

I just want to be me: Trans and Gender Diverse Communities’ Access to and Experiences of Palliative and End of Life Care

Tribute to Pip Blaylock

An adaptation of Charles Bukowski’s lyrics for his song Bluebird:

There was a bluebird in my heart and I let her out.

I was strong enough for her to do that. I used to say, stay in there. I cannot afford to let anyone see you.

I have freed the bluebird from my heart.

“We talk about the wonder of birth but being with dad at the end was the privilege of my life.” – Rebecca Blaylock

About Hospice UK

Hospice UK is the national charity for hospice and end of life care. We work to ensure everyone affected by death, dying and bereavement gets the care and support they need, when they need it.

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Foreword

Caring for people with life-limiting illness is one of the greatest privileges in healthcare. We see people at their most vulnerable and fragile as we try to listen and hear their story, help them live freely, and ultimately care for them with dignity and compassion as they die. There are few things as powerful when it's done well. There are few things that can cause as much harm when it's not.

People who are trans and gender diverse deserve that support as much as anyone else. We have a legal duty to improve care both from the Health and Care Act 2022 and the Equality Act 2010 but we also have a moral duty to improve this simply because it's the right thing to do.

I'm often asked why we should focus on such a small group of people when healthcare is stretched in so many ways. Evidence tells us making care better for one group makes it better for everyone. It is not one group versus another but rather, how can we make sure we provide the best care for all.

There is work to do for all marginalised communities and some amazing progress is being made with other groups. It is now time to help trans and gender diverse people as historically there has not been as much focus on their needs.

This report highlights so many challenges trans people face. The stripping away of who they are, their name, their pronouns, their personal care and the safety of their chosen family. The barriers to marrying and dying in the gender they've lived as. The isolation they face from familial rejection. The constant work they are doing having to educate their healthcare providers on how to provide them with care. All this leaves them feeling exhausted, anxious and unwelcome.

Yet there are some rays of light, of care that is individualised, of work that is inclusive and an openness to learn and develop services. I hope that this report is a starting point to make such care the standard across the sector. I know it will not change everything overnight but it is the start of a conversation.

It is a call to develop research, training and policy so that when trans people come through the door we are ready, secure in the knowledge they will be cared for as their whole selves. It is also an opportunity for healthcare leaders to see trans-inclusion as a priority and place it high on their agenda, both in terms of improving policy and training but also in reaching out to the community and making them know that they will be given high quality care in our services.

I hope that throughout my career we can improve the care we give to the trans and gender diverse community and that one day, when I turn to face death, I can focus on the life I've lived and the loves I've shared rather than worry about if I'm welcome.

Dr Ellie Kane
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Executive Summary

This report shows that in many instances, the end of life care that trans and gender diverse people receive is not inclusive of them, and despite best intentions and a willingness to learn, staff feel they lack the knowledge and training needed.

Trans and gender diverse people who had accessed palliative and end of life care at times experienced insensitivity from staff, misgendering and confusion over their identity and instances of poor physical care.

“My Dad’s gender identity has impacted her care in many ways. When in hospital, she was not offered a shower for ten days and I am convinced this is because of her being trans.” Rebecca Blaylock

Palliative and end of life care staff expressed a positive desire to learn and ensure their services are accessible, with those who had received end of life care sharing many positives about the staff they encountered. However, staff raised serious concerns over discriminatory views not being addressed in the workplace, a lack of training and understanding on LGBTQ+ issues, and a lack of access to information on providing medical and clinical care to trans people.

In wider trans and gender diverse communities, many expressed apprehension about one day having to access end of life care services, in part due to a range of negative experiences with other healthcare services. It is essential that palliative and end of life care providers put in the work to make their services inclusive to ensure that trans and gender diverse people do not miss out on vital quality care.

“I have not had great experiences as a trans person with accessing healthcare... as a result of the culmination of decades of microaggressions or outright transphobia, I am very, very wary about needing a palliative care provider.”- Community survey respondent

To do this, health and social care staff need to be better equipped to support trans people. They should receive training pre-registration on trans and gender diverse communities, and be supported to access further training throughout their career. Professional bodies and Royal Colleges should also produce guidance on providing medical and clinical care to trans and gender diverse people in palliative and end of life care.

To improve the end of life care experiences of trans and gender diverse people, and the experiences of trans staff and volunteers within end of life care, providers should develop robust policies that support trans and gender diverse people. Trans and gender diverse people within end of life care spaces must be protected from discrimination and supported to transition. This includes providing trans and gender diverse people with information on medical and physical transition and ensuring that being at end of life is not an additional barrier to transition related healthcare.

The experiences of trans and gender diverse people remain under recognised in end of life care. There has been little research or attempts to platform trans and gender diverse voices in

the sector. This report should be used as an opportunity to continue to make palliative and end of life care services more inclusive, and truly open to all. For Hospice UK, this is a first step and we look forward to developing this work.

Terminology

Palliative care is the treatment of patients with an illness for which a cure is no longer possible, the World Health Organization defines it as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’¹

End of life care is understood as care given in the final year of life, focusing on a person’s comfort, enabling a dignified death, and support families and loved ones

Trans/transgender is an umbrella term used to describe people whose gender is not the same as, or does not sit comfortably with, the sex they were assigned at birth. Trans people may describe themselves using one or more of a variety of terms, including (but not limited to) transgender, gender-queer, gender-fluid, non-binary, gender-variant, genderless, agender, nongender, third gender, bi-gender, trans man, trans woman, trans masculine, trans feminine and neutrois.² Terms such as transsexual and crossdresser may be used by some to describe themselves, however, to many these terms are outdated and offensive and so are generally avoided.

Trans man is a term used to describe someone who was assigned female at birth but identifies and lives as a man.²

Trans woman is a term used to describe someone who was assigned male at birth but identifies and lives as a woman.²

Non-binary is an umbrella term for people whose gender identity doesn’t sit comfortably with ‘man’ or ‘woman’. Non-binary identities are varied and can include people who identify with some aspects of binary identities, while others reject them entirely. Many people who are nonbinary also identify as trans.²

LGBTQ+ is the acronym for lesbian, gay, bisexual, trans, queer, questioning and ace. It is important to remember that trans people may also be lesbian, gay, bisexual, queer, questioning or ace.² Ace is an umbrella term used to describe a lack of, varying, or occasional experiences of sexual attraction.²

¹ World Health Organization. Palliative Care. [Online] 2020 [Cited 2023 Jan]. Available from: <https://www.who.int/news-room/factsheets/detail/palliative-care>.

² Stonewall. List of LGBTQ+ terms. [Online] [Cited 2023 Jan]. Available from: <https://www.stonewall.org.uk/list-lgbtq-terms>

Gender diverse relates to a person whose gender identity, including their gender expression, does not conform to socially defined gender norms, and/or do not place themselves in the male or female binary.³

Gender affirmation is an umbrella term for the range of actions and experiences that make someone feel more aligned with their gendered self. This can look different for every individual and may depend on what is personally affirming, what feels safe to do, and what is accessible.⁴

Cisgender is a term used to describe someone whose gender identity is the same as the sex they were assigned at birth.⁵

³ OHCHR. The struggle of trans and gender-diverse persons. [Online] [Cited 2023 Jan]. Available from: <https://www.ohchr.org/en/special-procedures/ie-sexual-orientation-and-gender-identity/struggle-trans-and-gender-diverse-persons>

⁴ TransHub. What is gender affirmation? [Online] [Cited 2023 Jan]. Available from: <https://www.transhub.org.au/101/gender-affirmation>

⁵ Stonewall. List of LGBTQ+ terms. [Online] [Cited 2023 Jan]. Available from: <https://www.stonewall.org.uk/list-lgbtq-terms>

