

'It's more than rainbows in receptions'



Working with LGBTQ+ People in Palliative and End-of-Life Care



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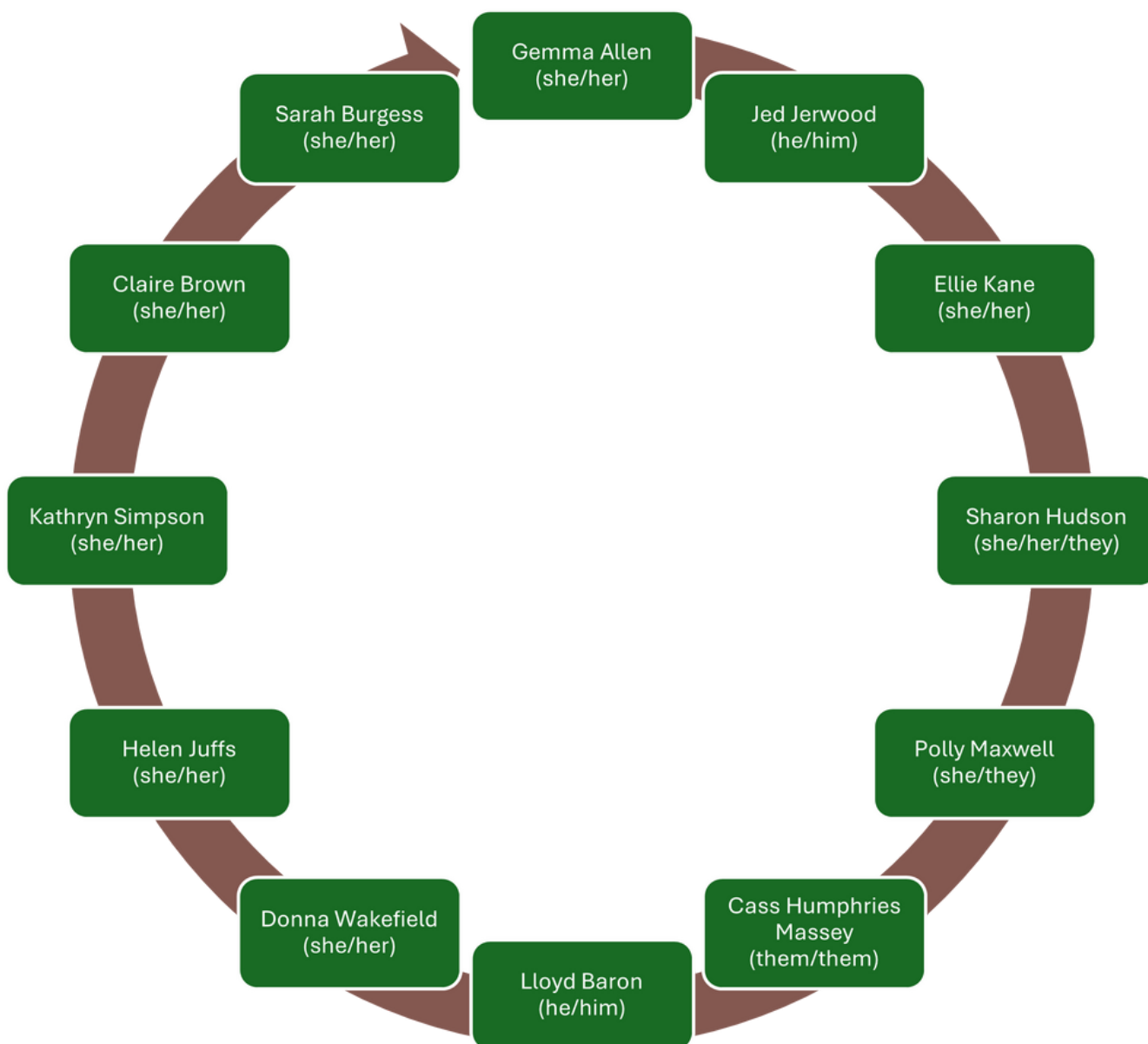
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Authors: This publication was co-authored by members of the co-production group.
Illustrations: Cass Humphries-Massey

INTRODUCTION

This resource includes the diverse voices of the lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) people who engaged in the *'It's more than rainbows in receptions'* project and shared their own experiences, values and opinions. It does not aim to include or collectively represent all LGBTQ+ people but is intended to act as a resource to prompt reflection and to help individuals and organisations listen more closely, think more inclusively and take action to make positive change.

