accept support.
- LGBT people may no longer be in touch with, or have complicated relationships with, biological family, so care and support available to heterosexual people in similar circumstances may not be available, or acceptable, to them.
- Memory problems may make it harder for people to remember what they have told others about their sexual orientation or gender identity.
- LGBT people are a minority, and a hidden one, So LGBT people living in formal care may feel they don't fit in, because everyone else seems to be heterosexual and there may be no-one else like them. They may feel that they are forced to change their lifestyle and may that they have to

² Being outed is having your sexual orientation or gender identity made known without your consent.

care. This inevitably means that for this group, societal and healthcare attitudes can be a very significant barrier to help-seeking and to getting a timely diagnosis and appropriate support. Greater understanding of LGBT people is required.

LGBT people are more likely to need to rely on formal care in later life, yet are less likely to receive it. Many fear discrimination in support settings. Some talk of having to return to not being 'out' when receiving care or support services and the detrimental impact this has on their access to support and their wider wellbeing.

keep quiet about their history – “going back into the closet”.

- An LGBT person with dementia may be cared for by someone who is not supportive of their identity, such as a child or sibling who is embarrassed by it.
- An LGBT person may be caring for someone with dementia who is not supportive of their LGBT identity, such as a parent. The person with dementia may, because of their dementia, be disinhibited and say things they would not have previously said, making the caring relationship difficult.

More ways LGBT people's experience of dementia may be different:

- LGBT people may have caring responsibilities in their family of choice³ as well as their family of origin, creating greater strains on their time, resources and wellbeing.
- Within the LGBT community men and non-binary people are as likely as women to provide informal care.
- People with dementia are often presumed to have children or partners to provide care; but LGBT older people are more likely not to have children, or to live alone.
- Older LGBT people are more likely to feel lonely and experience social isolation⁴. Dementia itself also increases isolation, so LGBT people with dementia may be even more lonely and excluded.

³ A 'family of choice' is the close and supportive friends around a person, who may feel like family, perhaps more so than their biological family.

⁴ *A Connected Scotland: our strategy for tackling social isolation and loneliness and building stronger social connections*, Scottish Government, 2018.

<https://www.gov.scot/publications/connected-scotland-strategy-tackling-social-isolation-loneliness-building-stronger-social-connections/>

- LGBT people may feel excluded from dementia support groups, especially if they don't feel comfortable being 'out'⁵.
- As dementia progresses people may lose the ability to make decisions. Some LGBT people may talk about their gender identity or sexual orientation by mistake. For example, they may refer to their partner without meaning to. This could mean that they 'out' their partner.
- For trans people, their body may not match their gender identity, making personal care difficult for them to accept.
- Trans people may be taking long term hormone therapy. Memory problems could make it harder to manage taking medication.
- Progression of dementia may bring back older memories rather than new ones. Some LGBT people may feel that they are in a time before they were out and this might bring distressing emotions. They may have had distressing experiences prejudice, discrimination and harassment.
- LGBT people with dementia may experience stigma because they are LGBT and stigma because they have dementia - a double stigma.
- Older LGBT people with dementia, and carers will have many different life experiences. They have lived during times when to be LGBT was much less accepted, sometimes dangerous and sometimes illegal. They may have experienced prejudice, abuse, violence and discrimination. They also may have had very positive experiences. Their experiences may be as different, for example, as the experience of life as a gay man before sex between men was legal; or as a trans person who lost their job and their children after transitioning, or as a lesbian who has been on every Pride march since 1969.

Future planning

Making a power of attorney is an important way for anyone with early stage dementia to choose who should take welfare and financial decisions for them if they become unable to do so in the future. Without someone holding power of attorney, it is possible that decisions may be made informally, or that someone may need to apply to court to be the person's guardian. That could mean that the decisions are taken by someone the person with dementia would not have chosen.

⁵ Being 'out' is being open about gender identity or sexual orientation. LGBT people may be out to some people but not to others. Whether to come out to an individual, group or organisation is a choice LGBT people have to make again and again, and it can be difficult to come out if you are not sure of the reaction you will get.

It may be particularly important for LGBT people to choose who makes their decisions, because they may be closer to their family of choice (friends) than to their biological family. There is potential for difficulties: for example, suppose the child of a trans woman with dementia wanted her to be dressed in male clothing?

Making a power of attorney means that the person with dementia can make sure they pick someone who know them well and respects their identity.

A welfare attorney can decide for the person how they dress, the pronouns they wish people to use and the activities and relationships they maintain.

Another way of setting out wishes for future care is by writing an advance statement.

There are two kinds of advance statement:

- An advance statement under the Mental Health Act⁶, which sets out wishes about medical treatment if the person has to have compulsory treatment in the future. This has legal status and if doctors override it they must report it to the Mental Welfare Commission. It needs to be in a specific format and to be witnessed, and it should be kept with the person's medical records. It can be accompanied by a personal statement about other aspects of care and support, but that does not have legal status.
- A general advance statement about the person's wishes. This could be in any form. It does not have specific legal status but is a record of what that person wanted and should be taken into account by anyone supporting them.

If your service is supporting an LGBT person who is not able to express their wishes, and does not have a welfare attorney, you should try to find out from the person and from the people close to them what their past and present wishes are. See if they have written a statement about their preferences and how they would like to be cared for.

Seeking diagnosis

There is currently no formal data on whether LGBT people are seeking diagnosis at the same rate as others. However, some LGBT people will have experienced past discrimination or had negative experiences with health or social care providers. Many LGBT have expressed fears about needing or accessing care. This means LGBT people may delay for fear of discrimination.

⁶ See <https://www.mwscot.org.uk/law-and-rights/advance-statements>

The lack of children or a partner to support the person in seeking a diagnosis may also lead to delay. Informal carers are likely to feel less able, or not know how best to, address concerns around early stage dementia.