Recommendations

- Education providers and those who have responsibility for developing staff training curricula should ensure health and social care staff receive pre-registration training on gender, including understanding what it means to be trans or gender diverse, and trans and gender diverse healthcare needs.
- After receiving training and developing comprehensive policies, palliative and end of life care providers should take steps to actively promote that they are a trans inclusive service provider.
- Palliative and end of life care providers should make sure that staff and volunteers are appropriately trained on the Gender Recognition Act and Gender Recognition Certificates, particularly the legal requirement not to disclose protected information.⁶
- The UK government should reform the Gender Recognition Act to de-medicalise the process and extend legal recognition to non-binary people.
- Professional bodies and Royal Colleges should produce up to date guidance on providing medical and clinical care to trans and gender diverse people in palliative and end of life care.
- All NHS and hospice IT and patient information systems should be updated, following consultation with trans and gender diverse communities, to ensure people's name, title, gender and trans status are captured and recorded accurately. This must be inclusive of non-binary and gender diverse identities.⁷
- Palliative and end of life care providers should ensure that trans and gender diverse people with a terminal diagnosis are signposted to high quality and accessible information and support on accessing transition support.
- Palliative and end of life care providers should develop clear workplace policies on protecting patients, visitors, staff and volunteers who are trans or gender diverse. This must include how discrimination will be handled and how a staff member or volunteer who begins their transition while employed by the provider will be supported.
- Gender Identity Clinics should support trans and gender diverse people with a terminal or life-limiting diagnosis to continue conversations about their transition and ensure that a terminal diagnosis is not, in itself, a barrier to medical or surgical transition.
- Health and social care regulators should consider how well a service meets the needs of trans and gender diverse communities in their assessments of services.
- Providers should be encouraged to implement a 'this is me' document, which can be held by the individual or implemented into digital shared care records, that includes information

⁶ UK Gov (2004) Gender Recognition Act 2004. [Online] [Cited 2023 Jan]. Available from: <https://www.legislation.gov.uk/ukpga/2004/7/contents>

⁷ London Assembly Health Committee (2022) Trans health matters: improving access to healthcare for trans and gender diverse Londoners.[Online] [Cited 2023 Jan]. Available from: https://www.london.gov.uk/sites/default/files/health_committee_-_report_-_trans_health_matters.pdf

important to the individual, such as information about their gender, presentation and transition related medical needs.

- NHS elearning platforms should include a module specifically focused on the needs and experiences of trans and gender diverse people in end of life care.
- Palliative and end of life care services should ensure that intake and referral forms capture an individual's preferred name and pronouns.
- Hospices should be supported to access training on gender and LGBTQ+ communities and to expand the delivery of training and good practice they have developed.
- Guidance produced by professional bodies on advance care planning should be updated to include consideration of gender affirmation and continuing transition at end of life.
- The research community should be supported, including through funding opportunities, to do further work looking at trans and gender diverse communities' access to and experiences of end of life care, including specific focus on additional barriers faced by non-binary people.
- All palliative and end of life care services should ensure experience of care feedback opportunities are inclusive of trans and gender diverse people and provide space to reflect on care that related to their gender and identity.
- Relevant public health bodies should fund awareness campaigns to help trans and gender diverse people to have confidence to disclose their gender status to palliative and end of life care providers.⁷
- National movements, such as Dying Matters, should platform trans and gender diverse communities' experiences of death, dying and grief.

Aims of the report

- To act as a platform for trans and gender diverse people to share their experiences and their perspectives on their end of life care.
- To highlight the palliative and end of life care needs of trans and gender diverse people.
- To highlight examples of good practice in end of life care that support trans and gender diverse people.
- To establish what stakeholders can do to improve the end of life care received by trans and gender diverse people and their access to end of life care – and support stakeholders to make these changes.

The importance of focusing on palliative and end of life care for trans and gender diverse communities

In 2021, Hospice UK published “Equality in hospice and end of life care - challenges and change”, which highlighted some of the communities that face inequity when accessing palliative and end of life care, including LGBTQ+ communities.

Literature reviews conducted at the beginning of this project found an encouraging amount of work looking at LGBTQ+ access to and experiences of palliative and end of life care. However, many of these afforded only brief mention to the specific barriers faced by trans and gender diverse communities and involved very few trans people. The needs of LGBTQ+ communities are often discussed in conjunction with one another, however, different communities face very different barriers.

Studies have found trans older adults report higher rates of disability, poor physical health, depression, victimisation, and discrimination than cisgender lesbian, gay, and bisexual older adults.⁸ Additionally, trans people are especially likely to be estranged from their family of origin or have conditional relationships with them, such as having to present as their assigned sex in order to see them.⁹

Trans and gender diverse people are also particularly disadvantaged when accessing health care. 70% of trans respondents to TransActuals 2021 Trans Lives survey reported being impacted by transphobia when accessing general healthcare services. 57% of trans people reported avoiding going to the doctor when unwell.¹⁰

The conversation around trans healthcare often centres around access to transition, and, while this is important, it is vital that trans and gender diverse people are considered across all healthcare services. It is important that we examine how barriers experienced across the healthcare system manifest in end of life care and work to address them. Failing to deliver

⁸ Fredriksen-Goldsen et al. The health equity promotion model: Reconceptualization of lesbian, gay, bisexual, and transgender (LGBT) health disparities. *American Journal of Orthopsychiatry*. 2014 [cited 2023 Jan]; 84(6) 653–663. Available from <https://psycnet.apa.org/record/2014-57192-008?doi=1>. Doi:10.1037/ort0000030.

⁹ Almack et al. *The Last Outing: exploring end of life experiences and care needs in the lives of older LGBT people*. Nottingham: University of Nottingham; 2015.

¹⁰ TransActual. *Trans lives survey 2021: Enduring the UK's hostile environment*. [Online] 2021 [cited 2023 Jan]. Available from: <https://www.transactual.org.uk/trans-lives-21>.

accessible and inclusive care to trans and gender diverse people means we are failing to uphold the central ethos of good palliative and end of life care, that is to deliver individualised, personcentred support.

In the 2021 England and Wales census, 0.5% of respondents, 262,000 people, answered that their gender identity was different to their sex registered at birth.¹¹ This is a significant population of people, at various stages of their transition, that will need end of life care that understands their needs.

The 2010 Equality Act for Great Britain includes 'gender reassignment' as a protected characteristic, which protects many trans people from discrimination. Many have called for gender identity to be added as a protected characteristic, as many trans people may not seek surgical or medical transition.¹² In 2020, a UK employment tribunal ruled that non-binary and genderfluid identities fall under the protected characteristic of gender reassignment. This means that trans and gender diverse people are legally protected from discrimination, and it is important that we ensure that this extends into end of life care settings.¹³

Over the past decade, insightful work and resources have been produced to better the experiences of LGBTQ+ people in palliative and end of life care. For example, in 2012, NHS England produced 'The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people', an important step in helping to make services more inclusive and addressing discrimination.¹⁴ In 2014, the Cicely Saunders Institute and the University of Nottingham began the ACCESSCare project, aiming to improve care for LGBT people with life-limiting illnesses.¹⁵ Following this, in 2016, Marie Curie produced their report 'Hiding who I am – the reality of end of life care for LGBT people', highlighting the experiences of LGBTQ+ people in end of life care. To continue this progress, it is important to highlight trans and gender diverse communities' experiences specifically, and to take action to address inequity and barriers to access.¹⁶

As an organisation, Hospice UK is consistently working to improve our learning and ensure we are inclusive of, and accessible to, trans and gender diverse people. We have not always given this the necessary attention or got it right, and we have work to do to ensure our approach and materials are where they should be. We welcome further opportunities to examine and improve our work and our inclusion of trans and gender diverse communities.