Whether you work at an individual, organisational or leadership level, and/or provide hands-on care or commission services, this resource will help us all to consider the services that we provide through a lens of LGBTQ+ inclusion. We hope this resource acts as a prompt to consider LGBTQ+ people in your own context, enabling each of us to contribute to safer, more equitable palliative care.

The project developed from a reflection from an LGBTQ+ person who noticed an increasing tendency for organisations to make efforts to display the rainbow flag (or progress flag) as a sign of LGBTQ+ inclusivity, but without deeper thought, culture change, training or improvements in care delivery. It formed the first provocation for the co-production group to consider: how does real LGBTQ+ inclusive care happen beyond just 'rainbows in receptions'?

CO-PRODUCTION

No Barriers Here provides an approach that is grounded in co-production, listening to the voices of people with lived experience and using these to positively impact palliative and end-of-life care, education, policy and practice.

This project and publication have been developed by a co-production team consisting of LGBTQ+ people and allies. The project aimed to offer everyone participating a safe environment to express themselves and to share their experiences, including when they had faced experiences and attitudes of bias, prejudice and discrimination, in relation to accessing and working in healthcare or when facing ill health.

The co-production team's contributions and their personal experiences in relation to healthcare, aging and palliative care have added richness and the impact of this publication lies with the voices of all those involved.

ACCESSING HEALTHCARE

Across the world, LGBTQ+ people continue to face persecution with sixty seven countries still criminalising sexual activity between consenting adults of the same sex and many more offering no protection against discrimination. The position globally for trans people is even worse. The UK has made some progress in recent years with changes to the law in 2007 (The Equality Act – Sexual Orientation) and in 2010 (The Equality Act – Gender Reassignment) for the first time making it illegal to discriminate against someone due to sexual orientation and making gender reassignment a protected characteristic. With such changes in the law some may assume that LGBTQ+ people are able to access healthcare in the same way as other people.

However, it is recognised that LGBTQ+ people experience persistent inequity in access to healthcare often due to discrimination and assumptions made by healthcare professionals. In addition, many LGBTQ+ people anticipate discriminatory behaviour and this can affect people in far-reaching ways (Hospice UK, 2023; Wakefield et al., 2021; Wilson & Kortess-Millere, K. Stinchombe, 2018).

“The sense of uncertainty and vulnerability that this position can bring might even stop us from seeking medical help at all.”

Negative experiences in wider healthcare contexts, including discrimination from other patients or service users, impacts upon perceptions amongst LGBTQ+ people of how inclusive palliative and end-of-life care might be and this can lead to a reluctance to seek care when it is needed most. For older LGBTQ+ individuals anticipatory discrimination is common due to previous traumatic experiences because of gender identity or sexuality, resulting in conflicting views and feelings about disclosing aspects of their identity.



I'm so often met with a flustered panic.

Examples of negative experiences include:

- Assumptions of heterosexuality when accessing cancer screening programmes
- Previous negative experiences creating a reluctance to access screening programmes or prevention services, leading to delayed diagnosis and poorer prognosis of physical health conditions
- Not being invited to the correct screening programmes, e.g. trans people not being invited to breast screening, cervical smears or prostate screening
- Ignorance in healthcare staff of trans bodies and how to have conversations about previous surgeries or preferred language
- Diagnostic overshadowing – whereby symptoms are attributed to sexuality or gender identity rather than to possible illness or disease
- Prejudicial views and being treated differently based on outdated stereotypes of LGBTQ+ people
- Excluding a person's chosen family from discussions denying them information
- Treatment side effects such as infertility and loss of libido not being discussed
- Assumptions about contraception and sexual health which are based on stereotyped views of LGBTQ+ people

“They looked incredibly uncomfortable when I said that yes, I am sexually active – but with a woman, no I don’t need a pregnancy test. Then they said, “but your notes say that you have a baby?” That’s not the discussion you want to have when you are worried that you have cancer!”

