



Your Community:
Connect. Learn. Share.

Bereavement in the LGBTQ Community

MyNHPCO Bereavement Community Chat

October 5, 2022

Presenter/Facilitator:

*Rev. Dr. Don Stouder, Volunteer and Bereavement Manager
Reliance Hospice, Palm Desert, California*

NHPCO Bereavement Steering Committee

MyNHPCO: Where do I find it, and what is it?

- Visit: <http://my.nhpc.org/home> and use your NHPCO email and password.
- A collaboration of 15 discipline-specific professional communities and issue-based communities.
- Interdisciplinary-focused
- MyNHPCO contains on-line resources, forums and networking will help you grow professionally, find new solutions, contribute to the field, and elevate the national profile of your program.

MyNHPCO



PROFESSIONAL
COMMUNITIES



DISCUSSION
POSTS



MONTHLY
CHATS



LIBRARY
ENTRIES



BLOG

Please contact us...



...if you have questions about membership,



...if you have topics you would like us to discuss,



...if you would like to become a community committee member, and



...stay connected at the Bereavement Professional MyNHPCO Community!



Land Acknowledgement

Housekeeping

- We call this hour a 'chat' for a reason
- Feel free to type in your questions in the chat feature on the side of your screen
- We want everyone to share their experiences
- We will offer suggestions but welcome everyone's participation and input
- You may introduce your self in the CHAT.
- Let's get started!

Some Credits

- Bella Care Hospice
- NHPCO LGBTQ+ Resource Guide
- Desert AIDS Project, Palm Springs
- Reliance Hospice, Palm Desert
- Desert Regional Medical Center
- University of California, San Diego

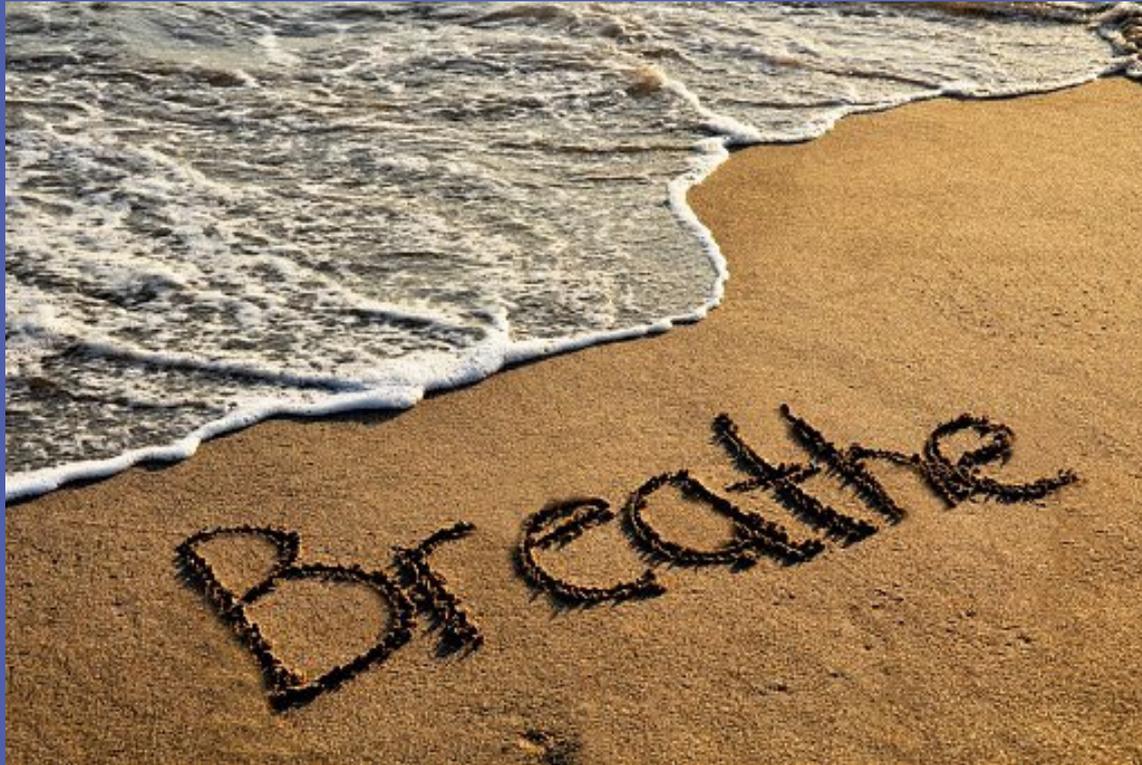


Learning Objectives

Deepen our empathy and sensitivity to the bereavement needs of the LGBTQ community.

