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I. Overview

Patients who are lesbian, gay, bisexual, transgender, queer, and other sexual and gender minorities (LGBTQ+) may require special care when they are experiencing serious illness and the end of life. Minority patients might have psychological and physical needs which may not be fully met without an interdisciplinary team that is trained to help them.

Hospice organizations are ideally suited to provide exceptional care for LGBTQ+ people – from specialized doctors and nurses to social workers and spiritual care providers, hospices care for the whole person. To learn how your hospice can better reach and serve LGBTQ+ communities, consider the resources and advice offered in this guide.

To treat LGBTQ+ patients respectfully and competently, it is important to understand and correctly use terms related to gender identity, expression, and sexual orientation. Please refer to the glossary to find a list of commonly used terms. For a regularly updated glossary, consult the Human Rights Campaign.\(^1\) Remember, though, that respect involves honoring individuals’ identities as they present them, and using individuals’ pronouns as instructed. These glossaries do not include all terms and identities individuals may use.

Throughout this guide, we will use the more inclusive term LGBTQ+ to refer to sexual and gender minorities, unless cited resources and research refer specifically to a subset of these communities. For some, adding the ‘Q’ to the term ‘LGBT+’ is hurtful, or conjures up painful feelings that represent an insult based on their own personal history with the word ‘queer.’ Others see ‘queer’ as an umbrella term, encompassing any identity that isn’t straight and cisgender. For purposes of this outreach guide, NHPCO is using the term LGBTQ+ to be inclusive of those who, for personal or political reasons, do not feel represented by lesbian, gay, bisexual, or transgender identifiers.

II. Healthcare Disparities

Snapshot of LGBTQ+ Health

LGBTQ+ people come from all communities, races, and backgrounds and frequently suffer from nearly all socioeconomic detriments of health at rates higher than heterosexual cis-gendered people. Unlike many minority communities, LGBTQ+ people are often invisible in their minority status. This leaves LGBTQ+ people particularly vulnerable to mistreatment, marginalization, and neglect.

LGBTQ+ people are also less likely than their straight peers to have the built-in support of adult children. In the 20 states (and DC) which have the highest proportion of LGBT citizens, 35% or less of LGBT adults are raising children.\(^2\) It is likely that LGBT people facing serious illness and the end of life may not have the same extended family support non-LGBT patients may have.

To learn more about the demographic make-up of LGBTQ+ people in your state and examine how this data responds to racial and gender distinctions, visit the Williams Institute, a research institution focused on sexual orientation and gender policy at UCLA.

Even without considering race and other critical factors, there are differences in access among lesbian, gay, bisexual people, and transgender people. The Center for American Progress illustrates these differences on the following page.

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Health disparities among the LGBTQ+ community may be explained by minority stress. Minority stress is chronic, and based on factors outside of the control of the individual, including social structures and prejudice. Sexual and/or gender minorities are not inherently less likely to have access to health care or be healthy. Rather, it is factors such as discrimination that cause these disparities.

LGBTQ+ communities contain members of all socioeconomic, racial, ethnic, and religious groups; as a result, LGBTQ+ communities themselves are not unified. Because LGBTQ+ people are every race, gender, age, and religion, the health care disparities which occur within society more broadly—racial, ethnic, socioeconomic—also occur within LGBTQ+ communities. It is important, as always, not to overgeneralize. The advice and insight in this outreach guide may not apply to all LGBTQ+ people.

4 Ibid.
5 University of Rochester Center for Community Stress. (n.d.). What is Minority Stress? Retrieved from https://www.urccp.org/article.cfm?ArticleNumber=69

The Center for American Progress, 3,4
Intersectionality and Barriers to End-of-Life Care

In addition to faring more poorly than straight cisgender patients in many ways, there are also disparities in health care access, and discrimination, within LGBTQ+ communities.