Am I allowed? Is this for me?



FOREGROUNDING AND FORGETTING SEXUALITY AND GENDER IDENTITY

There is a tendency amongst service providers to homogenize LGBTQ+ people, placing people into a singular collective identity. People can feel clustered into one group and this comes at the expense of individual needs and identities. LGBTQ+ identities can become foregrounded and other intersecting identities can get lost.

“I am just seen as trans – nothing else....not my profession, the fact I am a Dad, a husband, a brother, just that I am trans.”

Equally, when a person becomes ill or is dying, sexuality and gender identity can become invisible. Older LGBTQ+ people also speak of invisibility as their ageing identity becomes foregrounded.

“It’s as though there are no gay people in care homes, you are just the old frail person, everyone assumes you’re straight.”

For care to be delivered in an inclusive way, all people working in healthcare settings (including non-clinical staff) need to adopt an open-minded approach, a willingness to learn and to become informed. Staff need to feel confident about not knowing, sitting with uncertainty and not making assumptions. This might be as simple as how questions are asked. For example, asking who the significant people who provide a support network are rather than asking what ‘family’ a person has is a more open and inclusive question.

This form of question should be asked of everyone not just on the basis that someone is from the LGBTQ+ community. Equally, it is important not to assume someone may or may not have children or be married based on their sexuality or gender identity. Following up with appropriate questions, if needed, about contact with biological family and establishing if there are people who the person is not out too might also be important sometimes.

Examples of inclusive questions:

- *Can you tell me who is at home or who are the important people in your life?*
- *Can I check which pronouns you use, mine are she/her?*
- *What do they do? [When someone mentions their partner without pronouns]*
- *Can I ask you about how we can best care for you?*
- *Is there anything we need to know regarding your health, medications or past surgeries that might impact on how we care for you here?*

We have to hide



who we really are.

PALLIATIVE AND END-OF-LIFE CARE

USE OF IMAGERY AND REPRESENTATION

LGBTQ+ people needing to access palliative and end-of-life care may bring many negative past experiences in healthcare which will impact on how we might feel making new relationships with new services and teams. Early referral and time to build relationships is important for any group with experience of marginalisation in healthcare.

Demonstrating inclusivity through images and explicit references in publicity, the environment and use of visual cues are all important. The title of this publication refers to the tokenistic use of the rainbow flag. However, making sure routine publicity, information leaflets and images include same-sex couples and trans and non-binary people is important. Underpinning the visual cues with staff training, revision of policy and procedures and use of language is critical to avoid tokenism.

Examples of No Barriers Here recruitment material

"It's more than rainbows in receptions"
No Barriers Here

LGBTQ+ people are less likely to access healthcare for many reasons, including fear of discrimination. This can lead to members of our community missing out on the opportunity to discuss their future wishes, including how they would want to be cared for if they had a serious illness (Advance Care Planning).

It is vital that healthcare professionals know how to offer a safe space and competent care, beyond displaying rainbows in reception.

What is No Barriers Here?
No Barriers Here is an approach that uses co-production (working together) to listen to the voices of previously unheard communities through telling stories and sharing experiences. This will help us to understand barriers experienced and explore new ways we can improve care. Our aims are to improve both equity in access and quality of care for members of the LGBTQ+ community, especially supporting those requiring palliative and end-of-life care to plan for the future.

Interested in taking part?

- Are you part of the LGBTQ+ community?
- Are you over 18 years old?
- Do you live in Dudley, Birmingham or the Black Country?
- You are available to attend three consecutive workshops? Each workshop is approximately 2 hours and is free to attend.

Join us

Workshops Group 1 18:30-20:00
24 May 2023
31 May 2023
7 June 2023

Workshops Group 2 18:30-20:00
28 June 2023
5 July 2023
12 July 2023

Midlands Arts Centre (MAC) Cannon Hill Park, Edgbaston, B12 9QH.