Understand how the AIDS Pandemic informs contemporary grief responses.

Discover new ways of including the LGBTQ community in your grief and bereavement programming.





Grief is like the ocean;
it comes in waves,
ebbing and flowing.
Sometimes the water is calm,
and sometimes it is
overwhelming.
All we can do is learn to
swim.

Vicki Harrison

Canva



OCTOBER 11



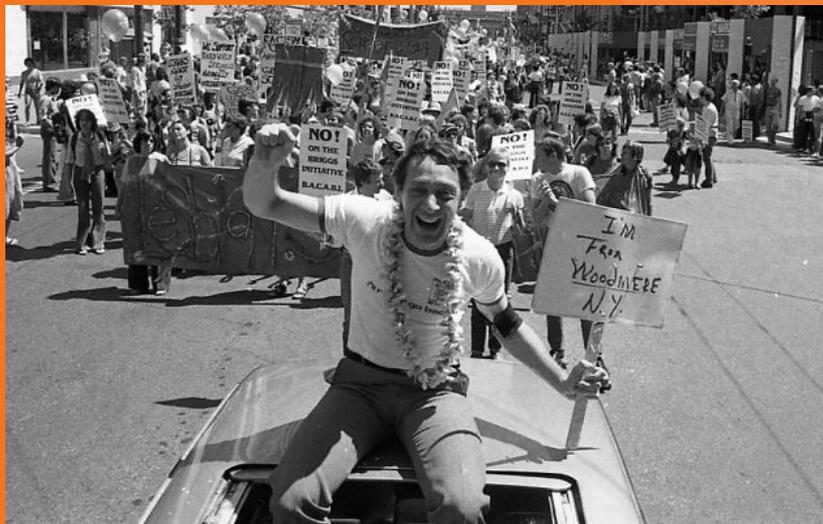
Turning Points

- Targeting by psychiatry.
- McCarthy era witch hunts.
- Random harassment and arrests.
- Religious oppression.
- Medical castration.
- Birth of gay liberation.
- Lesbian feminism, queer culture.
- The era of Gay Pride begins.



“As with all watersheds, these events’ impacts were filtered through such characteristics as gender, ethnicity, class, and [age at the time](#) of the event. For gay men and women born before 1930, whom [I interviewed in 1995](#) and who came of age in an era of political, medical, and scientific oppression, the emergence of [gay liberation](#) (which, sparked by the 1969 Stonewall and [similar uprisings](#), formed a new celebratory lesbian and gay culture based on the open expression of, and pride in, same-sex relationships) was the most significant event shaping their experience of gay life.”

Dr. Dana Rosenfeld



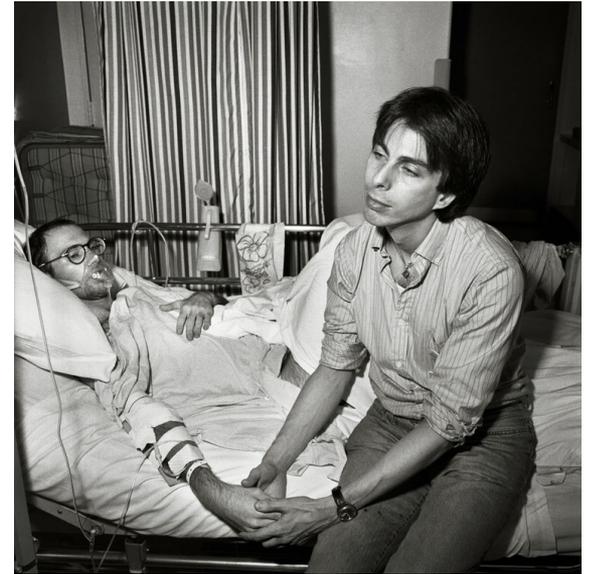
November 27, 1978







Photograph by Mark Peterson
© 1992 The NAMES Project AIDS Memorial Quilt



“While these older gay people were aged 50-70 in 1980, when HIV / AIDS emerged in the west, gay male [‘baby boomers’](#) (born 1946-1964) were aged 16-34. For them, the high number of AIDS deaths at the epidemic’s peak (1987-1996) shaped their personal, social, psychological, and community lives, during the epidemic, throughout their life course, and into later years. AIDS killed 324,029 men and women in the USA between 1987 and 1998 (death rates began to drop in 1995, with the introduction of effective anti-retroviral medications in 1996 fueling this decline). ”