Minority stress can be exacerbated for LGBTQ+ people of color, who face discrimination and microaggressions associated with both heterosexism and racism. The threat of violence is also increased for LGBTQ+ people of color. For example, research from the Human Rights Campaign shows that in 2020, 66% of victims of fatal violence against transgender and gender non-conforming individuals were Black and Latinx transgender women.6

A meta-analysis of end-of-life care disparities for LGBT people in the context of the United Kingdom, conducted within Hiding who I am – the reality of end-of-life care for LGBT people, finds disturbing trends in LGBT end-of-life care. LGBT people were most at risk of being discriminated against in access to quality palliative care and other end-of-life care,7 and LGBT patients felt that they might experience discrimination and that end-of-life care is not open to them.8

Marie Curie, a palliative care research organization in the UK, goes on to identify six key problems LGBTQ+ people face with regards to end-of-life care:9

1. “Anticipating discrimination” – Because LGBTQ+ people anticipate that they will face discrimination, they access palliative care later or avoid it entirely. Sixty percent of older gay people believe that care services will not be able to meet their needs.

2. “Complexities of religion and LGBT end-of-life care” – End-of-life and palliative care providers may not meet the spiritual needs of LGBTQ+ families to the same extent they address these issues for heterosexual and cisgender families.

3. “Assumptions about identity and family structure” – Some clinicians may discriminate against LGBTQ+ people in end-of-life care and make assumptions about patients’ identity and family structure.

4. “Varied support networks” – Kinship networks are varied, and LGBTQ+ patients may more often rely on chosen family than biological family at the end of life. Furthermore, they may fear that partners may not be respected as next of kin.

5. “Unsupported grief and bereavement” – While communities are offered many templates of how to support bereaved straight surviving spouses after the death of a partner, LGBTQ+ survivors may feel isolated in their grief.

6. “Increased pressure on LGBT care[givers]” – Because evidence shows that LGBT people are more likely to receive palliative care support late in the trajectory of an illness, or not receive that aid at all, there is additional burden on LGBTQ+ caregivers, who may not benefit from all the resources available to others when providing care for a loved one.

III. Serving LGBTQ+ Patients In Your Community

Know Your Patients’ Needs and Rights

LGBTQ+ patients may come into your care with more and different needs that other populations.

One study, “End-of-Life Care Perceptions and Preparations of Lesbian, Gay, Bisexual, and Transgender Older Adults,” found some themes among LGBT elders and commonalities in their desires around end-of-life care. This study found that LGBT

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8 Ibid.
9 Ibid. p. 17.
seniors value support for the chosen family and being able to be out at the end of life. Meanwhile, like many seniors, they are concerned about being a burden to others, and the cost of care.10

Some LGBTQ+ older adults are particularly concerned about participating in institutionalized care and are wary of religious organizations. These fears may be based in prior experience with religious group and institutional settings which were not welcoming of LGBTQ+ people.11

Since LGBTQ+ caregivers are often not recognized legally, having advance directives and legal documents in place can keep caregivers, such as life partners and family of choice, from being left out of the medical decision-making process and end of life care choices. When these documents are not in place, state laws give decision-making authority to the next-of-kin and blood relatives and this could result in surviving LGBTQ+ partners or other family of choice members being unable to carry out end-of-life decisions, funeral, and burial wishes and even inheritance and asset allocation. Documents such as Advance Directives, Living Will, and Medical POA/Health Care Proxy may be found on state websites. State-specific advance directives are available to download for free from NHPCO’s CaringInfo.org. It may benefit LGBTQ+ caregivers to contact an attorney or seek legal help to make sure documents are done correctly since laws can vary from state-to-state. For more in-depth information and additional resources, look to the LGBT Aging Center.