¹¹ Office for National Statistics. Gender identity, England and Wales: Census 2021 [Online] 2022 [Cited 2023 Jan]. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/genderidentity/bulletins/genderidentityenglandandwales/census2021>

¹² Equality Act 2010. [Online] 2010 [cited 2023 Jan]. Available from: <https://www.legislation.gov.uk/ukpga/2010/15/contents>

¹³ UK Parliament. Non-binary gender recognition: law and policy. [Online] 2022 [cited 2023 Jan]. Available from: [https://commonslibrary.parliament.uk/research-briefings/cbp-9515/#:~:text=Legal%20protection&text=In%202020%2C%20the%20Birmingham%20Employment,of%20gender%20reassignment%20\(PDF\).](https://commonslibrary.parliament.uk/research-briefings/cbp-9515/#:~:text=Legal%20protection&text=In%202020%2C%20the%20Birmingham%20Employment,of%20gender%20reassignment%20(PDF).)

¹⁴ National End of Life Care Programme. The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people. 2012. [Cited 2023 Jan]. Available from: <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/10/End-of-Life-Care-Route-to-Success-AchievingQuality.pdf>

¹⁵ Cicely Saunders Institute, University of Nottingham. ACCESSCare for lesbian, gay, bisexual and trans people approaching the end of life [Online]. [Cited 2023 Jan]. Available from: <https://www.nottingham.ac.uk/research/groups/ncare/completedprojects/projects/accesscare-lgbt.aspx>

¹⁶ Marie Curie. Hiding who I am – the reality of end of life care for LGBT people. London: Marie Curie; 2016.

“You feel on edge. For being yourself you can be faced with many challenges. I just want to be me” – Community survey respondent accessing palliative/end of life care services

Recommendations: The research community should be supported, including through funding opportunities, to do further work looking at trans and gender diverse communities’ access to and experiences of end of life care, including specific focus on additional barriers faced by non-binary people.

Project findings

The findings of this project, including the surveys and the experiences of people with lived experience cover five key areas:

- Planning for the end of life
- Approaching care providers
- Retaining identity and dignity
- Physical care
- Workforce and training

Planning for the end of life

For everyone, it is important to think about and plan for death, including the care they would like to receive, where they would like to die and funeral arrangements. This project has revealed that often, for trans and gender diverse people, their motivation for making plans or preparations, and considerations about the end of life, were different from the general cisgender population, or factored in additional concerns.

68% of respondents to our survey answered that being trans and/or gender diverse had affected why they thought about their plans and wishes for the end of their life and after their death. 66% said that their plans or instructions in some way related specifically to being trans and/or gender diverse.

“As a transgender individual, I have settled with the fact that not everyone will agree with my chosen gender identity and it may put me at risk of harm of those that disagree with my gender identity. Therefore if I die, I want to be prepared.” – Community survey respondent

Some expressed that they anticipated facing discrimination when receiving end of life care, and so felt they had to prepare for this.

Multiple respondents mentioned that they have unsupportive family that they worry would seek to go against their wishes at the end of their life, and so found this motivated them to prepare for their end of life care and death. Previous research has found that trans people were often estranged from their family of origin or had conditional relationships with them, and have identified these conditional family relationships and lack of support as a barrier to trans people accessing care at the end of their lives.⁹

“One of my parents is not supportive of my trans identity so I have had to give thought to what I would like to happen when I die because the fear is that I will be buried or memorialised with the wrong name.” – Community survey respondent

“As a non-binary person I have been unable to marry my long-term partner as I cannot do so as myself, only by posing as my assigned gender at birth. This means I cannot access the legal protection that marriage would give me in terms of him being my automatic next of kin; I must consider what I need to put in place to prevent family members who do not accept me for who I am having the power to override his decisions in the event of my death. I live in fear that I will die and be buried under a headstone that is not for me, or that my family of origin will organise a religious service against my wishes, where they will speak about me as though I was someone else. The people I love would be deeply hurt by this and I wouldn’t be here to protect them.” – Community survey respondent

“A non-binary friend of mine died, sadly by suicide, and their funeral was attended by a really wonderful mix of their queer “chosen” family and their blended family and relatives. I was incredibly moved by how sensitive the grieving family were in using the correct pronouns of my friend and referring to them by their gender identity rather than gender assigned at birth. I realised that my own family are probably not similarly motivated or sensitive, and that I might need to put something in place for my own plans to prevent being misgendered or inappropriately referred to (which would upset my partner and friends) by my own family.” – Community survey respondent

Tip: Don’t assume that a person’s next of kin will be a blood relation or an official spouse, always respect the person’s choice of nominated person.

One respondent also spoke about their concerns navigating gendered religious ceremonies, and how it would hurt their loved ones to have their gender questioned after their death.

“I am Jewish and a trans woman with a gender recognition certificate. Jewish funeral rites differ for men and women. I obviously want the female rites. Jews normally bury & don’t cremate. Before burial is a cleansing rite called Tahara, which is carried out by women for a woman and men for a man. It is not done for cremation candidates. I have opted in my will for cremation because I don’t want someone distressing my descendants by questioning my right to female Tahara; or questioning my right to be buried in a Jewish cemetery after the event. In short, I don’t trust Jewish officialdom to honour my wishes.” – Community survey respondent

Several people mentioned that they had witnessed the end of life care given to someone close to them, and that this raised particular concerns for what care they would receive. They highlighted that the standard approach to end of life and death did not leave room for their needs. This emphasises that it is also vital we ensure that the trans and gender diverse loved ones of those in palliative and end of life care are supported, so they feel empowered to access care themselves later in life.

“Seeing someone close who was given palliative care have their own wishes ignored in favour of expectation made me think more about my own future needs. It seemed hard to know how to advocate for their treatment as there was a one size fits all approach by the hospice.” – Community survey respondent

Another respondent shared their perspectives of death within trans and gender diverse communities, and said that this awareness of loss has led to them planning for their own end of life.

“Seeing my trans siblings die so often prematurely has made me realise that I need to start planning for my own death ASAP. I am not even 30 yet, so it is a very scary prospect. But I want to be in control of my own legacy, so that needs to involve outing myself to many different organisations.” – Community survey respondent

Approaching care providers

Many of those who completed the survey, who had not experienced palliative or end of life care but were thinking about care they may need in the future, expressed anxiety and concern over approaching a palliative or end of life care provider. We received insight into the range of barriers that people face when approaching a care provider, as well as suggestions on how to address this.

“I wouldn’t feel comfortable approaching someone unless I knew they were explicitly trans friendly” – Community survey respondent

Concerns and Barriers

In their responses to the survey, people raised concerns that their identity would be ignored in end of life care spaces, or that they would have to suppress this. Specifically, several respondents mentioned concern over the medicalisation of death taking away from the aspects of themselves that are most important to them. It is particularly important when thinking about end of life care for trans and gender diverse communities to remember how much of end of life care is about supporting the individual and understanding what is important to them.

“I worry about being misgendered in death & about the queerness of my life being masked in order to meet a heteronormative standard of expectations around what death & funerals should be like.” – Community survey respondent

“I am a death positive person however I am scared of approaching Health/Death care as a non-binary Queer person as I feel this very important part of me will be ignored/glossed over and the medicalness of death/EOL will over take it all” – Community survey respondent

“Because I live so fiercely as who I am and I don’t want that erased when I die. I’d like to inspire others” – Community survey respondent

Stewart O’Callaghan, CEO of Live Through This, also highlighted that when people receive care, there is a risk of them going back into the closet or diminishing themselves out of fear of discrimination or wanting to ensure they do not receive worse care. Everyone should be able to be completely themselves, especially when at the end of their life when time is precious.

‘We want people to be able to be themselves, to bring in their partners, and to have their full support structure around them. That’s why the environments have to be aware and inclusive’ – Stewart O’Callaghan, Live Through This

Several people cited their multiple previous negative healthcare experiences, such as being misgendered and staff making insensitive comments, as contributing significantly to their fears over accessing end of life care. There is already a breadth of evidence showing trans and gender diverse people's negative experiences of healthcare services and how this can lead to them avoiding services.¹⁷ This is also impacting on how comfortable trans and gender diverse people feel approaching end of life care services and so as a result means that they do not have equal access to care. It is vital that the needs of trans and gender diverse people are addressed across the breadth of the healthcare system.