This may mean that many LGBT people with dementia are missing their window of opportunity to use post-diagnostic support to plan for their future.

Dementia Friendly Communities

Much of the focus of work on dementia friendly communities is focussed on keeping people connected to their high street, neighbours and local groups. But the LGBT community is a 'community of interest', not a geographical community. The LGBT community is a community based on shared experiences, culture and values, without living near each other.

It is important that your service can help people connect to the LGBT community as well. Whilst not every area in Scotland will necessarily have a thriving LGBT community, where possible dementia friendly community projects should work with LGBT groups and organisations to help them to become dementia-friendly.



2 - Experiences of LGBT carers

Many of the issues experienced by LGBT carers, such as the need for information about dementia, and recognition and support for caring will be similar to other carers. However, LGBT carers often also experience a number of additional concerns that are specific to them.

Drawing on personal experience shared by LGBT carers at our 'Carers' Meet Up', these specific concerns include:

- LGBT people are more likely to be estranged from their family of origin and therefore have less extended support when they take on caring roles.
- Many LGBT people are not 'out' to the people they are caring for, which can cause considerable stress; for example, someone may be caring for a parent with dementia who says negative things about LGBT people. It may also mean they cannot rely on their partner or family of choice for support with caring.
- LGBT people may be caring for people who are aware of but unsupportive of their LGBT identity. They may experience discrimination at very close quarters. For example, this might include someone misgendering⁷ their trans carer or using their old name ('dead-naming').
- LGBT carers are more likely to experience poorer mental health. This is because LGBT people in general experience poorer mental health than the general population, and so do carers. This can mean they need additional support to support their mental wellbeing.
- Older LGBT people also highlight that as they are more likely to be single and childless. Often people assume that this means they have more time and capacity to take on a caring role.
- Bisexual carers often report feeling invisible. For example, if they are caring for a partner of a different gender they are assumed to be straight and similarly, if they are caring for a partner of the same gender, it is assumed that they are lesbian or gay.

⁷ Misgendering is using the wrong pronouns for a trans person, such as calling a trans man 'she'

For more information see the briefing paper about LGBT carers produced by LGBT Health and Wellbeing and MECOPP.⁸

During this project we have consulted with the LGBT community about their needs, fears and suggestions for change through two community discussions. These brought together community members and professionals to discuss challenges facing the LGBT community in accessing health services.

These highlighted differences for LGBT carers:

- Potentially having to care for family members who have never validated or respected their identity.
- Not being out to the person you are providing care for - having to conceal relationships, or expression of gender, and the psychological impact this may have.
- Not having their identities acknowledged in care plans.

LGBT carers whose partners or friends have moved into long stay care may well be losing their connection to their community, so it's important as part of supporting them to check in about remaining connected to the LGBT community.

You can read both Community Discussion Reports:

- **Forget Us Not:**
<https://www.lgbthealth.org.uk/resource/forget-us-not-community-discussion>
- **Over the Rainbow:**
<https://www.lgbthealth.org.uk/resource/over-the-rainbow-community-discussion>

⁸ Informal caring within the LGBT community, MECOPP & LGBT Health and Wellbeing, 2019.
<https://www.mecopp.org.uk/mecopp-publications/2019/10/7/briefing-sheet-13-informal-caring-within-the-lgbt-community>

3 - Case studies

The following case studies can be used by practitioners in training, discussions or simply for personal learning. Some of them are anonymised summaries of a real life situation we came across, and some are fictional, but based on issues people have told us about.

With each case study you will find questions that this experience raises for services to reflect on.

Jean

Jean is 78 and is a lesbian. She lives alone and does not have a partner. She has no children. She is fairly isolated geographically but goes along to a local LGBT meet up once a month and knows people there.

She is sure she has dementia but is struggling to get support or a diagnosis. She has been struggling for a few months now trying to get the help she wants. She says she doesn't always understand or remember what is happening at the doctor – what they have said and what tests they have done. Jean was asked to bring someone with her to her next doctor's appointment. The doctor said it should be someone who she sees every day and who would be able to talk about changes in her behaviour. Jean doesn't feel she has anyone like this. She wonders if the doctor has assumed she has children. She's not out to her doctor because she never felt it was the right time to say anything, and she has never been asked.

Jean is finding it all very distressing, but she hasn't told many people at her LGBT group about her memory worries because it makes her feel stupid, and it upsets her to think about it.

- **What are the barriers for Jean getting a diagnosis?**
- **What assumptions have been made about Jean and her situation?**
- **What could have been better?**
- **What might help Jean in her situation?**

Shirley

Shirley is a trans woman in her 50s. She and her wife are caring for her mother-in-law. She came out to her wife a few years ago and had begun her transition. Then her mother-in-law got dementia and moved in with her and her family. She has power of attorney for her mother-in-law.

Shirley is not out to her mother-in-law, or to any of the dementia services supporting the family. She hasn't come out to her grown up children because she is not out to their grandmother.

Shirley is now not able to dress the way she wants, or even use her name, because her mother-in-law is living in the house, and because the support workers who help her mother-in-law every day don't know either. She is afraid that they would react badly if she told them. Shirley feels as though her whole life is on hold, and this is affecting her mental health badly.

- **What is the impact of this situation on Shirley?**
- **What might make it possible for her to come out to the support service?**
- **What could be done to help Shirley?**

Sam

Sam is in their 70s and lives alone. Born into a male body, Sam spent much of their life feeling that something was wrong, and 20 years ago started to transition to female. They took hormones which made their breasts develop, but never had surgery to remove their male genitals. In recent years, Sam has started to identify as non-binary, and uses gender-neutral pronouns (they, them and their instead of he or she etc).

Sam developed dementia a couple of years ago, and the social work department arranged for support from a local provider. The social worker was aware of Sam's story, and informed the provider. However, Sam has now started to need personal care, and one of the support workers helping them with bathing screamed when she saw Sam's male genitals. Sam is now very anxious and unwilling to let anyone help with personal care.