Spiritual Care for LGBTQ+ Communities

It’s important to educate your spiritual care providers on LGBTQ+ issues, because while religion can be a source of comfort to LGBTQ+ people, some have had to separate from their religious communities because of bias against sexual and gender minorities.12

However, within nearly every religious denomination there are now supportive groups for LGBTQ+ people. Spiritual care providers should recognize that LGBTQ+ patients may have very different experiences and preferences regarding religion. Here are some guidelines on providing spiritual care for LGBTQ+ patients:

- Search for institutions of faith that already have a relationship with the LGBTQ+ community and see what programs and resources that they have to offer. Look to meet with members of that faith community to offer educational in-services. Discuss barriers that can be addressed as an agency and collaborate to overcome those issues.
- Never call in the patient’s spiritual care provider or clergy without their permission. The patient may or may not wish to have religious support at the end of life.
- For LGBTQ+ patients that do seek spiritual care, it is vital that your organization support this need with affirming spiritual care and other providers.
- Provide spiritual care without diving into specific religious language which may evoke early trauma in the LGBTQ+ person.
- Speak about the meaning of life using meta-language which connects to religion for many, but does not specifically recall religion. For some, connecting the patient’s life to religious stories may be comforting.
- Many religious texts can be affirming. Connecting those stories with the patient’s experience may be valuable for some patients.
- Plan for visits with LGBTQ+ patients by finding art, poetry, or other creative works which may speak to their story. Representation is important, so include art which is made by or includes LGBTQ+ people.
- Focus on building relationships. In your work, attempt to build a partnership with the patient, whose specific needs may vary. Focus on trust and follow the patient’s lead.
- Spiritual care providers should also feel comfortable referring patients to LGBTQ+-affirming providers. Your organization may consider keeping a list of LGBTQ+-affirming spiritual care providers and referring patients who may benefit from their support.

11 Ibid.
For more information and recommendations, visit the websites for Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders (SAGE) and the National Resource Center on LGBT Aging.¹³

Making Your Hospice LGBTQ+ Inclusive

Making your hospice LGBTQ+ inclusive should be central to your mission as health care providers. To do so, you have to take stock of your current resources, discover the needs of your community, plan, and get buy-in from your organization and the wider community. Here are some first steps that will help your hospice serve all your LGBTQ+ patients.¹⁴

A. Collect Data and Survey Community

- Gathering local demographic as well as your own organization’s current trends will bring awareness to what LGBTQ+ people in the community already know about hospice and palliative care needs. Surveys are one of the best ways to find the quantitative information that your organization may want to know. They can be written, face to face, or done by telephone.¹⁵
- Use public forums, focus groups, and listening sessions to learn qualitative information. These links provide detailed information about how to gather, utilize and understand the process of collecting data from your community and your organization if you need help to get started.¹⁶

B. Assess Your Organization’s Literature and Language¹⁷

- Are there photos of people on your organization’s website? What are the presumed sex, race, gender, economic status, and job roles pictured? The same goes for the images of family members and couples that are presently pictured. Is there any representation of same-sex couples or transgender patients or employees? These images are just some examples of what LGBTQ+ inclusive awareness would begin with.
- Is there a nondiscrimination statement or policy? The nondiscrimination statement should appear on the organization’s website and literature and should be easily accessible. This statement should also be posted throughout the public areas within an organization.
- All patient forms, such as intake and registration forms, should contain inclusive, gender-neutral language that allows for self-identification. Make it easy for patients to self-identify but be aware that some may choose not to do so.
- Use neutral and inclusive language in interviews, when talking with all patients, and add LGBTQ+–inclusive language to job notices. Interactions with patients that are sensitive and nonjudgmental will pave the way for more effective patient–provider communication and can make patients more comfortable with disclosing information relevant to their care. Ensure that the phrasing of questions does not assume heterosexuality.¹⁸
- Engage external LGBTQ+ community organizations in the development and review of existing educational programming to ensure that it is inclusive.

¹⁶ Ibid.
C. Plan of Action

**Develop a Plan**

- Plan outreach that is linked to your existing marketing strategies. Will the overall financial health of your organization be able to support additional expenses that will arise as you conduct your outreach and your census increases?
- Do you already have a staff member whose role could encompass this outreach? Can you afford to hire new staff? Based on data and feedback, when should your plan begin? Who will you work with to accomplish this? Which community partners? What will you do as an agency to accomplish this?
- Discuss short and long-term goals and expectations. How will you measure these goals and how will you accomplish this?
- Tap into existing networks, particularly the LGBTQ+ hospice outreach programs operating across the country.