"I have not had great experiences as a trans person with accessing healthcare... as a result of the culmination of decades of microaggressions or outright transphobia, I am very, very wary about needing a palliative care provider. I'd feel pretty uncomfortable and vulnerable in this situation without reassurance that the end-of-life team had been trained, and were supportive of, treating trans patients." – Community survey respondent

"After recent personal experience in hospital receiving emergency and then outpatient care my experiences as a trans person have been very disappointing, from staff not 'knowing what to do with me' (their words), misgendering me despite me passing very well as male, and seemingly not understanding when my trans status is and isn't relevant to care. I am therefore concerned that should I need ongoing or end of life care at any point this would be something that would make me uncomfortable" – Community survey respondent

For older trans and gender diverse people who may be approaching end of life and accessing care now, some of their previous experiences of healthcare as a trans person may have been actively hostile, such as conversion therapy, making it even more intimidating to access services later in life.

Hospices can be particularly intimidating for trans and gender diverse people to access. Along with being healthcare organisations and therefore associated with previous negative experiences, there can also be a perception that hospices have close links to Christianity, which some LGBTQ+ people may have historic negative associations with.

"I think there will be a part of the population that might be concerned about hospices historical link with religion and therefore being openly queer in those spaces" – Stewart O'Callaghan, Live Through This

"A legitimate concern is if I was unable to be cared for at home, that the place would be LGBT+ Friendly. As someone who was brought up in the church and was told I was a sinner for being LGBT+, I would not want to go to a place that had religious affiliation." – Community survey respondent

Individuals also linked their comfort, or discomfort, with approaching palliative and end of life care services to their transition and what official recognition they had of this. Those with Gender Recognition certificates (GRC) expressed that they would be more comfortable accessing care because of this.

¹⁷ Hobster K, McLuskey J. Transgender patients' experiences of health care. British Journal of Nursing [Online]. 2020. [cited 2023 Jan] 29(22): 1348-1353. doi: 10.12968/bjon.2020.29.22.1348

“I don’t think I’d have problems approaching a palliative care provider. I hold a GRC.” – Community survey respondent

LGBTQ+ organisations have highlighted problems with the Gender Recognition Act. In June 2020, a report published by the European Commission ranked the UK procedure for acquiring a gender recognition certificate as amongst the worst in Europe due in part to ‘intrusive medical requirements’.¹⁸ The process can also take a long time, requiring someone to have transitioned two years before a GRC is issued, and applications are normally seen by a panel up to 22 weeks after being submitted.¹⁹ Many trans people feel they cannot face this process, which then means, without a GRC, there are barriers to having their death recorded respectfully.²⁰

Previous research has documented trans people with advanced illness expressing concerns over acquiring a GRC in time to have their gender accurately reflected on their death certificate and memorials.²¹

It is important to note that non-binary people do not have access to a GRC that recognises their non-binary identity, making it more difficult for them to access services without the reassurance that their identity will be understood and respected.

“Yes it’s still very binary male or female and I identify as non-binary really but am being pushed more towards trans man by the thought of being trapped in care and treated as a hairy female due to my physical body on hormones but lack of a GRC option or ID documents for non-binary people.” – Community survey respondent

In addition to concerns about not receiving appropriate care, facing micro-aggressions and not having their identity understood, people also raised fears of facing outright discrimination in a care setting, whether this be from staff or other patients.

“I would be deeply apprehensive about encountering anti-trans people or people with a lack of relevant knowledge of trans people.” – Community survey respondent

One gender diverse individual that completed the survey expressed that if they were to access services and find them exclusionary or discriminatory, they would be likely to disengage without ever feeling able to raise their concerns. It is key to recognise that this may already be happening within palliative and end of life care services, where trans and gender diverse people may have not been able to talk about their identity or their concerns and have not received the support they need as a result.

¹⁸ European Commission, Directorate-General for Justice and Consumers, Legal gender recognition in the EU: the journeys of trans people towards full equality. Publications Office; 2020. Available from: doi/10.2838/50202

¹⁹ Gov UK. Apply for a Gender Recognition Certificate [Online]. [Cited 2023 Jan]. Available from: <https://www.gov.uk/apply-genderrecognition-certificate>

²⁰ Stonewall. The truth about trans [Online]. [Cited 2023 Jan]. Available from: <https://www.stonewall.org.uk/the-truth-abouttrans#trans-daily-life>

²¹ Bristowe K, Hodson M, Wee B, Almack K, Johnson K, Daveson BA, Koffman J, McEnhill L, Harding R. Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. *Palliat Med*. 2018 Jan;32(1):23-35. doi: 10.1177/0269216317705102.

“If I needed care I would approach services and see how the treatment was, if I felt it was bad because of being queer and gender diverse then I would likely disengage but would be unlikely to make the reasons known.” – Community survey respondent

“You don’t know what environment you’re coming into, especially when intersecting with older patients” – Pip Blaylock, on her experience of receiving end of life care as a trans woman.

Addressing these barriers

Policies

In the professionals survey, some respondents raised concerns about discriminatory views or language within their workplace. This is of serious concern and must be addressed before attempting to break down barriers and encourage trans and gender diverse people and their loved ones to access services.

“I think the Hospice as a whole is trying to support a more inclusive approach however I have heard negative or discriminative language from staff on the floor and this isn’t always challenged and it doesn’t feel like we are supported to challenge this either.” – Professionals Survey Respondent

Dr Ellie Kane, Consultant in Palliative Medicine, spoke about her experiences as a trans woman working in end of life care, and, while the majority of her experience has been positive, she expressed that she has experienced people making ‘quite exclusionary statements, basically calling trans people unwell or perverted in some way’.

There is a need to address this through training and creating workplace policy and organisational culture that does not allow room for transphobia. NHS and independent palliative and end of life care providers must have a specific policy which is clear on what is expected of staff and volunteers regarding equality, equity and inclusion for trans and gender diverse people and on what is considered harassment and discrimination. This should include behavior such as repeated misgendering or using the wrong name (also known as dead-naming), to allow the organisation to point to what is discriminatory behaviour and act accordingly.

Once an effective policy has been created, a big step towards supporting trans and gender diverse communities to access services is to have a visible statement of inclusion to show commitment to the policy. This should be specific, listing communities by name, but does not have to focus on only trans and gender diverse communities. This allows people to see that the care provider has considered their needs, and allows them to have something to hold the provider accountable to, should anything occur. Dr Ellie Kane explained that a visible inclusion statement ‘relieves a lot of the disclosure anxiety and anticipatory discrimination’ felt when attempting to access services as a trans person. Following an extensive national qualitative interview study, ACCESSCare also recommends providers ‘make clear statement of policies and procedures related to discrimination’.¹⁹

“Standards by which the organisation can be held to being openly presented to service users, for example as a commitment, promise or pledge, allows the service user to evaluate the care

they are receiving and report if they feel that these standards are not being met. It's about accountability to our commitments.” – Stewart O’Callaghan, Live Through This

Hospices in particular often speak of being ‘open to all’ and aim to provide individualised person-centred care to everyone who uses their services. For trans and gender diverse people, many of whom have experienced discrimination, and face the barriers discussed above, they cannot assume that ‘open to all’ truly applies to them. It is vitally important to proactively take additional steps to make your services safe and inclusive for trans and gender diverse people, and then take responsibility for communicating this with those communities.