- **What went wrong?**
- **What should have happened?**
- **What is the impact on Sam?**

Christine

Christine's partner June has dementia and is in a care home. Christine is 15 years younger than June, who is in her late 70s. They had known each other as close friends for many decades. June had been in an unhappy marriage, until her husband died a few years ago. Christine and June then started a relationship, but had kept this secret as they feared the reactions of their peers, family and in particular, June's adult children. Christine also feared being out in her work where she held a high-profile position.

June's children live a long distance from their mother, but hold power of attorney for her. As June's dementia developed, Christine was her sole carer. When June's condition worsened, Christine informed June's children about their relationship.

June eventually had to move into a care home to have her needs met. June's family started to discourage Christine from visiting June. They claimed her visits were upsetting and tiring for June. Because June's children were biological family and held power of attorney, staff followed their decisions, and did not acknowledge Christine's position.

June's communication was poor and her decision-making capacity was being questioned. The children put up pictures of June's husband around her room, which had been against June's previous (but unrecorded) wishes. They were also considering moving June to a care home nearer to them, which would effectively prevent Christine from visiting at all.

Christine felt she couldn't ask for help from local services as she feared doing so would 'out' her publicly. She also worried if she pushed too strongly back at the children, they would prevent her from seeing June completely.

- **What responsibility do the care home staff have toward June and towards Christine?**
- **Do you think Christine has been able to talk to care home staff about her relationship with June?**
- **What are June's rights?**
- **What are Christine's rights?**
- **What might help the situation?**

Mahmood and Alan

Mahmood and Alan have lived together for almost 30 years. They have been out within the LGBT community all that time, and have a comfortable home, full of LGBT books and LGBT artwork they have collected together over the years, and photos of them and their friends at pride marches.

A few years back, Alan's memory started to fail. He was diagnosed with dementia, but he and Mahmood managed fine for a long time. However, Alan's dementia is getting worse, and Mahmood is struggling to manage the caring. He wants to get some help, but he is extremely anxious about having care staff in their home. He is worried that he and Alan will be judged for being gay, and that social workers and care staff will disapprove of their lifestyle. He has delayed asking for a community care assessment for over a year since he first thought about it, and he is buckling under the strain.

Finally, Mahmood has made an appointment, and a social worker is coming round on Monday. He spends the entire weekend putting away everything that might show that they are gay, hiding pictures, putting books in cupboards and taking down photographs. He plans to tell the social worker that he and Alan are good friends.

- **Why is Mahmood worried?**
- **What might stop him worrying and feeling the need to 'de-gay' the house?**
- **If he doesn't feel able to come out to the social worker, what impact might this have for Alan and for Mahmood?**

Ben

Ben is a gay man in his 40s who is caring for his dad who has dementia. He has always had to have a good social life in the LGBT community. He is not out to his family – and says he never will be. His mum also cares for his father but he is becoming more aggressive and Ben worries about leaving his mum alone. He says it is assumed he has lots of time to care for his father because he doesn't have children or a partner.

- **What is the impact of this situation on Ben?**
- **What is different for Ben from a straight man in a similar situation?**
- **What might help Ben?**

4 - Starting the conversation

Attitudes towards LGBT people have undergone significant and positive change over recent decades. In general, LGBT visibility is much higher, and significant legislative advances such as the Equality Act (2010) have given LGBT people greater legal protection from discrimination. However, negative attitudes and stereotypes continue.

It is important that your team has shared values and understanding in relation to your work with LGBT people and that they are consistently put into practice. Some of the difficulties that LGBT people face in accessing services which best meet their needs stem from a lack of general understanding of their needs.

Equality does not mean treating everyone the same. Everyone is different and everyone should have a right to be who they are.

- You may think that no LGBT people are using your service because no one has come out to you; but this is highly unlikely.
- Don't assume because someone hasn't told you they are LGBT that they are not. This could lead to you unintentionally misinterpreting their needs. LGBT people constitute a very significant minority, around 5-7% (1 in 16) of the adult population.
- Assuming that people are heterosexual is common. Making assumptions about sexual orientation may not be intentional but it can make people feel excluded and isolated.
- The LGBT people you support might have had negative experiences coming out to services in the past.
- Often LGBT people fear discrimination from other service users.

A team approach

It is important that your team feel able to talk openly about this topic and ask the questions that they need answers to. It is also important that your service is a safe space for people who might be LGBT themselves or have friends or loved ones who are.

Feedback from the practitioners we have worked with through this project has identified some key pointers about starting conversations around LGBT identities.

General worries about starting the conversation

Concerns from staff and managers may include:

- Reluctance to bring up LGBT issues because they think it is 'personal' or emotive.
- Fear that opening discussion could cause upset in the team.
- Concern that equalities work 'singles people out'.
- Worry that they won't be equipped to deliver best practice to LGBT people if they do come out for fear of 'getting it wrong' or 'offending' someone.
- Concern that the sexuality or gender identity of people using the service is a private matter.
- Embarrassment or fear of offending colleagues.

If you think that these worries may exist for you or your team it might be helpful to start with a facilitated conversation on the topic before starting the training. Start off by making it clear that the discussion is a safe space where it is ok to ask questions, and it is ok not to know everything. Ask participants to allow colleagues to get it wrong, without being offended.

In order to keep the space safe for all staff - and particularly LGBT staff - remember to be guided by your internal policies around safety and confidentiality.



'Creating a safe space' resource:
<https://www.lgbthealth.org.uk/resource/creating-safe-space>

Discussion topics

Some useful discussion topics might include:

- Thinking about how central relationships are to most people's lives.
- What assumptions do you make when you meet a new person?
- The need to understand what is important to people in order to deliver person-centred care.
- The parallels with understanding the cultural needs of people from minority ethnic groups using your service – LGBT people have their own culture too.
- People often worry about using the right language or not knowing the right language so it may be helpful to include an exercise on.
- Discussing some of the issues set out in section 1.