Decimation of gay male baby boomers

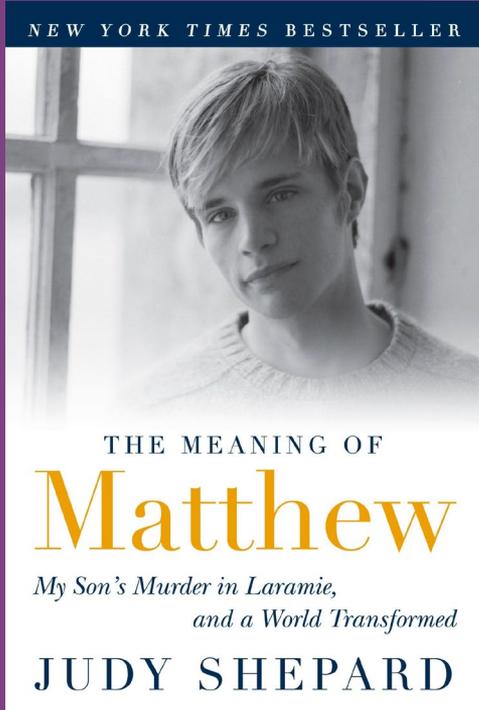
“As [I and colleagues](#) established, the epidemic hit male baby boomers much harder than it did older and younger men, causing high numbers of premature deaths, especially among those aged 25-44 (and, in this age group, among those aged 35-44), with gay men suffering ‘the most AIDS deaths by far at the epidemic’s height’. In the USA, by 1995, [one gay man in nine had been diagnosed with AIDS, one in fifteen had died, and 10% of the 1,600,000 men aged 25-44 who identified as gay had died](#) – a literal decimation of this cohort of gay men born 1951-1970.”



LOS ANGELES LGBT CENTER

NATIONAL COMING OUT DAY

October 11



October 6, 1998



June 24, 1973
UpStairs Lounge
32 dead.
15 injured.

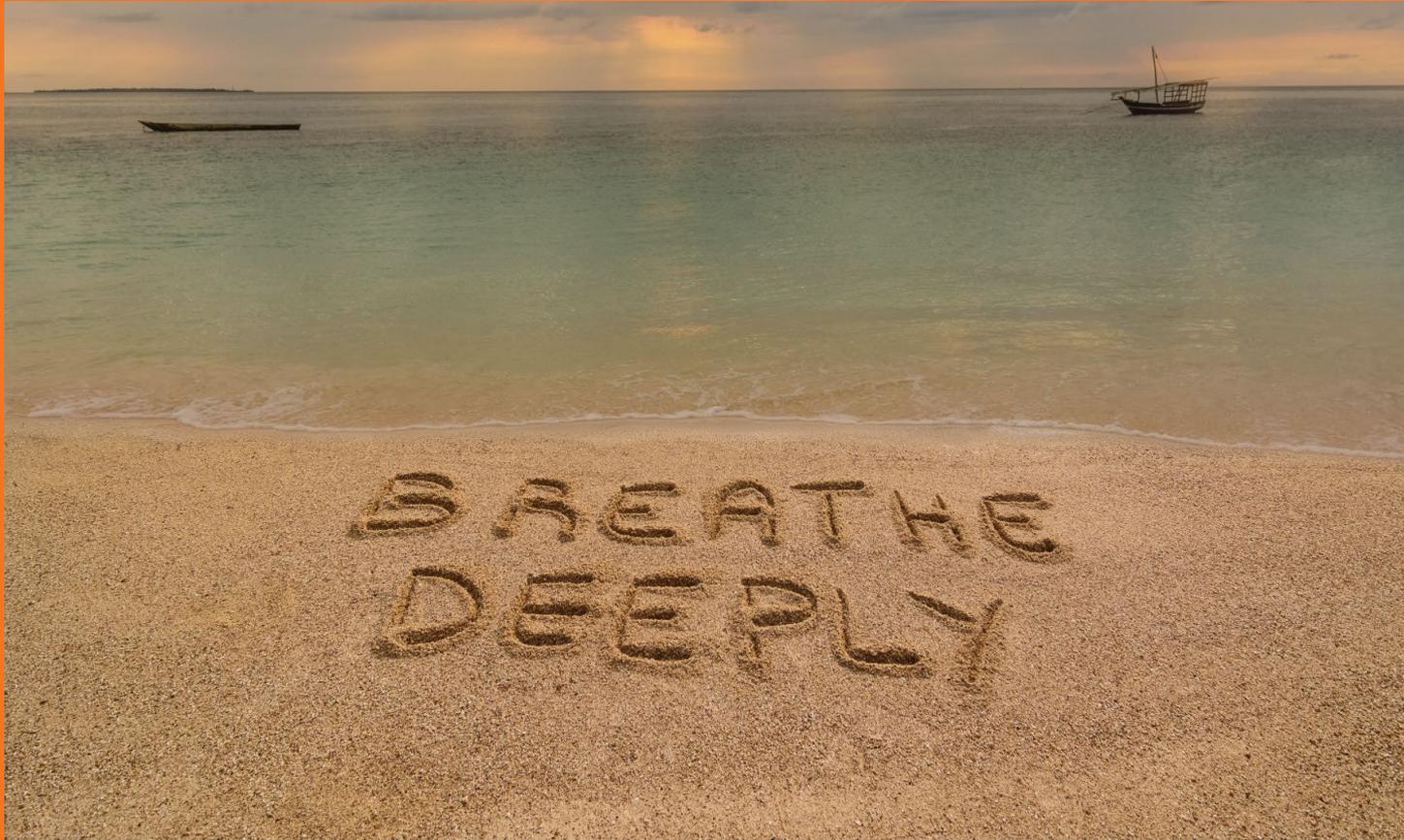
June 12, 2016
49 dead.
52 injured.