“If you asked most people at a hospice, do we care for people regardless of their background, I think most people would say yes, but the truth is as a trans person I don’t have the luxury of assuming that...Rather than expecting trans people to assume we’re ‘safe’ we need to make it explicit that we are by making it really clear that they’re welcome and we want them there and they’ll be treated as they are with respect and dignity” – Dr Ellie Kane

Other research has highlighted the importance of reaching out to local organisations and communities to work in partnership to improve access and inclusion.¹⁹ Hospices have begun to explore new ways to connect with local LGBTQ+ communities and show their service is LGBTQ+ inclusive. For example, Ellenor hospice, appointed an ED & I Consultant, who has worked to form connections and partnerships with local communities and find out how their care can be more accessible to them. The team have also recorded podcasts with LGBTQ+ staff members and members of the community speaking about their perspectives on end of life care and the services they offer.

Feedback processes

It is also important to make sure feedback processes are inclusive for trans and gender diverse people. Whether these are feedback processes involving the individual following a specific procedure or treatment, or feedback from those closest to an end of life care patient after their death. Palliative and end of life care services need to know where their care has fallen short of expected standards or not made a trans individual feel welcome or supported, so that they can address these issues. Equally, it is also important that services know when they get it right.

“It’s so important to give people time and space to feed back about their experiences. When you’re anxious or worried, or if you’ve experienced microaggressions or transphobia it can be difficult to express that by filling out a form in the place where it happened. People need to feel safe that their feedback won’t impact their care, and to be given enough time to process what they’ve been through” – Ash Hayhurst, GIREs

Once services have educated staff and created a foundation, trans people with lived experience and their loved ones have also expressed the value of services highlighting the work they have done, and supporting trans people to share their experiences. Sharing the stories of trans and gender diverse people can be a powerful way to signal that a service is inclusive, and empower other trans and gender diverse people to access support.

“Hospices and care homes should advertise and provide testimonies from previous clients if they have cared for trans people before. This would make the process of choosing somewhere for your loved one to be cared for much less stressful.” – Rebecca Blaylock

Recommendations:

The UK government should reform the Gender Recognition Act to de-medicalise the process and extend legal recognition to non-binary people.²²

Palliative and end of life care providers should develop clear workplace policies on protecting patients, visitors, staff and volunteers who are trans or gender diverse. This must include how discrimination will be handled and how a staff member or volunteer who begins their transition while employed by the provider will be supported.

All palliative and end of life care services should ensure experience of care feedback opportunities are inclusive of trans and gender diverse people and provide space to reflect on care that related to their gender and identity.

After receiving training and developing comprehensive policy, palliative and end of life care providers should take steps to actively promote that they are a trans inclusive service provider. Health and social care regulators should consider how well a service meets the needs of trans and gender diverse communities in their assessments of services.

National movements, such as Dying Matters, should platform trans and gender diverse communities experiences of death, dying and grief.

Tips

Display a visible commitment to inclusion in your service to empower people to hold services to account.

Support trans and gender diverse people accessing your services to share their stories in the way they would like, if this is something they want.

Connect with local trans and LGBTQ+ organisations and community groups.

Retaining identity and dignity

'It's more important for them to understand who I am, what I am, than probably what [illness] I've got.' – Pip Blaylock, on her experience of receiving end of life care as a trans woman.

The need to be supported and able to retain your identity and dignity, and present yourself in a way that reflects who you are, was a common theme raised by trans and gender diverse communities. A central part of this is gender affirmation, referring to ways in which someone receives support and recognition of their gender identity and expression.²³ In the community

²² Stonewall. What does the UK Government announcement on the Gender Recognition Act mean? [Online]. [Cited 2023 Jan]. Available from: [https:// www.stonewall.org.uk/what-does-uk-government-announcement-genderrecognition-act-mean](https://www.stonewall.org.uk/what-does-uk-government-announcement-genderrecognition-act-mean)

²³ Sevelius J. Gender Affirmation: A Framework for Conceptualizing Risk behaviour among Transgender Women of Color. *Sex Roles*. 2013. 68(11-12):675-689. doi: 10.1007/s11199-012-0216-5.

survey, we asked about various aspects of identity and gender affirmation that would be important in a healthcare setting and received mixed responses on whether these were being fulfilled.

Names, pronouns and titles

One key area of concern related to gender affirmation raised by members of trans and gender diverse communities in the survey and in conversation with us was the use of their name and pronouns.

Those who filled out the surveys who had not accessed care themselves but were thinking about the care they might receive in the future expressed serious concern over whether their name, pronouns and identity would be respected by those providing their care.

“I dread being misgendered and not treated as my legal status.” – Community survey respondent

Several individuals responding to the survey on behalf of a trans loved one expressed that their loved ones correct name and pronouns were only partly used by those providing their care, or were not used at all. From the accounts we received, it appears to be more common that the correct name will be used by health care providers, but the use of correct pronouns was less consistent.

Pip and her daughter Rebecca shared that while Pip was receiving end of life care across a range of settings and services in 2021, she was regularly misgendered.

She was referred to as ‘Sir’ and ‘Mr Pippa’ at times and despite originally receiving prescriptions addressed to ‘Ms Pippa’ these quickly switched back to ‘Mr’ with no explanation. Rebecca and Pip tried to chase this but did not see any positive change. This was upsetting both for Pip and the people around her, and caused unnecessary distress and challenges for them at such a vulnerable time. This should not be something that people at the end of their lives, and those close to them, have to manage.

“Dad [Pip] is constantly misgendered, and has almost given up trying to correct them.” – Rebecca Blaylock

Rebecca expressed that sometimes misgendering simply resulted from confusion and could be avoided if providers had inclusive conversations with people on how they would like to be referred to, and how they refer to each other.

“If I say dad, then sometimes people revert to ‘he’, because then they get confused, actually all they need to do is ask ‘so what do you call each other?’” – Rebecca Blaylock

Rebecca expressed that sometimes misgendering simply resulted from confusion and could be avoided if providers had inclusive conversations with people on how they would like to be referred to, and how they refer to each other.

Professionals in palliative and end of life care also reflected on the prevalence of misgendering. Dr Ellie Kane expressed that she has been ‘regularly’ misgendered in the workplace, and how tiring this can be. She did, however, stress that while this should not happen, often this is done without any malice or bad intent, and there are ways to address this internally by promoting learning and moving forward positively. Having an organisational culture that allows staff to privately ask questions in good faith, and supports them to learn, is key to developing an inclusive environment.

“It’s really important that if people hear people accidentally misgendering that they call it out so that it’s not always the person having to say ‘actually you misgendered me’, other people call them out on it, because that’s tiring.” – Dr Ellie Kane

This must be balanced with policies that make it clear that when someone crosses a line, repeatedly or intentionally misgendering someone, this must be taken seriously, recognised as discrimination and addressed as such. Ellie also stressed that when it comes to a vulnerable patient, it is even more vital to make sure to address them correctly.

Professionals working in palliative and end of life care who completed the survey expressed that there were mixed levels of understanding around sharing pronouns within their organisations. Some expressed that they would only ask for someone’s pronouns or preferred name if they were “highlighted as LGBTQ+” or if they “knew or thought someone may be trans”.

Professionals also made us aware of systemic problems that were resulting in people being misgendered.

“We use NHS records where gender is presented as a binary option and we are unable to change this.” – Professionals Survey Respondent

It is important that trans and gender diverse people, including non-binary people, are able to have their gender identity recorded accurately and consistently when accessing services. Monitoring data on gender identity allows health and social care providers to understand the communities that are accessing their services and allows the sector as a whole to better understand health inequalities and recognise where they need to be addressed.²⁴

“Trans and gender diverse people deserve to be recognised in all stages of life, dying, death and bereavement. Sometimes a person’s circumstances mean it’s not possible for them to change their name or update their NHS records, and many people don’t appreciate just how time-consuming it is. You have to update your bank, library, dentist, healthcare provider, utility companies, landlord... the list is extensive. If someone is vulnerable or receiving end-of-life care this can seem like an impossible task and it’s not made easier when some companies don’t have clear policies in place. All healthcare providers should offer to record an alternative name on their system and make clear to staff which name to use, so that everyone can be treated with respect and dignity.” – Ash Hayhurst, GIRE

²⁴ LGBT Foundation. If we’re not counted we don’t count: Good practice guide to monitoring sexual orientation and trans status 2021 [Online]. 2021 [Cited 2023 Jan]. Available from: <https://lgbt.foundation/monitoring>

For many of those who shared their perspectives with us, it was important to be able to talk about their gender identity and be understood to ensure they receive gender appropriate and trans appropriate care, and so they can be fully who they are. It is important to recognise that some trans people may not wish to disclose this information, or disclose this only to specific people. Health and social care providers must respect this, and be provided with training and information to understand the legal requirements to keep knowledge of a person's trans status private if they have a Gender Recognition Certificate.