You don't need to know everything to facilitate the conversation well. It's okay to reach a point as a team where you 'don't know'. At least you are then aware of what you do and don't know.

Some of the exercises in our training module may be helpful, or you might want to revisit the discussions in the training.

Our **Glossary of terms** (Appendix 1) is also a good reference for anyone looking to learn and can be used in training.

You may want to look at some of our resources before any session to help you focus on likely discussion topics:

- **LGBT Dementia Impact Report:**
<https://www.lgbthealth.org.uk/resource/lgbt-dementia-impact-report>
- **Forget Us Not:**
<https://www.lgbthealth.org.uk/resource/forget-us-not-community-discussion>
- **Over the Rainbow:**
<https://www.lgbthealth.org.uk/resource/over-the-rainbow-community-discussion>
- **LGBT People and Dementia Briefing:**
<https://www.lgbthealth.org.uk/national-lgbt-dementia-project-september-2018-brief>

5 - Reminiscence

Reminiscence therapy is considered a helpful way to support people with dementia not only to have fun and enjoy social contact, but also to share their memories in a safe space.

Talking about past life events can be positive for people with dementia, including LGBT people. Think about how you can make your reminiscence group welcoming for LGBT people.

Some older LGBT people may worry about how they will be received in groups, or may find it difficult to join in fully.

Here are some top tips for helping them feel safe, welcome and involved:

- Be proactive and advertise that your group is LGBT friendly.
- Remember LGBT people may be in the group whether they have come out to you or not.
- Try to ask open ended questions that allow everyone to join in. For example, 'who is the most important person to you?' rather than 'are/were you married?' or instead of making an assumption and asking about a husband or wife.
- Minorities often have what is referred to as a 'sub-culture'. Our fashion, music, cultural and historical references and points of significance may be radically different based on our identity. Make sure there is space for everyone's experience in your group and don't make assumptions!
- Older LGBT people are less likely to be or have been married or have children; but that's not true for everyone. Ensuring it's a safe place for LGBT people to talk about their family, or whoever is important to them, is key to a successful group. You can help to do this by making sure you explicitly mention lesbian, gay, bisexual and transgender people.
- LGBT people may have different triggers or 'red flags' for topics or memories which upset them. Ensuring they feel safe to talk to you about this is really important. For example, reminiscence could rekindle feelings of rejection, prejudice and exclusion. Be sensitive to difficult feelings the discussion may bring up.
- Make it clear from the start that the group is a safe space for everyone, and that no-one should be judging anyone else. Ensure you challenge any discriminatory remarks or comments from group attenders. This helps create a safe space for all, and ensures your inclusive practice is understood by everyone.

6 - Policy and practice guidance

This toolkit is intended to be a helpful tool for reflection and self-assessment.

It may highlight aspects of your practice which work very well for LGBT people, and also areas which could be improved. We understand that changes to your service cannot always be made immediately, and that some changes may require more planning and resources than others.

Throughout the course of the LGBT Dementia Project we worked with a number of care homes, dementia services and carer support services to identify the key areas of importance in ensuring best results for LGBT people. Some key organisational issues to consider as part of your commitment to inclusion include equalities monitoring and staff training and recruitment.

Equalities monitoring

Does your equalities monitoring process currently allow you to monitor sexual orientation and gender identity for people using your service? Most services monitor other equality areas, such as ethnicity and religion. But many fail to monitor LGBT status.

It is important to do this to know who is using your service - or perhaps who is not using your service, so that you can work out why, and look at how you can improve.

Many practitioners worry about asking identity-based questions. However, you can do this in a sensitive way by including 'prefer not to say' options and perhaps waiting until you have built up a relationship and trust with the individual before introducing equality monitoring.

Some tips:

- Explain why you are doing it, and why you think it makes your services better for everyone.
- Be clear about what you do with the information.
- Use language on your forms that people recognise and think about how different questions may affect different LGBT people. For example, don't only offer man/woman options. Use a question which for collecting data on gender is inclusive. This will help to indicate to non-binary people they are safe and recognised in your service.



The Scottish Trans Alliance has produced guidance on equality monitoring of staff and service users, including suggested wording for questions about gender, trans status and sexual orientation.⁹

Recruitment and staff development

- Recruit people who reflect the values of your service and ask people about this at their interview. You could ask something like ‘what does anti discriminatory practice mean to you?’
- Having LGBT members of staff does not guarantee an LGBT-friendly environment, but it may help demonstrate an open and supportive culture.
- Ensure that your Equality and Diversity and Confidentiality policies are up to date and fit for purpose for LGBT people, and ensure all employees know they are expected to uphold them.
- What equalities training do you provide for staff at the point of induction and throughout the course of their employment? You may want to look at running an LGBT Awareness session as part of your training plan or as a staff development day. See Section 8 for help with thinking about this.