Bereavement Overload

Multiple ongoing individual and community losses that are coupled with complicating factors that lead to an unending source of grief. Bereavement overload may involve disclosure of gender identity to unsupportive family, friends and social institutions, which can complicate matters.



L.G.B.T.Q.
NOT A
MONOLITH



Gay Grief Is Different



Photo by Yui Mok PA Images via Getty Images

On this 30th anniversary of World AIDS Day, Sue Rakowski explains how LGBTQ mourning is singular.

BY SUE RAKOWSKI
DECEMBER 01 2018 2:24 PM EST

“Grieving the loss of a loved one is horrific enough, but it is even harder when you're a member of the LGBTQ community. I know. I've felt this disenfranchised grief. Gay grief is marginalized. Many of us, depending on where we live and what kind of network we have, are excluded from experiencing society's mourning process.”



The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: A systematic review, thematic synthesis and modelling of the literature

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Katherine Bristowe¹, Steve Marshall² and Richard Harding¹

Abstract

Background: Socially excluded populations have poorer access to care; however, little attention has been paid to lesbian, gay, bisexual and/or trans* people. Lesbian, gay, bisexual and/or trans* people are at increased risk of certain life-limiting illnesses and may not receive the care and support they need at the end of life and into bereavement.

Aim: To identify and appraise the evidence of the bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner and develop an explanatory model of lesbian, gay, bisexual and/or trans* partner bereavement.

Design: Systematic review (in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines) and thematic synthesis with assessment of reporting and rigour. Quantitative or qualitative articles reporting bereavement experiences of lesbian, gay, bisexual and/or trans* partners were included, excluding articles reporting multiple losses in the context of HIV or AIDS.

Data sources: PsycINFO, MEDLINE, Web of Science, Scopus, Cochrane Library. Inclusion dates: database inception – 30 April 2015.

Results: A total of 23 articles reporting on 13 studies were identified. Studies described universal experiences of the pain of losing a partner; however, additional barriers and stressors were reported for lesbian, gay, bisexual and/or trans* people, including homophobia, failure to acknowledge the relationship, additional legal and financial issues and the 'shadow' of HIV or AIDS. A novel model was developed to explain how the experience for lesbian, gay, bisexual and/or trans* people is shaped by whether the relationship was disclosed and acknowledged in life and into bereavement and how this impacts upon needs and access to care.