Booking essential.
To register your place, please contact:
gemma.allen@marystevenshospice.co.uk
nobarriershere.org

Follow us @NoBarriersHere

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MAINTAINING IDENTITY

Accepting and understanding that a person's LGBTQ+ identity is valid and recognised by everyone involved in healthcare ensures that the care a person receives is aligned to their individual needs and delivered with both dignity and compassion. This may include asking someone about maintaining their identity as illness progresses or if they become unable to make decisions. Inviting discussion and questions around these areas is key to best understanding and influencing better care.

"As people get ill, identity gets wiped."



PERSONAL AND MEDICAL CARE

Palliative and end-of-life care often involves personal and intimate care. For some LGBTQ+ people this may be anxiety-provoking. Being cared for by staff who feel confident about their use of language and ability to ask questions appropriately can help alleviate anxiety.

“They kept coming in and trying to do my hair for me, I hated it, and then there were all these pampering sessions for the ‘ladies’ and I wanted to scream! I just wanted a barber to come in and cut my hair how I like it.”

Using the prompts below may help to develop understanding in areas such as clothing, make-up, shaving, hormone therapy, medication and other aspects of care which may be different to what is expected.

‘What is important to you with regard to your healthcare – is there anything specific around your identity?’

‘How can we support you to maintain your identity if you are no longer able to do so?’

‘Have you thought about writing an Advance Care Plan including your wishes to avoid any debate about your future care?’

‘Is there anyone who can advise us about maintaining your identity if you are no longer able to? This could be a friend, relative or partner.’

“I dread the thought of getting old or unwell and having to have personal care, I have had gender-affirming surgery but I’m sure they won’t know how it all works – I dread needing to be catheterised or someone not giving me my testosterone. If my partner isn’t around, I don’t know who will make sure this all happens.”

SPIRITUAL CARE

Spiritual care is a key part of palliative and end-of-life care and it is important to ensure access to LGBTQ+ inclusive Spiritual Care Practitioners. Spiritual care is not necessarily religious care, although this may form a part of the care received where appropriate. Spirituality encompasses all that matters most to a person; the meaning they make of their life, the hopes and fears they hold, including about their death. Thus spirituality may be understood as the:

“dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.”

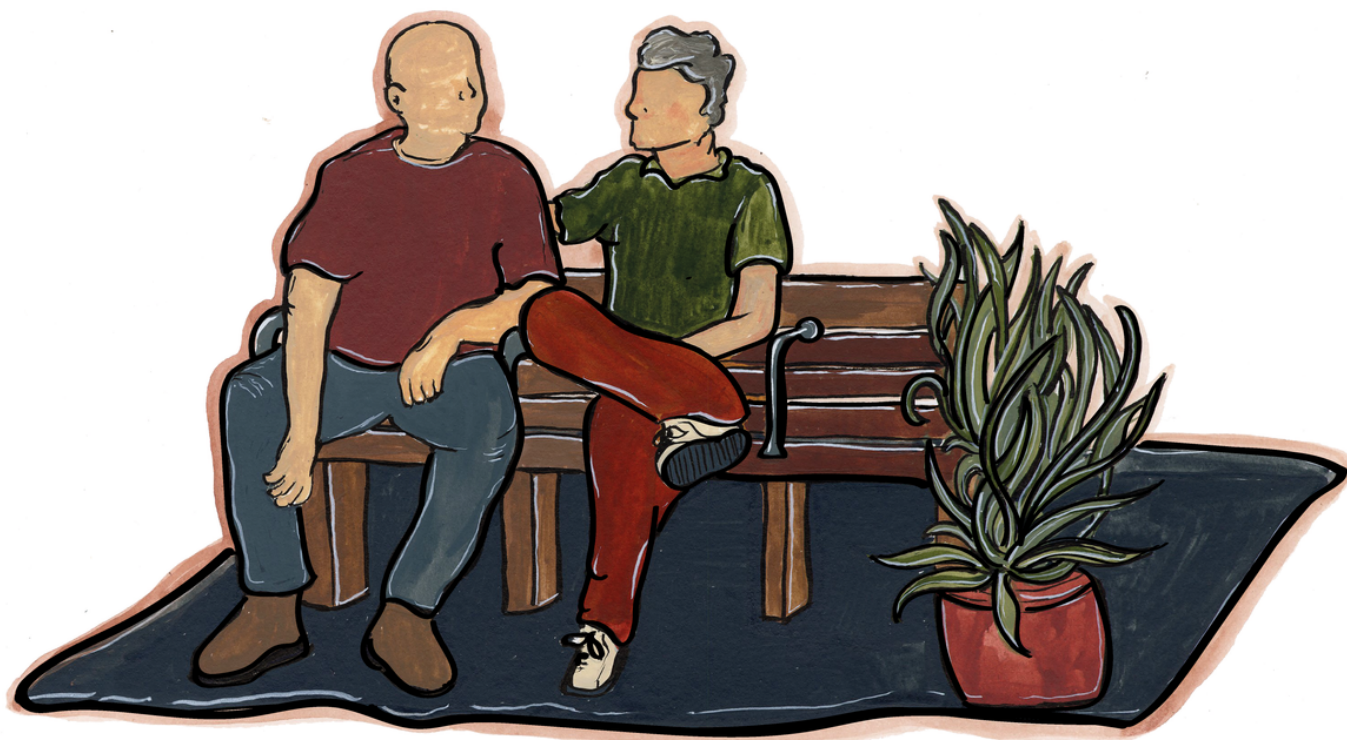
(Puchalski CM et al., 2014)