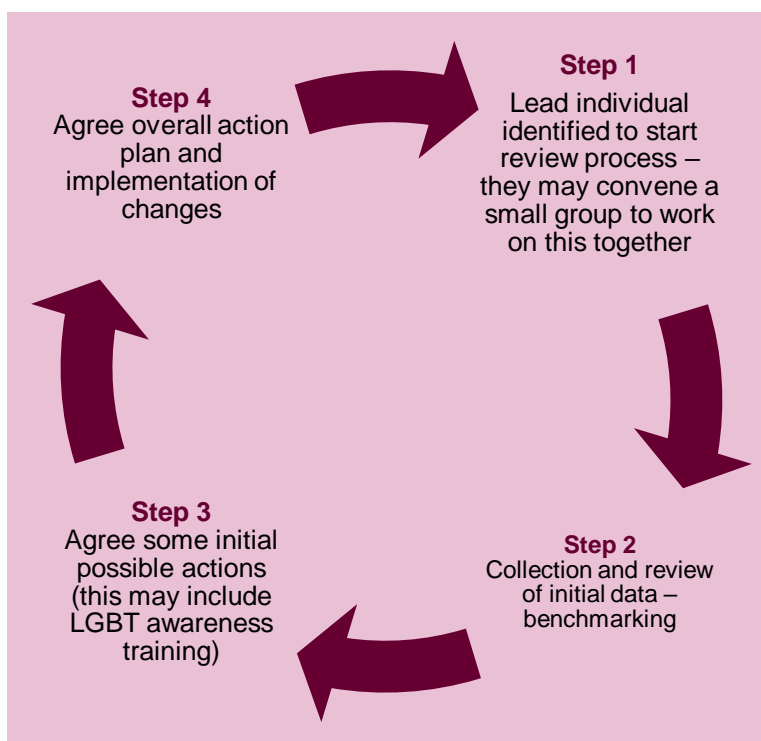
⁹ *Getting equalities monitoring right*, Scottish Trans Alliance, https://www.scottishtrans.org/wp-content/uploads/2017/06/getting_equalities_monitoring_right.pdf

7- Proud to Care: LGBT and Dementia Self-Audit Tool

This self-audit tool has been created through consultation with LGBT people, a wide range of dementia care practitioners and carer support organisations, as well as regulating bodies including Scottish Care and the Care Inspectorate. The development of the self-audit tool has been guided by the principles in the Scottish National Health and Social Care Standards. The 'outcomes' column reflects the care standards at the time of publication of the tool. The Standards are underpinned by five principles: dignity and respect, compassion, be included, responsive care and support and wellbeing.

The self audit tool is designed to help you think about the practical steps that you can take to develop your service and team. Remember, small changes can have massive impacts on people's experiences! The tool should also be used to highlight and promote good practice.

You can start the self audit process at any time. However, you need to think about the circular nature of the review process.



Feedback from the Care Inspectorate LGBT Charter Champion Group

“We are delighted to see the introduction of Proud to Care, a resource that promotes best practice with health and social care staff working with LGBT people with dementia. We know that LGBT people receiving care can face barriers and discrimination. The individual case studies are person centred and help to share experiences more widely with health and social care staff to ensure their practice is inclusive. LGBT Dementia Project toolkit facilitates and enables meaningful, person-centred conversations that will matter to people.

Proud to Care brings the Health and Social Care Standards to life and will make a positive difference to LGBT inclusion.”

Thinking about evidence gathering

You do not need to physically gather all the evidence but the main thing is that you know it exists. Evidence can be gathered from various sources; some examples may include:

- Service literature, including promotional brochures and leaflets
- Care and support plans
- Assessment paperwork
- Daily case notes
- Review paperwork
- Complaints and suggestions log
- Activities programme and communications with those who use services and their carers.
- Training records and plans, induction records and plans
- Service or organisational newsletters
- Information from your website or social media (including signposting to LGBT sources of further support)
- Results from annual surveys or inspection reports
- Annual monitoring information around demographics and diversity
- Discussion notes from team meetings, team days
- Feedback from those using the service and carers

Outcomes	Indicators		Self-Assessment		
	Good Practice	Best Practice	Evidence - where can I find evidence?	What we are doing well?	What we could improve?
<p>1. I experience high quality care and support that is right for me.</p>	<p>a) We monitor whether LGBT people are using our service - with 'prefer not to say' options (see Section 6).</p> <p>b) Our promotional and informational materials (including website) reflect the diversity of the community we support through LGBT-inclusive language and images.</p> <p>c) Case files include reference to identity in the language the person would use.</p> <p>d) We clearly explain to people how we will hold their information and if people confide information in us we are clear about how it will be recorded and handled - in line with GDPR.</p>	<p>a) LGBT people are using our service and feel comfortable to express their identity.</p> <p>b) We consult with LGBT people and, where appropriate, provide LGBT-specific spaces, activities, resources and referrals.</p>	<p><i>Reports and annual statistics.</i></p> <p><i>Promotional materials.</i></p> <p><i>Confidentiality policy.</i></p>		

Outcomes	Indicators		Self-Assessment		
	Good Practice	Best Practice	Evidence - where can I find evidence?	What we are doing well?	What we could improve?
	<p>e) We clearly explain to people how we will hold their information and if people confide information in us we are clear about how it will be recorded and handled - in line with GDPR.</p>				
<p>2. I am fully involved in all decisions about my care and support.</p>	<p>a) We do not make assumptions about the relationships the people we support have with the family, friends and community members who may be involved in their life. We communicate this to people directly.</p> <p>b) We proactively identify who holds power of attorney for the people we support.</p>	<p>a) We work to ensure the LGBT people we support understand how advance statements and powers of attorney can be utilised to uphold their rights and ensure their views are taken into account.</p> <p>b) We create regular consultation opportunities with people we support which are participative and offer space for LGBT people to feel safe to...</p>	<p><i>Care and support plans and notes, review notes, promotional material.</i></p> <p><i>Records of consultation meetings.</i></p>		

Outcomes	Indicators		Self-Assessment		
	Good Practice	Best Practice	Evidence - where can I find evidence?	What we are doing well?	What we could improve?
	<p>c) We proactively identify who holds power of attorney for the people we support.</p> <p>d) We don't make assumptions about people's wishes based on their gender identity or sexual orientation - for example how people dress, or the activities they choose.</p> <p>e) We have a personal care plan for each person we support which includes their needs as an LGBT person if relevant.</p>	<p>...express their own wishes and needs.</p>			