Conclusion: There is a need for healthcare providers to avoid hetero-normative assumptions; be mindful of additional stressors in bereavement for lesbian, gay, bisexual and/or trans* people; and consider additional sources of support to deliver individualised holistic care.

Disenfranchised Grief

“This is grief that occurs when someone experiences a loss that is not, or cannot, be openly acknowledged, publicly mourned or socially supported. The relationship may be viewed as unimportant, replaceable or stigmatized and it may be ignored or rejected altogether. As a result, the bereaved are not given full permission to grieve their loss openly and publicly. LGBTs may be denied the right to grieve and receive much needed social support. Being deprived of social validation and the inability to heal are two ingredients, when combined produce the sad experience of disenfranchised grief. “

Exclusion of “Chosen” Families

“Members of the LGBTQ+ community are more likely to be estranged from their relatives and instead rely on a close network of friends. This is often referred to as a “chosen family.” Families of origin may not accept this friendship network and exclude them from funeral planning or memorializing the person. It’s important that all those who were close to the person are included in the grieving process and are able to pay their respects. Members of the LGBTQ+ community are more likely to be estranged from their relatives and instead rely on a close network of friends. This is often referred to as a “chosen family.” Families of origin may not accept this friendship network and exclude them from funeral planning or memorializing the person. It’s important that all those who were close to the person are included in the grieving process and are able to pay their respects.”

Misgendering

For trans people there are a number of barriers to acquiring legal documentation that reflects their gender identity. In death, this can lead to healthcare workers or funeral practitioners misgendering or “deadnaming” them (calling them by a name they used before they transitioned). For friends and family, this can be particularly distressing at a time when they are most vulnerable.

Older LGBT individuals have relationships that are as long term as many marriages...20, 30, 40, 50 years or more. ***Yet the significance of their relationships is often minimized by heterosexual culture.***

Even for those who knew the couple, ***the loss may not be recognized at the same level as the death of a different sex spouse.*** (“I am not his/her friend or his/her roommate. I am his/her husband/wife.”) This attitude can cause increased vulnerability in mourning and may sometimes develop into mental health issues.

There is a difference between tolerance and respect so it may be difficult to access positive, consistent supports. Local assisted living and retirement communities sometimes don't accept LGBT couples. ***LGBT couples could face prejudice from staff or other residents which may lead to inadequate care.***

One partner may have been more open about sexual orientation than the other.

This may lead to a conflict for the surviving partner about how to refer to the deceased and how much to reveal to family and friends.

LGBT survivors may not feel comfortable ***joining overwhelmingly heterosexual support groups***, contributing to additional vulnerability during an already vulnerable time.

Documentation, even for legally married gay couples, needs to be carried during travel or vacations. Hospitals ***require legal papers in hand as proof of the partner's right to make medical decisions***, end of life decisions, or even call a funeral home to have the deceased moved from the hospital bed.

Many state laws contribute to lack of rights and access to resources such as inheritance, adoption, equal and fair housing practices, and fair hiring and workplace conditions. Some LGBT individuals ***may fear the risk of losing employment if openly mourning their gay partner.***

When seeking comfort during a time of grief and loss, LGBT couples with strong religious faith ***often experience judgment rather than support*** in many churches and synagogues.

Some Common Issues

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.



"It's important for us as healthcare workers to affirm LGBTQ+ people, acknowledge their right to healthcare and hospice access, and treat them with human respect and dignity."

Rabbi Jane Rachel Litman | VITAS Chaplain

VITAS[®]
Healthcare



What Does Inclusive Bereavement Care Look Like?

1. Knowing when and where to refer.
2. Recognizing many definitions of “family”.
3. Different levels of “openness”.
4. Treating couples like couples:
 1. Provide relationship validation.
5. Be delicate with spiritual issues.
6. If you can't be genuinely present, withdraw.
7. Watch out for hetero-normative assumptions.
8. Watch out for isolation.