Spiritual Care Practitioners should be able to hold the breadth and nuance of each individual and their spiritual care needs – be these broadly pastoral or specifically religious, and all in-between. With regard to care for LGBTQ+ people, NHS England recommends that all Chaplains and Spiritual Care Practitioners should register with the UK Board of Healthcare Chaplains (UKBHC) and abide by the Code of Conduct for Chaplains (NHS Improvement: Equality and Health Inequalities Assessment (EHIA), 2020). This includes treating all those receiving spiritual care ‘with equal respect and dignity’ (UK Board of Healthcare Chaplains, 2014).

“I found myself wanting to speak to a priest, but I have been disconnected from the Catholic Church for so long I didn’t know where to go, whether I would be welcome and then the hospice sent an Anglican vicar to see me who clearly felt uncomfortable with my sexuality.”

The reality is that many LGBTQ+ people will have experienced negative treatment within faith communities and may not be linked into local support. Becoming ill and facing mortality can prompt people to reconnect with their faith and may require sensitive and specialised support in dealing with spiritual pain including potential rejection from some faith groups. Understandably there may also be suspicion or concern about requesting time with a Chaplain or Spiritual Care Practitioner for fear of judgement. It is crucial that spiritual care is communicated as a person-centred and non-judgemental service for all and that practitioners are trained and resourced accordingly, including holding their own personal theology or religious viewpoint appropriately within a wider pastoral practice. Organisations may require an audit of accessibility to spiritual care services and consider recruiting additional members of a volunteer chaplaincy team where necessary.

“Although I work as a person of faith in my role as a Chaplain, my practice is wide and inclusive and is actually not often about specific ‘religious’ care. More often, I am invited to listen into the stories of life, of loss, of pain and of hope – the deepest parts of what it means to be human: of what does and does not make sense in light of a complex diagnosis or approaching death.”



PSYCHOLOGICAL SUPPORT

LGBTQ+ people may wish to access psychological support like anyone else accessing palliative and end-of-life care. However, there may be some concerns about whether psychological practitioners offer inclusive care.

Ensuring psychological practitioners have sufficient training and cultural competence is essential, as are clear statements of inclusivity. Statements supporting things like the ban on conversion therapy and statements of trans inclusivity also support the building of trust.



“I just felt judged. The counsellor was well-meaning, but seemed to be unsure of her language about simple things like asking if I had a partner or a husband, and I felt like the spectacle, the different one, the unusual one – as a gay man this shouldn’t be the case in this day and age.”

ADVANCE CARE PLANNING

"I've spent so much of my life addressing prejudice that I have never had the time to think about how I want to be looked after or what my end-of-life wishes are, and as someone in a non-nuclear family, it's really important to say who and what is important."