**Train Your Team**

- It is important that health care providers be adequately trained to address LGBTQ+ health disparities. The American Psychological Association (APA) believes such training is necessary, and by training your staff to meet the needs of these communities, your hospice is doing your part. Make sure your hospice incorporates diversity training into your staff orientation or on-going in-services education, including by inviting guest speakers from local LGBTQ+ organizations and other experts in the field.
- Consider creating an Employee Resource Group, or subgroup within your Diversity, Equity, and Inclusion workgroup, to address LGBTQ+ issues and strengthen your providers’ knowledge base over time.
- Train all your staff, including administrative and clinical personnel.
- Use inclusive language when getting to know your patients. Instead of asking “Are you married?” ask who the biggest supporters are in their life and who they would want in the room with them. Instead of asking the patient to tell you about their family, ask them, “Who do you consider family?”
- Emphasize the following end-of-life care issues specific to LGBTQ+ communities: healthcare history, healthcare disparities, spiritual aspects of care, and sociological and cultural perspectives on death.
- Programs such as SAGECare and Fenway Institute LGBTQIA+ Health Education Center offer cultural humility training. There may also be other training programs serving your region.

IV. Strategies for Reaching Out to LGBTQ+ Communities

**Marketing, Outreach and Community Engagement**

The most successful outreach programs evolve over time and develop slowly. Think outside the box and consider new options for reaching LGBTQ+ communities. Above all, remember the historical issues, discrimination, and stigma surrounding the LGBTQ+ community, and be sensitive to these in your interactions.

**Select a Messenger**

If no one on your team is a point person on this issue, consider hiring a new employee, or adapting an existing staff member’s portfolio to act in this capacity. Think outside the box. It is possible a hospice volunteer or community member could fill this...
role? Consider if this person is:

- open-minded and creative?
- able to cultivate long-lasting relationships?
- comfortable with public speaking?
- able to engage with diverse groups of people?
- committed to the position?
- willing to work after hours and attend a variety of functions in the area?

**Build Partnerships**

1. The foundation for all outreach is relationships, built over time on deep trust and understanding. There are numerous groups, committees, organizations, and coalitions within your community geared specifically towards LGBTQ+ interests and needs. Consult the appendix to find additional national resources and advocacy organizations.

2. While you may be asked to attend a specific group meeting because of the relationships you build, also be proactive and join them. Contact their leadership first and ask whether they have any topics they would like you to address at one of their upcoming meetings. If they do not have something in mind, offer your own presentation ideas, but set aside a singular agenda of promoting your own hospice. Use these opportunities to get to know the members and to learn about their needs. Ask the LGBTQ+ community partner if they can list your hospice as a community partner and resource on their website and in their literature, and vice-versa.

**Educate, Support and Listen to Your Community**

Informing, caring for and genuinely hearing the needs of the LGBTQ+ community are essential elements in your outreach, and enrich the opportunity for positive community-building. Approach these relationships with an open mind. Demonstrate your support for LGBTQ+ family systems and caregivers, ask questions and listen, and focus on education. This is an opportunity to dispel those myths and demonstrate how your organization’s interdisciplinary, person-centered care can provide support to all people facing a serious or life limiting illness and their loved ones.

**V. Appendices**

**Terminology**

- **Ally:** “A term used to describe someone who is actively supportive of LGBTQ people. It encompasses straight and cisgender allies, as well as those within the LGBTQ community who support each other (e.g., a lesbian who is an ally to the bisexual community).”

- **Aromantic:** Someone who “experiences little or no romantic attraction to other people.”

- **Asexual:** “The lack of a sexual attraction or desire for other people.”

- **Biphobia:** “The fear and hatred of, or discomfort with, people who love and are sexually attracted to more than one gender.”

- **Bisexual:** “A person emotionally, romantically, or sexually attracted to more than one sex, gender, or gender identity though not necessarily simultaneously, in the same way or to the same degree. Sometimes used interchangeably with pansexual.”

- **Cisgender:** “A term used to describe a person whose gender identity and/or expression aligns with those typically associated with the sex assigned to them at birth.”