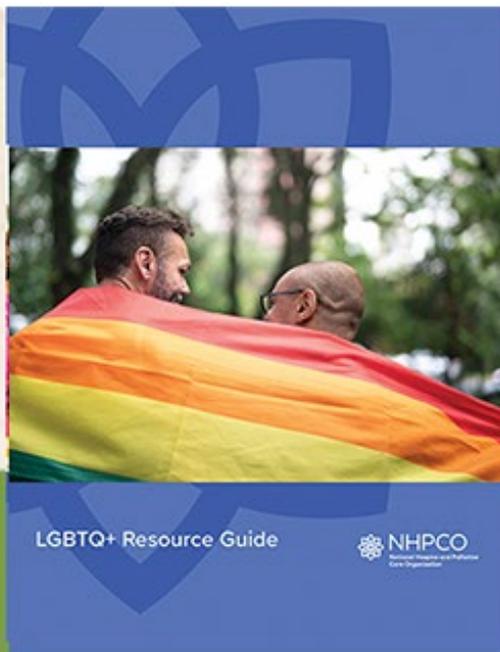


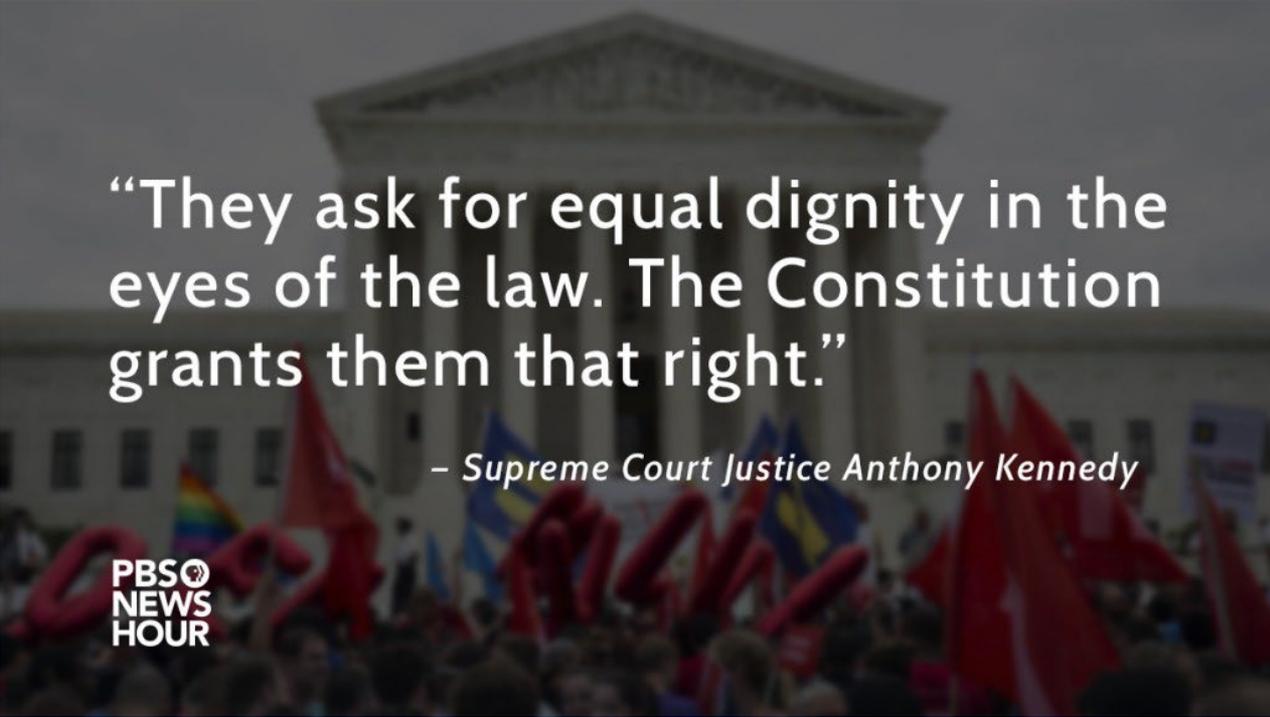
Inclusive Bereavement Care, continued.....

- 1. Remember how young some of us were.**
- 2. Gently probe about survivor guilt.**
- 3. Respect a spectrum of confidentiality.**
- 4. Be prepared for anger.**
- 5. Encourage our tendency to rebuild, reconcile, and re-engage.**
- 6. Be open to discovery.**

NEW RESOURCE

LGBTQ+ Resource Guide
Download free of charge
nhpco.org/diversity





“They ask for equal dignity in the eyes of the law. The Constitution grants them that right.”

– *Supreme Court Justice Anthony Kennedy*

PBS
NEWS
HOUR

June 26, 2015



Questions?

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