Outcomes	Indicators		Self-Assessment		
	Good Practice	Best Practice	Evidence - where can I find evidence?	What we are doing well?	What we could improve?
	<p>f) We do not make assumptions about the relationships the people we support have with the family, friends and community members who may be involved in their life. We communicate this to people directly.</p> <p>g) We proactively identify who holds power of attorney for the people we support.</p> <p>h) We don't make assumptions about people's wishes based on their gender identity or sexual orientation – for example how people dress, or the activities they choose.</p>	<p>c) We work to ensure the LGBT people we support understand how advance statements and powers of attorney can be utilised to uphold their rights and ensure their views are taken into account.</p> <p>d) We create regular consultation opportunities with people we support which are participative and offer space for LGBT people to feel safe to express their own wishes and needs.</p>	<p><i>Care and support plans and notes, review notes, promotional material.</i></p> <p><i>Records of consultation meetings.</i></p>		

Outcomes	Indicators		Self-Assessment		
	Good Practice	Best Practice	Evidence - where can I find evidence?	What we are doing well?	What we could improve?
	<p>i) We have a personal care plan for each person we support which includes their needs as an LGBT person if relevant.</p>				
<p>3. I have confidence in the people who support and care for me.</p>	<p>a) Our staff use inclusive language and remain up to date with appropriate language around how people identify.</p> <p>b) Our staff are respectful of different identities and the views of the people they support.</p> <p>c) Our staff and volunteers know about local LGBT groups and organisations and how the people we support can access them.</p>	<p>a) We work in partnership with local and national LGBT groups to ensure that we can link the people we support into these.</p> <p>b) Individuals proactively signal commitment to inclusion in visible ways, such as a safe space policy and adoption of rainbow lanyard / badge schemes.</p> <p>c) We celebrate LGBT inclusion by promoting LGBT History Month and Pride events.</p>	<p><i>Records of online learning or learning resources you have shared as a team, including resources listed in this toolkit.</i></p> <p><i>Number of events, meetings, links with LGBT organisations.</i></p>		

Outcomes	Indicators		Self-Assessment		
	Good Practice	Best Practice	Evidence - where can I find evidence?	What we are doing well?	What we could improve?
<p>4. I have confidence in the organisation providing my care and support.</p>	<p>a) Our complaints process is displayed and specifically references examples of how to respond to discrimination, using LGBT examples where appropriate.</p> <p>b) We display our commitment to inclusive practice and diversity in our premises.</p> <p>c) Staff have undertaken learning in inclusive practice for LGBT people affected by dementia.</p>	<p>a) Our complaints process gives examples of how LGBT people should expect to be treated.</p> <p>b) We are visible as an organisation in supporting LGBT rights and community events such as History Month and Pride.</p> <p>c) Information and examples about LGBT experiences are mainstreamed in internal learning and development / training programmes. We include diversity training in our staff and volunteer induction.</p>	<p><i>Complaints procedure, policy and leaflet.</i></p> <p><i>Activities programme and communications with those who use services and their carers.</i></p> <p><i>Take photos of how you have displayed things to keep a visual record.</i></p>		

Outcomes	Indicators		Self-Assessment		
	Good Practice	Best Practice	Evidence - where can I find evidence?	What we are doing well?	What we could improve?
<p>5. I experience a high-quality environment (if the organisation provides the premises).</p>	<p>a) Same gender couples have equal access to opportunities for receiving visitors and maintaining intimate relationships.</p> <p>b) Group activities such as reminiscence groups are inclusive of all identities and histories.</p> <p>c) Communal spaces signal inclusion and are utilised for activities which celebrate the diversity of the people you support.</p>	<p>a) We proactively display LGBT affirming literature and share our work in this area visibly – photos in our promotional material, pictures, rainbow flags etc.</p> <p>b) We consider ways for make LGBT people feel comfortable. For example, use of gender neutral toilets.</p> <p>c) LGBT people feel comfortable to display their personal photos and talk openly about their experiences and identity.</p>	<p><i>Care and support plans and notes.</i></p> <p><i>Activities programme.</i></p> <p><i>Take photos of how you have displayed things to keep a visual record.</i></p>		

Next Steps

By now you will have thought about some tangible ways that you can continue to promote LGBT-inclusive practice, as well as ways that you want to further develop this.

Be realistic and ensure a range of people follow up on these action points as this will help your service keep the momentum going.

Remember to promote what you are doing and encourage others to do the same!

The top 5 things that we will continue to do:

- 1.
- 2.
- 3.
- 4.
- 5.

The top 5 things we are going to change – indicate what, how and when:

- 1.
- 2.
- 3.
- 4.
- 5.

8 – Training and resources

When you complete the self audit process you may identify that you need to develop some of your practice. There are many ways in which you can do this. This section gives a few suggestions as to how you can upskill yourself and your team.

Resources

LGBT Health and Wellbeing have an online resources section on their website: www.lgbthealth.org.uk

Look at this for further suggestions, background reading and sources of support for people your service works with.

You may also wish to deliver some awareness raising training in your team to generate team cohesion and commitment to inclusive practice.

Planning awareness raising training



Learning is essential to improving practice and supporting practitioners to feel confident in their work. If you are delivering some awareness raising training as a result of your self audit you will need to think about how to structure this. The training plan in this section will help you do this.

You don't need to be an expert on the topic to deliver this training. You simply need to feel committed to improving LGBT inclusion for everybody within your service. Before delivering the training you may want to consider our 'Starting the Conversation' section of this Toolkit.

These are some tips and things to consider before you start:

1. Try to explicitly create a safe space for learning and make sure your participants understand and buy in to this at the outset – our ‘Section 4 - Starting the Conversation’ can help here.
2. This can be emotive and personally relevant subject matter – you aren’t likely (nor do you need) to know the personal circumstances of everyone in the room. Prepare beforehand so you have information of relevant support organisations, as some participants may want to seek further help or information after your session. They may wish to do this privately, so have written information available. This could include the LGBT Helpline Scotland (0300 123 2523, helpline@lgbthealth.org.uk).
3. During the session, some participants may volunteer personal information or recount personal stories, they may discuss workplace circumstances or incidents – make sure the group are mindful of respecting their and service users’ confidentiality.
4. Think about numbers of participants – is it a small enough group to allow for everyone to actively get involved?
5. Think about the location and environment. Is there enough peace and quiet to allow for group discussion and some privacy?
6. Inclusion is everyone’s job, so consider opening your training up to a broad range of staff and volunteers.
7. Equipment and materials. You may want to share the case studies included in this toolkit.
8. Enjoy delivering the training and pass your enthusiasm on to your participants!