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26 Ibid.
28 Ibid. p. 5.
29 Ibid. p. 7.
• **Coming Out:** “The process in which a person first acknowledges, accepts and appreciates their sexual orientation or gender identity and begins to share that with others.”

• **Deadname:** “The name that a transgender person was given at birth and no longer uses upon transitioning”, or, as a verb “to speak of or address (someone) by their deadname” 32

• **Gay:** “A person who is emotionally, romantically, or sexually attracted to members of the same gender. Men, women and non-binary people may use this term to describe themselves.”

• **Gender Dysphoria:** “Clinically significant distress caused when a person’s assigned birth gender is not the same as the one with which they identify.”

• **Gender Fluid:** “A person who does not identify with a single fixed gender or has a fluid or unfixed gender identity.”

• **Gender Expression:** “External appearance of one’s gender identity, usually expressed through behavior, clothing, body characteristics or voice, and which may or may not conform to socially defined behaviors and characteristics typically associated with being either masculine or feminine.”

• **Gender Identity:** “One’s innermost concept of self as male, female, a blend of both or neither – how individuals perceive themselves and what they call themselves. One’s gender identity can be the same or different from their sex assigned at birth.”

• **Gender Nonconforming:** “A broad term referring to people who do not behave in a way that conforms to the traditional expectations of their gender, or whose gender expression does not fit neatly into a category. While many also identify as transgender, not all gender non-conforming people do.”

• **Gender Transition:** “A process some transgender people undergo to match their gender identity more closely with their outward appearance. This can include changing clothes, names, or pronouns to fit their gender identity. It may also include healthcare needs such as hormones or surgeries.”

• **Genderqueer:** “Genderqueer people typically reject notions of static categories of gender and embrace a fluidity of gender identity and often, though not always, sexual orientation. People who identify as “genderqueer” may see themselves as being both male and female, neither male nor female or as falling completely outside these categories.”

• **Homophobia:** “The fear and hatred of or discomfort with people who are attracted to members of the same sex.”

• **Intersex:** “Intersex people are born with a variety of differences in their sex traits and reproductive anatomy. There is a wide variety of difference among intersex variations, including differences in genitalia, chromosomes, gonads, internal sex organs, hormone production, hormone response, and/or secondary sex traits.”

• **LGBT:** An acronym for “lesbian, gay, bisexual, and/or transgender.”

• **LGBTQ+:** An acronym for Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, and other sexual and gender minorities.

• **Lesbian:** “A woman who is emotionally, romantically, or sexually attracted to other women. Women and non-binary people may use this term to describe themselves.”

• **Non-binary:** “An adjective describing a person who does not identify exclusively as a man or a woman. Non-binary people may identify as being both a man and a woman, somewhere in between, or as falling completely outside these categories. While many also identify as transgender, not all non-binary people do. Non-binary can also be used as an umbrella term encompassing identities such as agender, bigender, genderqueer or gender-fluid.”

• **Outing:** “Exposing someone’s lesbian, gay, bisexual transgender or gender non-binary identity to others without their permission. Outing someone can have serious repercussions on employment, economic stability, personal safety or religious or family situations.”

• **Pansexual:** “Describes someone who has the potential for emotional, romantic, or sexual attraction to people of any gender though not necessarily simultaneously, in the same way or to the same degree. Sometimes used interchangeably with bisexual.”

• **Queer:** “A term people often use to express a spectrum of identities and orientations that are counter to the mainstream. Queer is often used as a catch-all to include many people, including those who do not identify as exclusively straight and/or folks who have non-binary or gender expansive identities. This term was previously used as a slur but has been reclaimed by many parts of the LGBTQ movement.”

• **Questioning:** “A term used to describe people who are in the process of exploring their sexual orientation or gender identity.”

• **Sex Assigned at Birth:** “The sex (male or female) given to a child at birth, most often based on the child’s external anatomy.”

• **Sexual Orientation:** “An inherent or immutable enduring emotional, romantic or sexual attraction to other people. Note: an individual's sexual orientation is independent of their gender identity.”