"I would want to die in a place where I felt comfortable, with the people who I felt comfortable being around. I would need them to know I was trans, and know that they would respect my body and wishes." - Community survey respondent

It is important that, wherever possible, people are able to describe their gender in their own terms, and that care providers follow the individual's lead on what language they identify with. Stewart O'Callaghan, CEO of Live Through This, highlighted that it is particularly important in end of life care to remember that "different generations will have different ways in which they refer to themselves" and different language that they may be comfortable with due to their experiences.

Recommendations:

All NHS and hospice IT and patient information systems should be updated, following consultation with trans and gender diverse communities, to ensure people's name, title, gender and trans status are captured and recorded accurately. This must be inclusive of non-binary and gender diverse identities.

Palliative and end of life care services should ensure that intake and referral forms capture an individual's preferred name and pronouns

Palliative and end of life care providers should make sure that staff and volunteers are appropriately trained on the Gender Recognition Act and Gender Recognition Certificates, particularly the legal requirement not to disclose protected information.

Relevant public health bodies should fund awareness campaigns to help trans and gender diverse people to have the confidence to disclose their gender status to palliative and end of life care providers.

Tips

Don't make assumptions about someone's gender or what their needs may be.

Use neutral language (they/them pronouns, 'partner') until you are sure of how someone identifies.

If you are comfortable, introduce yourself with your own pronouns and display them, for example in your email signature.

Clothing

A key way in which many people express their identity is through their clothing. Clothing is often a key aspect of gender expression and gender affirmation. At end of life, it is important that people have access to clothing that affirms their gender and helps them to feel comfortable and confident.

It was positive to find that the majority of trans and gender diverse people receiving end of life or palliative care who shared their experiences with us had their choice of clothing respected. Despite this, we were concerned to receive two examples in the community survey where the trans or gender diverse person receiving care did not have their choice of clothing respected.

Dr Ellie Kane also recalled the experiences of an elderly trans man under the care of a nursing home. This man had come out later in life, and then was diagnosed with a condition that meant he was unable to medically transition. When he was taken into the nursing home after developing dementia, despite the home being told that he was, and that he lived as, a trans man, they viewed him as a woman and so dressed him in feminine clothing and misgendered him regularly.

‘Whilst he, because of his illness, wasn’t necessarily particularly aware that that was being done, actually it makes it even more important that we respect the dignity of people when they are not able to advocate for themselves.’ – Dr Ellie Kane

It is vital that regardless of an individual’s current condition and ability to advocate for themselves, care providers maintain the each person’s identity and dignity and ensure that they use what they know about them as an individual to make sure that they are dressed, or supported to dress, in a way which is true to them.

Tips

Don’t make assumptions regarding what clothing someone may be comfortable in, and where there are gendered options, ask the person what they would prefer.

Accessing transition related healthcare

“Transition isn’t just a tick box, ‘right I’m done, I’m there’.” – Rebecca Blaylock.

Palliative and end of life care is very individual and will look different for everyone. For some trans people at end of life, being able to continue their transition and access transition related healthcare will be very important. Previous research has also highlighted the importance of continuing conversations about medical transition at end of life.¹⁹

“Transitioning isn’t just about having surgery. Hormone replacement therapy, voice therapy, hair removal and access to information about gender-affirming items for packing, padding, binding or tucking can be hugely important in affirming someone’s gender. Trans and gender diverse people should be able to have conversations about transition related care, with appropriate signposting, while receiving end-of-life or palliative care.” – Ash Hayhurst, GIRE

For Pip, continuing with her transition, despite her diagnosis, was very important. It was a priority that appointments and conversations about her potential medical transition continued at

end of life, and her doctors and family supported her in this. Surgery was still being considered in her final months so that she could be buried in a body that felt 'right'.

In the survey, it was revealed that several trans and gender diverse people did not have full access to transition related healthcare. Furthermore, two responses to the survey revealed circumstances where individuals were not able to feel in control of their hormone replacement therapy when in palliative or end of life care, and multiple who only felt partly in control of this.

Palliative and end of life care providers are not expected to be experts on transition related healthcare, however, being aware that this is something a trans person receiving end of life care may be interested in, and supporting them where possible to access this, is important.

It is also important to recognise that, while end of life treatment and pathways may have to move quickly, transition related healthcare often moves very slowly. Therefore, a patient can feel stuck between services and may find that their treatment for their terminal or life-limiting diagnosis will take precedence over '*potentially life-saving transition related care*'.²⁵

"That position that some trans people will be in where there is a point of medical care that might interact with or override their transition can be incredibly difficult on that individual." – Stewart O'Callaghan, Live Through This

Someone who has already begun their medical transition, or transitioned a long time ago, may still need support with transition related healthcare, such as continuing hormone therapy at end of life. A patient may no longer be able to take them orally and so may need to transfer to using a patch method.

Recommendations:

Palliative and end of life care providers should ensure that trans and gender diverse people with a terminal diagnosis are signposted to high quality and accessible information and support on accessing transition support.

Gender Identity Clinics should support trans and gender diverse people with a terminal or life-limiting diagnosis to continue conversations about their transition and ensure that a terminal diagnosis is not, in itself, a barrier to medical or surgical transition.

Guidance produced by professional bodies on advance care planning should be updated to include consideration of gender affirmation and continuing transition at end of life.

Gender affirming personal care

Gender affirming personal care is personal care that helps someone to affirm and present as their lived gender - examples include shaving and haircuts. Individuals who shared their experiences of end of life care in the survey had mixed reflections on their access to gender affirming care. Several did not receive full access to gender affirming personal care while receiving end of life care.

²⁵ Quote from Stewart O'Callaghan, Live Through This.

“Sometimes parts of our gender expression, like clothing, hair, or make-up, that might affirm our identity are taken away from us when we become seriously unwell, for example through inpatient cancer treatment. So, when that patient enters hospice care, we must still take the time to understand and accept them as who they are without making assumptions.” – Stewart O’Callaghan, Live Through This

For Pip, personal care and presentation was very important, particularly when undergoing treatment and end of life care. This, however, was not always handled sensitively or appropriately by health and care staff.

“One of the most important [things] for a trans person is how you look – how you present...if you end up in the hospital with a beard and try to present as trans male to female, that’s difficult”

Rebecca, Pip’s daughter, recalls an upsetting incident when a GP stood over Pip’s bed and said to her ‘a lady like you shouldn’t have facial hair like that’. Furthermore, Pip was often not afforded privacy to complete gender affirming personal care. Pip spoke of people coming in and out of her room throughout the day, and when she would tell them she was shaving, they would respond ‘it doesn’t matter, I don’t mind’.

“That’s the wrong answer, it matters to me, not you” – Pip Blaylock

End of life care and treatments a person may be under can impact gender presentation and personal care, for example treatments resulting in hair loss or weight gain. Pip found it particularly difficult seeing the effects the steroid treatments she was on had on her body and appearance. Gender presentation is particularly important for trans and gender diverse people, and these physical changes were difficult to manage. One thing that Pip found to be helpful, was an album her friends had made for her, with pictures of her before she became ill.