Advance Care Planning (ACP) is important for everyone. However, for people from communities and groups often excluded or marginalised in palliative care, it is even more important. LGBTQ+ people still do not have all of the legal protections which others have. Family structures may be different and include friends, parenting arrangements might be different and some LGBTQ+ people might be estranged from biological family.

Considering the likelihood of LGBTQ+ people experiencing inequitable access to palliative and end-of-life care suggests a greater need to support LGBTQ+ people to plan ahead for growing older and the end-of-life.

Decision making and thinking about end-of-life care wishes should be prioritised through early advance care planning conversations, supporting the individual to focus on their preferred choices and wishes and seeking to understand what matters most to them. It also offers the opportunity to explore legal matters and supporting a person to put their affairs in order such as appointing a lasting power of attorney or writing a will.

Advance Care Planning provides the time and space to discuss a person's fears and concerns. This is particularly important when considering the underlying issues of trust, safety, discrimination and previous negative experiences LGBTQ+ people may have. There may be concerns about expressing these wishes on paper which would need attending to sensitively.

"So many of us have faced prejudice in healthcare as we have heard just in this small group of people, it's no wonder people don't come forward to talk about this [end-of-life care] but as people in non-traditional family units, we need to get our wishes down and tell those important to us."

WHAT DOES CARE BEYOND 'RAINBOWS IN RECEPTIONS' LOOK LIKE?

The following sections introduce some ideas for developing inclusive care for LGBTQ+ people at individual, organisational and leadership levels. We offer this resource as an introductory guide, a starting point, and a place to consider our own contexts and how we can improve the care of LGBTQ+ people. Our case studies aim to situate this guidance. We encourage you to engage with this section actively and connect with the resources below to further improve your approaches to care.



INDIVIDUAL LEVEL

There are a range of things we can all do to take personal responsibility for providing LGBTQ+ inclusive care, for example:

- Think about how you might signify that you are an inclusive practitioner: the use of name badges, pronouns on name badges and email signatures communicate more than aspects of your own identity and highlight that you recognise difference.
- Take responsibility for enhancing our own knowledge through attending training and workshops.
- Be respectfully curious about difference and valuing diversity and inclusion.
- Think about language on forms, letters and in how you work with people – could your language be more inclusive?
- Hold differences in family and relationships in mind in all encounters – not all difference is visible.
- Respect that for some LGBTQ+ people, declaring their identity and being out still feels frightening, particularly for some older LGBTQ+ people. Fostering an inclusive and accepting environment is essential for providing inclusive care, as well as understanding that some people may not wish to disclose their identity on first meeting you.
- Think about how you can educate colleagues and how to challenge behaviours and attitudes that may harm LGBTQ+ people (patients and colleagues).
- Being aware of people's chosen family and ensuring the nominated significant people are given priority in discussions and care planning.
- Use reflective spaces to think about your own resistance due to your own beliefs. How might you integrate inclusive practice where you feel personal values conflicts?

“They just didn’t place any value on that part of my identity and I wasn’t seen.”

ORGANISATIONAL LEVEL

At an organisational and service level we know changing behaviour and attitudes can feel intimidating. We recognise there may be barriers to improving cultures and services. There are lots of ways to integrate your intentions as an LGBTQ+ positive organisation and to provide safer services for LGBTQ+ people.

- Co-design and co-production approaches offer opportunities to design and improve services by putting LGBTQ+ people (patients and colleagues) at the centre.
- Making links with LGBTQ+ people and organisations local to your service can strengthen your service and foster community approaches to care.
- Consider inviting LGBTQ+ people into your service for the purpose of feedback. Ask how it feels to be in your service, what can you do to maintain inclusive practice, how can you welcome and support LGBTQ+ people. What might it be like to work here? Be open to challenging feedback and open to making changes.
- Consider developing a co-production group of staff, service users and partner agencies to review and re-design publicity information, flyers, forms and other visual materials with LGBTQ+ inclusivity centred. Ensure there is sufficient funding available to pay people for their time and recognise the potential for consultation fatigue.
- Look to your workforce – is it representative of your local community? Are LGBTQ+ people visible in your workforce? If not, why not? Do staff feel safe to be out at work? Are you an appealing place for LGBTQ+ people to work?
- Review workforce training and development – what training and reflective spaces are available to staff?
- How do policies intersect? Are there any conflicts between the needs of different minoritised communities? How can these be addressed? Consider how homophobia and transphobia will be addressed when expressed by patients and families, not just staff.
- Are there any inclusivity initiatives you can sign up to? See Resources section for ideas.