• **Transgender:** “An umbrella term for people whose gender identity and/or expression is different from cultural expectations based on the sex they were assigned at birth. Being transgender does not imply any specific sexual orientation. Therefore, transgender people may identify as straight, gay, lesbian, bisexual, etc.”

### Notable LGBTQ+ Awareness Dates

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<thead>
<tr>
<th>Month</th>
<th>Date</th>
<th>Event</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>February</td>
<td>First Full Week After Valentine’s Day - Aromantic Spectrum Awareness Week</td>
<td>is meant to spread information and awareness about aromantic spectrum identities and the issues that are faced, as well as making more people aware of the existence of aromantic people while celebrating it.</td>
<td></td>
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<tr>
<td>March</td>
<td>March 31 - International Transgender Day of Visibility</td>
<td>celebrates transgender people and their contributions to society. It may also bring awareness about the discrimination transgender people face.</td>
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<tr>
<td>April</td>
<td>Second Friday in April – The Day of Silence</td>
<td>supports LGBTQ+ students facing bullying and harassment.</td>
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<tr>
<td>May</td>
<td>May 16 – National Honor our LGBT Elders Day</td>
<td>celebrates the valuable contributions of LGBT elders.</td>
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**May 17 - International Day Against Homophobia** aims to coordinate international events that raise awareness of LGBTQ+ rights violations and stimulate interest in LGBTQ+ rights work worldwide.

**May 22 - Harvey Milk Day** is a day to celebrate the trailblazers in LGBTQ+ movement and call attention to some of the challenges still facing the community as it ages, and to shine a light on the vulnerable position LGBTQ+ seniors sometimes find themselves in when they require care.

| June | Pride Month | is celebrated each June to commemorate the Stonewall Uprising. |

**June 27 - Stonewall Riots Anniversary** recognizes the Stonewall riots, which are sometimes referred to as the Stonewall uprising or rebellion, a catalytic event in the LGBTQ+ rights movement which occurred on June 27, 1969.

| September | Sept. 23 - Celebrate Bisexuality Day | recognizes and celebrate bisexual people, the bisexual community, and the history of bisexuality. |

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| October | **LGBT History Month** is a month-long celebration of LGBTQ+ history, especially with regards to LGBTQ+ civil rights.  
**Oct. 11 - National Coming Out Day** is an annual LGBTQ+ awareness day to support lesbian, gay, bisexual, and transgender people to “come out of the closet.”  
**Third Thursday of October** - Spirit Day is observed by wearing purple to honor LGBTQ+ people who have died by suicide, support LGBTQ+ youth, and stand against bullying. It is part of National Bullying Prevention Month.  
**Oct 20 - Oct 26 - Asexuality Awareness Week or Ace Week** is an annual event that celebrates asexual people, and campaigns for understanding and acceptance of people and identities on the asexual spectrum.  
**Oct. 26 - Intersex Awareness Day** is designed to highlight human rights issues faced by intersex people. |
| November | **November 8 - Intersex Day of Remembrance, or Intersex Solidarity Day**, highlights discrimination and other adverse circumstances faced by intersex people.  
**Nov. 20 - Transgender Day of Remembrance** offer a chance to honor transgender people who have died as a result of anti-transgender violence |
| December | **December 1 - World AIDS Day** raises awareness of HIV/AIDS worldwide and commemorates the lives of those who have died of AIDS. |

**National Resources and Advocacy Organizations:**
- **SAGE** (Advocacy and Services for LGBT Elders)
- **National Resource Center for LGBT Aging**
- **National Center for Transgender Equality**
- **National LGBTQ Task Force**
- **National Center for Lesbian Rights**
- **Human Rights Campaign**
- **GLMA** (previously Gay and Lesbian Medical Association)
- **CenterLink** (Community of LGBT Centers - Exists to support the development of strong, sustainable LGBT community centers and to build a unified center movement)
- **LGBT Health Link**

There are also likely LGBTQ+ community groups or centers in your town. Find a center near you with the directory from CenterLink.

**Reference List**