Training plan

This session, if delivered in full will take roughly 3-4 hours. However, the content has been colour coded if you find you need to adapt and provide a shorter session.

If you want to deliver this training using our standard PowerPoint presentation get in contact with us and we can share this with you: admin@lgbthealth.co.uk

How to use this training structure

Red content is essential for people to hear and for the training to have context.

Amber content is aimed to increase knowledge and allow participants to hear from the LGBT community.

Green content allows time for discussion and group exploration.

Slide 1: Intro

Introduce yourself

Complete any housekeeping tasks you would normally complete in training sessions. Housekeeping – Fire procedure, fire exits, toilets. Outline expected length of session and planned breaks.

Training topic 'Lesbian, Gay, Bisexual and Trans Inclusion in Dementia Services'.

Explain that whilst you might not be an expert on the topic, at the end there will be a slide with relevant contacts if anyone feels they would benefit from more specialist information.

Slide 2: About this training

Where does the training come from?

Produced as part of the 2-year national LGBT and Dementia Project, run by LGBT Health and Wellbeing. They work to improve the health and wellbeing of all LGBT people across Scotland.

Summary results of your self-audit

Slide 3: Why focus on LGBT people and dementia?

Who and what is this about?

LGBT people affected by dementia

LGBT people who have dementia and LGBT people who care for someone with dementia.

Equal access to support is a matter of human rights.

Slide 4: Aim of training

Increase awareness about LGBT people's lives and issues they may face, especially in relation to being affected by dementia.

Encourage exploration of ways your practice and your service can become more inclusive

Slide 5: LGBT people and dementia

We currently have no prevalence data for the proportion of LGBT people affected by dementia, as we do for some other equalities groups. E.g. older people are more likely to be affected by dementia; women are more likely to be affected by dementia

But we do know that as 5-7 % of the population (1 in 16 people) is lesbian, gay, bisexual or trans, it's likely that 1 in 16 of the people we work with are LGBT.

Slide 6: Language exercise

Split into small groups

In this section use the glossary (Appendix 1 of this toolkit) to match up the descriptions

Ensure you go through each section

In this section some people will feel more confident with some words and what they mean than others.

From delivery in our national project we found this was a good time for further discussion regarding identities which are often less talked about – for example non-binary and intersex identities.

It is helpful to let people know:

- They don't need to understand everything about someone to accept them and uphold their right to self-definition.
- Intersex is an umbrella term used to describe a wide range of natural variations where a person's physical characteristics are neither fully male nor fully female. In some cases, this is noticeable at birth while in others, not until puberty. According to experts, between 0.05% and 1.7% of the population has intersex traits – the upper estimate is similar to the number of red haired people. For more info (www.unfe.org or www.equality-network.org/intersex/)
- Intersex people often experience negative, overly medicalised views of their bodies from birth or adolescence. It is important to consider what worries intersex people may have about personal care and accessing help.
- Non-binary people often face dismissal and disbelief in many areas of their life. Using pronouns correctly including 'they/them' when asked can go a long way to making someone feel safe and included. Imagine what it would be like as a non-binary person in your service? From filling in forms to using facilities would it be possible to be out and safe and well as a non-binary person there?

Slide 7: Some key facts

What do we know? Key facts

- Overall LGBT population: in Scotland, about as many LGBT people as live in Aberdeen and Dundee put together
- Older LGBT people are much less likely to use services for older people – so, are they getting the support they need? Why is this a problem when it comes to dementia services? What could they be missing out on? An early/timely diagnosis? Medication? Benefits? Future planning? Carer support? Peer support?
- Why aren't they using services?
- Evidence from existing research, the LGBT Age Project and discussions with LGBT community members consistently reveal fears of discrimination and lack of understanding or respect about their lives and needs, poor past experience, complex situations where people feared being 'outed'.

Slide 8: Two short films

A Long Line of Glitter is a film produced by LGBT Health and Wellbeing's LGBT Age Community Action Project. (16 minutes)

Return to the Closet is a community led film - older LGBT people speak about their thoughts, fears and hopes about the future and care. This was developed by LGBT Health and Wellbeing and Luminare. (14 minutes)

Both films can be found on www.lgbthealth.org.uk

Once the group has watched the film(s) get the group to think about the key themes and issues raised:

- What is different for LGBT people?
- Do the ways we tend to consider dementia fit the lives and experiences of LGBT people?
- What might the impact be for an LGBT person caring for someone who doesn't support their LGBT identity?
- LGBT people may be part of a family of choice (explain what this is) as well as a family of origin (explain what that is).
- Amongst the LGBT community, men and non-binary people are as likely as women to be carers.
- LGBT people might be more likely to live alone – what might this mean if they develop dementia?
- LGBT people may have experienced higher rates of mental health issues
- The LGBT community is a community of interest, not necessarily geographically close by – how might this affect the experience of LGBT people with dementia and carers?

Slide 9: Case study exercise

Use the case studies as a basis of discussion

Split trainees into pairs and give each pair a case study and the associated questions to discuss (allow at least 15 minutes)

Then consider them as a group

If time allows, each pair could consider more than one case study.

Slide 10: Inclusive practice

How could your practice be more inclusive?

How could your service be more inclusive?

Discussion in the whole group. Trainer can use '10 Top Tips for becoming more inclusive for LGBT people: A guide for services and organisations working with older people: www.lgbthealth.org.uk/wp-content/uploads/2014/07/Top-Ten-Tips.pdf

Slide 11: Coming out exercise

10-minute exercise (see Appendix 2) and brief discussion about how participants felt during it.