“Other patients were homophobic, the Hospice and some staff aren’t prepared to take it seriously.”

LEADERSHIP LEVEL

At a leadership level, there are things which leaders of systems can do to improve inclusivity throughout palliative and wider healthcare systems. Key questions and considerations for those developing and overseeing services might include:

Co-design and involvement

- The voices of people with lived experience must be centralised to any service improvement and development strategies.
- System leaders should ensure that systemic change happens only with the involvement of LGBTQ+ people. Using a co-designed and co-produced approach to ensure inclusion and quality outcomes is fundamental. Whilst consultation is often important this is not co-production as at this stage the work has already been decided.
- Culturally competent care training which is designed and delivered by LGBTQ+ people should be provided.

Policy and decision-making

Some key policy and decision-making aims should be:

- To address health inequity and barriers to care for LGBTQ+ people.
- To encourage health promotion and initiatives, including for older populations.
- To consider additional services to support LGBTQ+ people as service users and members of the workforce.
- To look at how data about gender and sexuality are collected and to ensure that this is put to effective use for commissioning. Consider how well you know your community and how accessible services are for everyone to use.

Funding and research

- Is research activity being funded sufficiently? Is funding available to improve access to LGBTQ+ healthcare, delivery and experiences?

Workforce Strategies

- Is your workforce reflective of the local community?
- Are LGBTQ+ people visible in your workforce at all levels?

“Our community doesn’t deserve shortcuts.”

USING THE NO BARRIERS HERE APPROACH WITH LGBTQ+ PEOPLE – A CASE STUDY

Georgina*, 67

Georgina, or George as she prefers to be known, attended a *No Barriers Here* advance care planning series of workshops. This is her story.

George came out when she was 23 after leaving home following pressure to get married. At the time, being a lesbian was less accepted than it is today, and George kept her identity secret from all but a few close friends for many years. In her early 30's she found a breast lump and was successfully treated for breast cancer. However, George recalled how difficult it was to undergo treatment without the support of her girlfriend due to their relationship being kept secret. She also shared her experiences of the way healthcare staff talked to her about the impact of the treatment on her body and alluded to how her husband might react. When George explained she didn't have a husband, she felt the staff treated her differently as an unmarried woman in her 30's.

George underwent many months of surgical and medical treatment without ever being able to talk about her sexuality. Following her treatment for breast cancer, George became quite anxious and sought support from her GP for low mood. Again, George experienced assumptions that she was heterosexual with her GP commenting that anti-depressants might impact her sexual life and her relationship with her husband.

By the time George was in her early 60's she had come out more widely and was openly living with her partner of nearly 25 years. They had a civil partnership and were part of a wide group of close friends who supported each other. George's partner became unwell and sadly, died just over a year ago. She was not able to access hospice care and died at home after a short illness. George talked about how reluctant they both were to seek help and support because of the negative experiences they had been through earlier in their lives in different healthcare settings. George talked about how difficult it had been to care for her partner on her own, of how limited the help from their GP had been and how they had struggled to ask for support when her partner was in hospital. She had repeatedly been excluded from discussions about her partner's care when in hospital and had only been visited once by the hospital palliative care team who had assumed she was her partner's sister.

During the *No Barriers Here* workshops, George was able to explore her past experiences and take time to understand how they might have impacted on her feelings about accessing care now and in the future. She was able to hear from others and have her experiences affirmed as well as hearing about more positive experiences and building a relationship with the facilitators. George was able to make images and artefacts which expressed her identity as a lesbian, her preferences for care and her wishes for her future. She was able to explain who her support networks included, why there were more friends than biological family and to think about her identity as a lesbian. She was also able to include other aspects of her life and identity – her commitment to the voluntary work she does, the fact that she had been a keen sportswoman, her career as a teacher and her role as an aunt. George was also able to find out about what options were available to her, to contribute to the development of more inclusive care and to work out who she needed to talk about her plans with.