“That made such a difference...this is Pip, that’s what Pip looked like” – Pip Blaylock

Tips

Discuss with a patient what personal care and presentation tasks they would like continued if they are not able to continue these themselves

Recommendations

Providers should be encouraged to implement a ‘this is me’ document, which can be held by the individual or implemented into digital shared care records, that includes information important to the individual, such as information about their gender, presentation and transition related medical needs.

Physical care

Differences in medical care

Professionals in end of life care, individuals receiving care and those thinking about care in the future raised concerns regarding the physical and clinical care trans people receive at end of life.

‘When we talk about people going through hospice or end of life care, much like in my work when we think about people with cancer, they are in a position whereby they should be able to just focus on themselves, and the position of health that they are in, and that’s it. I think it’s wholly unfair for them to also, in that vulnerable position, be expected to take on the educator role just to try and receive a similar standard of care to cisgender peers, though some people may elect to take this on for the betterment of the community.’ – Stewart O’Callaghan, Live Through This

In answers to our survey, numerous palliative and end of life care professionals expressed concern over their lack of medical knowledge specific to trans and gender diverse people receiving end of life care, and awareness of how certain care may differ.

Some highlighted specific areas or procedures that caused them concern, these included;

- Anatomical differences following gender affirming surgery and how this may affect medical assessments and care including catheterisation.
- Knowing what medical treatment, including hormone supplements, will have to continue until the end of their life.
- How to score a person on an assessment when there are only binary male and female options.
- How a trans patient may be affected by hormonal anticancer treatments.

One professional expressed that they had to seek out their own information regarding catheterisation of people who have had gender affirmation surgery and worried that because of this others providing care would not be as prepared.

Similarly, Pip and Rebecca shared that, in their experience, prescribing did not seem to account for trans people. When Pip was first prescribed anti-seizure medication she experienced a lot of difficult side effects. An alternative medication was available that can have fewer side effects, but is not often prescribed to cis-women of reproductive age as it causes harm to fetuses. Rebecca feels if they had acknowledged that Pip was trans and accounted for this in prescribing, Pip would not have had to go through what she did.

Trans and gender diverse people have raised concerns over having to educate care providers on their medical care. Research by TransActual found that 45% of trans people said their GP did not have a good understanding of their needs as a trans person, rising to 55% for non-binary respondents.

“It is extremely common for trans people to feel that they need to educate healthcare providers about their needs. Given that trans inclusive practice is rarely included within the initial training curriculum, this is hardly surprising.” - Chay Brown, Director of Operations at TransActual

It is vital that palliative and end of life care providers are informed on how to provide high quality medical care to trans and gender diverse people at various stages of transition and to account for their specific needs and differences. Stewart O’Callaghan emphasised that it is also important to have good handover, to make sure that “lessons learned from that patient in the previous setting can be pulled into the new one, but always be sure you have consent before revealing any part of their identity in patient notes or referrals”.

Recommendations: Professional bodies and Royal Colleges should produce up to date guidance on providing medical and clinical care to trans and gender diverse people in palliative and end of life care

Personal care

Trans and gender diverse people who filled out our survey also expressed concerns around the personal care they would receive at the end of their life and whether being trans would affect this.

“I cared for my grandmother through to the end of her life, and worried about what kind of personal/hygiene care I would safely be able to access in my old age as a trans person.” – Community survey respondent

Rebecca shared that at times, Pip received poor personal care, or none at all, due to the care providers approach to her being trans.

“My Dad’s gender identity has impacted her care in many ways. When in hospital, she was not offered a shower for ten days and I am convinced this is because of her being trans.” – Rebecca Blaylock

This experience was deeply upsetting for Pip and her loved ones. It is unacceptable that someone may not receive the personal care they need at the end of their life due to their gender identity. This needs to be addressed throughout the health and care sector, acknowledging that everyone has an equal right to care.

“I want to retain my dignity in situations where I need intimate care or nursing, which means that the people giving care to me see me as a whole person and have a good professional understanding of why my body is the way it is and what I find OK or difficult in these situations” – Community survey respondent

Trans and gender diverse people should be empowered to have conversations with their care providers about their needs and boundaries so they can feel safe and comfortable with the care they receive. It is important that people are given a choice of staff members they trust, who they would prefer to perform personal care tasks.

Tips

Only ask about someone's gender or transition when it is necessary to the healthcare being provided.

Do not make assumptions about an individual's body.

Workforce and training

"A lot of people were willing to learn. The hospice said that my Dad's stay there was absolutely transformative to their service and staff, and that meant the world to us." – Rebecca Blaylock

This research highlighted real positives within the end of life care workforce that can be built upon to ensure trans and gender diverse people receive the best possible care at end of life. Pip and Rebecca spoke positively about the care they received at Butterfly Hospice and how the staff there made them feel welcome and understood, always seeking to learn and meet their needs. Another respondent to the survey also spoke of the high quality of care their partner received at the end of their life.

"They treated my dying partner and myself with dignity at all times." – Community survey respondent that witnessed the care of a trans or gender diverse person.

Dr Ellie Kane described the care of a trans person that entered the care of a local hospice. They had not had gender confirmation surgery and this was 'accepted fully' and did not interfere with her care in anyway. Importantly, while some had questions initially, these were asked in private, never in front of the patient, allowing them to move forward without issue. The individual was consistently treated as she wished to be, and as she was, as a woman.

As a member of the palliative and end of life care workforce, Ellie also emphasised how much of her experience as a trans woman in the sector has been positive.

"It has been lovely for me to discover that the vast majority of my colleagues are supportive...the overwhelming response has been one of care and support." – Dr Ellie Kane

Workplace policy

It is essential that when we think about making palliative and end of life care accessible and inclusive for trans communities, that we think about trans members of the workforce as well. Some organisations are already paving the way.

Dr Ellie Kane spoke about the importance of having a workplace policy to support and protect trans and gender diverse people. A good workplace policy should include how you support trans and gender diverse people at work, look after their needs and avoid discrimination. This includes knowing how to support a trans staff member or volunteer that is transitioning, including practical tasks like how to sensitively carry out a Disclosure and Barring Service (DBS), Criminal Record or Disclosure check for someone who has changed their name.

“A good workplace policy for trans staff is one that is co-produced with the trans community, one that makes our place in the organisation clear... we're welcome and equal to other people.” – Dr Ellie Kane

Training

Training and education is essential to empower the palliative and end of life care workforce to support trans communities. This is something that many individuals with lived experience and stakeholders called for throughout this research.

People with lived experience expressed that end of life care providers appeared to need more training on providing inclusive care for trans and gender diverse people. One respondent to the community survey who was accessing care felt their needs were only partly met, with any trans specific needs not being met. They expressed that they felt that people were ‘unprepared’ to care for them.

Another individual experiencing care themselves expressed that staff and volunteers lacked training on trans specific care.

This applies to care providers across the system, where people have found widely varying levels of knowledge and training. Rebecca, Pip's daughter, informed us of their negative experience of one care setting where the staff did not seem to have been trained on LGBTQ+ care. We also received insight from palliative and end of life care professionals who expressed concern over their own, or their colleagues', lack of training and how this could affect the care they deliver to a trans or gender diverse person.

This applies to care providers across the system, where people have found widely varying levels of knowledge and training. Rebecca, Pip's daughter, informed us of their negative experience of one care setting where the staff did not seem to have been trained on LGBTQ+ care.

“She is currently in a nursing home, and they are a lot less informed about gender identity - conflating it with sexuality, ‘cross dressing’.” – Rebecca Blaylock

We also received insight from palliative and end of life care professionals who expressed concern over their own, or their colleagues', lack of training and how this could affect the care they deliver to a trans or gender diverse person.