Slide 12: Summary and close

Ask participants to discuss in two groups 3 things they have learned or would like to change about their practice or about the service.

Feed back to whole group.

List of helpful contacts / organisations

- National LGBT Helpline Scotland
- Alzheimer Scotland 24 Hour National Dementia Helpline
- Care Inspectorate

Appendix 1: Glossary of terms

Words matter. The way we use language can help to signal to people that our services and spaces are inclusive and supportive of their identities. The following definitions cover some of the words you might most commonly hear in relation to LGBT people, their experiences and their communities.

Asexual / Asexuality	Describes a lack of sexual attraction. Asexual people may experience romantic attraction, but do not feel the urge to act on these feelings sexually. Asexuality exists on a spectrum, with diversity in people's experiences and desires for relationships, attraction, and arousal.
Bisexual	A person who is attracted to people of more than one gender or regardless of gender.
Cisgender	A person whose gender identity corresponds with the sex they were assigned at birth e.g. birth sex male, gender identity/expression male.
Community of interest	A community not based on a local area. The LGBT community is a community based on shared experiences, culture and values, without living near each other.
Cross dresser	A person who wears clothing traditionally associated with another gender to their gender identity, either occasionally or regularly.
Dead naming	When someone, intentionally or not, refers to a person who is transgender by the name they used before they transitioned. You may also hear it described as referring to someone by their "birth name" or their "given name." This can cause offence.
FTM / Trans man	A person who was assigned female at birth but has a male gender identity and therefore transitions to live as a man.
Gay	A person who is attracted only to members of the same gender. It can be used for any gender (e.g. gay man, gay woman, gay person).
Gender	The socially constructed roles, behaviours, activities and attributes that society considers appropriate for men and women.
Gender identity	Each person's deeply felt internal and individual experience of gender. This may or may not correspond with the gender assigned at birth. This includes the personal sense of the body and other expressions of gender, including dress, speech and mannerisms.
Heterosexual	A person who is only attracted to members of the opposite gender.
Intersectionality	The impact of interconnections between different categorisations such as race, class, and gender (i.e being gay and Muslim or transgender and disabled). This can create overlapping discrimination or disadvantage.

Intersex	Umbrella term used for people who are born with variations of physical sex characteristics, which do not always fit society's perception of male or female bodies. Intersex is not the same as gender identity (our sense of self) or sexual orientation (who we are attracted to) but is about the physical body we are born with.
Lesbian	A woman who is only attracted to other women.
LGBT / LGBTI / LGBTQIA	Stands for Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual. Many people use the term LGBT, but some prefer LGBTI or LGBTQIA as more inclusive. You may also see LGBT+, or LGBTQIA+, where the plus sign stands for including other groups.
Misgendering	Another individual referring to someone, (especially a transgender person) using a word that does not correctly reflect the gender with which they identify. For example, referring to or calling another individual 'sir' if they identify as female. This is an offensive act.
MTF / Trans woman	A person who was assigned male at birth but has a female gender identity and therefore transitions to live as a woman.
Non-binary	A person identifying as either having a gender which is in-between 'man' and 'woman', as fluctuating between 'man' and 'woman', or as having no gender, either consistently or some of the time.
Sexual orientation	A person's attraction to a person of the same and/or different gender. Includes gay, lesbian, bisexual and heterosexual.
Trans / Transgender	Inclusive umbrella terms for a wide range of people whose gender identity does not fully correspond with the gender they were assigned at birth.
Transitioning	Also known as gender reassignment. Some trans people take hormones and some also have surgery to bring their physical bodies in line with their gender identity. Transitioning can also include someone changing their name, or expressing themselves in their preferred gender (clothes, hair etc.).
Queer	An umbrella term for sexual and gender minorities. Originally offensive, it started to be reclaimed and used by some LGBT people in the 1980s. However, other LGBT people are not comfortable with this term.
Questioning	People who are exploring or discovering their identity and still discovering what feels right in terms of their sexual orientation or gender identity.

Appendix 2: Coming out exercise

During the course of the project, some people who hadn't personally experienced coming out, said that since society had moved forward in recent years, they couldn't really understand why it may still be difficult for people to be out.

This very simple, short exercise aims to create greater empathy and insight. It is important to note however that 'coming out' is usually not one straightforward stand-alone event in a person's life, it's often a series of repeated instances when someone has to decide how much they disclose about themselves to those they come into contact with. Sometimes LGBT people face those decisions on a daily basis – these disclosures can be large or small, from loved ones to strangers, colleagues to clients, at home, at work and in social settings.

Step 1 - Ask the group to think about a secret they have (they don't have to disclose it). Give them a few moments to think of it and ask them to keep it in their thoughts.

Step 2 - Ask them to imagine one of their friends has found out about it. Ask them to think about how that makes them feel. Give them a few moments to contemplate this, as before.

Step 3 - Now ask them to imagine all of their colleagues know.

Step 4 - Tell them their GP now knows their secret. Give them a few seconds to think about it.

Step 5 - Now inform them that someone has put their secret in the newspaper.

Step 6 - Now ask them to think of a person they'd choose to tell their secret to.

Step 7 - Group discussion and reflection.

Remind individuals they don't have to disclose their secret.

Invite them to consider the points below. This can be done as an informal group discussion and if you wish, notes can be taken on a flipchart detailing the main points people make.

Ask them to share how the process of disclosure made them feel.

- Was it different at different stages or when different people knew?
- Why did you choose the person you chose to tell? What characteristics do they have that influenced your choice?

What response would they want from the person they disclosed to? Other general points for consideration might include a sense of a loss of control, fear, stigma, judgment, relief, confidentiality, consequences of disclosure.



The National LGBT Dementia Project was delivered
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