I've been lost in the process and thinking through my elements,
I find that so hard to do normally.

WHAT WOULD INCLUSIVE CARE LOOK LIKE? AN EXERCISE

Matty, 27

Matty is a non-binary person with multiple partners (polyamorous). Their pronouns are they/them. Matty is estranged from their biological family and lives with their primary partner, a close friend and their dog. They also have a second partner who lives in another town, who they see one weekend a month. Matty has cystic fibrosis and a diagnosis of complex post-traumatic stress disorder (C-PTSD). They have found it hard to manage the relationships with their care teams from both physical and mental health services.

They had experienced many negative encounters with healthcare services and had very negative views about accessing care. Matty is aware of their likely shortened life expectancy and need for future palliative care and advance care planning.

- What are some of the key questions you might ask Matty to ensure the provision of inclusive care?
- What would you need to do for yourself to ensure you are informed and confident in your approach?
- In thinking about your own organisation or setting, how might it not be inclusive for Matty? What areas of improvement can you identify?
- What other agencies can you think of who could support you?

Notes

FINAL THOUGHTS

Everyone should receive equitable and inclusive palliative and end-of-life care regardless of their sexuality, gender identity or other aspects of identity. It is important for healthcare organisations and professionals to aim for gold standard care for everyone. Getting things right for minoritised groups and individuals always leads to better care for everyone.

Sadly, as the project behind this resource highlighted, LGBTQ+ inclusive care is still not available consistently. There is a long way to go to move beyond just tokenistic gestures such as displaying rainbows in receptions. There is much good practice taking place and highlighting the issues has allowed it to surface and be shared.

The ability of healthcare organisations to listen to those wanting to access services, and those already accessing them, is a measure of inclusivity. In addition, to not know, to sit with uncertainty and to be open to learn and ask individuals about their care preferences, their lives and identities, can lead to far more inclusive care than to try and apply overarching policies to groups of people. It is important to remember that LGBTQ+ people not only access services, but also work in them, lead them and inclusivity extends to our organisations as both workplaces and places of care. The LGBTQ+ community is wide and diverse and must be treated as such.

This resource has been developed by LGBTQ+ people, with experience of working in and accessing healthcare services. It was developed through sharing, reflecting, listening, learning and acting.

We urge you to encourage the same in your organisations.



USEFUL RESOURCES

Age UK <https://www.ageuk.org.uk/information-advice/health-wellbeing/relationships-family/lgbt/health-care>

European Association of Palliative Care – Providing LGBT+ Inclusive Palliative and End-of-life Care <https://eapcnet.eu/eapc-groups/task-forces/improving-palliative-and-end-of-life-care-for-lgbt-people/>

Gendered Intelligence <https://genderedintelligence.co.uk/>

GIRES <https://www.gires.org.uk/>

Hospice UK 'I Just Want to Be Me' report <https://www.hospiceuk.org/publications-and-resources/i-just-want-be-me>

LGBT Foundation <https://lgbt.foundation/help/hidden-figures-lgbt-health-inequalities-in-the-uk/>

LGBT Hero <https://www.lgbthero.org.uk/>

Marie Curie LGBTQ+ resources <https://www.mariecurie.org.uk/help/support/lgbtq>

NHS England <https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/lgbt-health/lgbt-action-plan-priorities/>

No Barriers Here www.nobarriershere.org

Stonewall <https://www.stonewall.org.uk/>

ABOUT NO BARRIERS HERE

No Barriers Here is an equity-oriented, arts-based approach to advance care planning, informed through working in co-production with and alongside people with lived experience. It acts as a tool for thinking about advance care planning with people and communities who experience inequity in palliative care. It is also a research methodology for understanding people's experiences, barriers, and expectations for palliative and end-of-life care.

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