“I think there is a big gap in Colleague's knowledge in this area. Understanding different identities/antioppressive language etc. It is not malicious they just have no point of reference or background in it.” – Professionals survey respondent

Wider workforce pressures and challenges may affect a provider's ability to access training and provide individualised care. One respondent to the community survey expressed:

“As far as I can tell there is no difference with how social services and hospitals deal with trans gender individuals to anyone else - they are just understaffed and untrained overall - they do the best they can but are ill equipped for anyone that is not the ‘norm’.” – Community survey respondent who witnessed the care of a trans or gender diverse person close to them.

Despite these challenges, it is critical that care providers have the training they need to approach the care of a trans person with knowledge and understanding. The survey, and wider work with palliative and end of life care providers has revealed so much enthusiasm to undertake such training and to learn. Training must cover definitions of widely used terms, non-oppressive language, and understanding of the wider challenges faced by trans communities.

“Training is so important in making sure the needs of everyone are met when giving end-of-life and palliative care. When I deliver training with GIREs, people will tell me they’re worried about saying the wrong thing, or accidentally offending a trans person. I like to remind them that it all just comes down to compassion, asking open questions, and accepting people as they are. By the end of the session you can see the relief on some people’s faces when they realise it’s not as complicated as they thought it would be.” – Ash Hayhurst, GIREs

Several hospices have begun to develop their own solutions. Using a grant provided by Hospice UK’s partnership with the Masonic Charitable Foundation, Ellen Coleman was hired as LGBTQ+ Inclusion Officer across St Luke’s Cheshire Hospice, East Cheshire Hospice and Hospice of the Good Shepherd to increase accessibility to Cheshire hospices for LGBTQ+ people. A key part of this project has been offering LGBTQ+ awareness training to staff across the three hospices.

“During these sessions, colleagues have shared that they fear saying the wrong thing so much that they often think saying nothing might be a safer option. It is this professional anxiety that I strongly believe is one of our biggest barriers for the development of inclusive practice... Since starting the project, I have already observed staff using their initiative and implementing what they have learnt during organised training in their own work. Training isn’t just about teaching colleagues what specific words mean or how to ask for certain information, it’s also about making it clear why these conversations are so important.” – Ellen Coleman, LGBTQ+ Inclusion Officer

Keech Hospice Care have also developed training for staff working in palliative and end of life care. The objective of these sessions was to give people an understanding of LGBTQ+ communities and the additional concerns and needs they may have when diagnosed with a palliative illness. Responses to the training have been positive, with many expressing that they had not understood or appreciated the need to ensure services were LGBTQ+ inclusive before receiving the training.

Recommendations

Education providers and those who have responsibility for developing staff training curricula should ensure health and social care staff receive preregistration training on gender, including understanding what it means to be trans or gender diverse, and trans and gender diverse healthcare needs.

NHS elearning platforms should include a module specifically focused on the needs and experiences of trans and gender diverse people in end of life care.

Hospices should be supported to access training on gender and LGBTQ+ communities and to expand the delivery of training and good practice they have developed.

Methodology

The surveys

Hospice UK has been working in partnership with GIRES and Stonewall on the Being Ready project, which was set up to address the needs of trans and gender diverse people during all stages of dying, death and bereavement. GIRES is a UK charity promoting research and education on trans and gender diversity issues.

As part of this work, together with GIRES we produced two surveys. One was targeted at members of trans and gender diverse communities and the people close to them, to better understand their access to, and experiences of, end of life care. The other was aimed at professionals working in death, dying and bereavement, to understand their perspectives and their current knowledge base. These surveys ran from June to August 2022.

When producing these surveys, we were led by GIRES, and worked in collaboration with trans people and representatives of LGBTQ+ organisations to ensure the surveys spoke to what they felt was important and were accessible to these communities.

The first survey was aimed at trans and gender diverse people, and those close to them, and asked questions about the experiences of trans and gender diverse people who have accessed palliative and end of life services. This survey also asked about the experiences of intersex people, however we did not receive responses on this and therefore have not been able to represent them in the report. This survey also asked questions of trans and gender diverse people who may not have accessed services themselves, about their perspectives on care they may need in the future and how comfortable they would feel accessing this.

The community survey received 80 authentic responses. This included answers from a range of age demographics, although lacking in responses from those aged 70+. Respondents also identified across a wide spectrum of sexualities. 49% of respondents indicated that they identify as disabled and/or neurodivergent. We received responses from a range of faiths. 52% of respondents identified as atheist or agnostic, and 21% (the single largest religion reported) identified as Christian. The overwhelming majority of respondents, 89%, were white.

Intersectionality can play a significant role in the experiences of trans and gender diverse people accessing healthcare, and so it is important to note that the results may not accurately represent the experiences of non-white trans people, and those with non-Christian faiths or spiritual beliefs.

It is important to note that when analysing the community survey results, we found a significant number of fake answers completed by people attempting to disrupt the responses by sharing discriminatory views against trans and gender diverse people. This is a stark reminder of the hostility trans communities face and demonstrates just how vital it is to work in this space.

The second survey was aimed at professionals working in fields related to death, dying and bereavement, assessing their knowledge base and how they could be supported to address the barriers trans communities face. This survey received 158 authentic responses.

These surveys were vital to providing us with a good understanding of the experiences and concerns of trans and gender diverse people and ensuring our work reflects this. The two surveys together allowed us to form recommendations to end of life care providers and decision makers that address the concerns of trans and gender diverse people.

Conclusion

This report was informed by the experiences of trans and gender diverse people, including those receiving palliative or end of life care or affected by it and those who are considering a future where they may need to access these services.

This research found that trans and gender diverse people report a variety of negative experiences in end of life care. Trans and gender diverse people at end of life have been misgendered, faced insensitive and inappropriate comments and have at times not had their identity and expression respected and supported.

The wider trans and gender diverse community expressed concern over accessing palliative and end of life care. Lack of professional understanding of trans people's needs, discrimination throughout society and concerns over advocating for yourself when in this vulnerable position have led many to be fearful of accessing end of life care and unsure whether they would be cared for appropriately.

Palliative and end of life care professionals too have expressed concerns over a lack of knowledge within their workplace and even hostility towards trans and gender diverse people. It is unacceptable that trans and gender diverse people do not have the same access to high quality palliative and end of life care as cisgender people, where their needs are understood and addressed.

This report also highlighted that there are ways we can address this, and things we need to do to make sure palliative and end of life care is truly accessible to all. The professional's survey and our conversations with hospices shone a light on the passion across end of life care to improve the experiences of LGBTQ+ communities, and providers are already developing projects to address these inequities.

The wider health and social care system, and individuals working in palliative and end of life care, must take action. The recommendations in this report demonstrate key steps to providing equitable access and experiences for trans and gender diverse people at end of life, and taking action against discrimination in these spaces.

Resources

Marie Curie – Getting care and planning for the future: Information for LGBTQ+ people and those close to them.²⁶

Live Through This - Provider Pack: Breaking down barriers to LGBTQ+ inclusive cancer care.²⁷

Stonewall – List of LGBTQ+ Terms.²

NHS England - The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people.¹⁴

British Medical Journal - I am your trans patient - EmmaBen Lewis, Ben Vincent, Alex Brett and Sarah Gibson.²⁸

LGBT Foundation - If we're not counted we don't count: Good practice guide to monitoring sexual orientation and trans status 2021.²²

²⁶ Marie Curie; 2022. [Cited 2023 Jan]. Available from: <https://www.mariecurie.org.uk/help/support/publications/all/lgbtq-booklet>

²⁷ Live Through This. Provider Pack: Breaking down barriers to LGBTQ+ inclusive cancer care. Live Through This; 2021. [Cited 2023 Jan]. Available from: <https://livethroughthis.co.uk/wp-content/uploads/2022/07/Provider-Pack-MasterDoc-v1.1.pdf>

²⁸ Lewis EB, Vincent B, Brett A, Gibson S, Walsh R J. I am your trans patient. BMJ. 2017; Jun 30; 357:j2963. doi: 10.1136/bmj.j2963.