

Serious Illness and End of Life in LGBTQIA+ Older Adults

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“He’s my dad!” Mr. H’s daughter fiercely reported in the family meeting. Mr. H was receiving mechanical ventilation in the Intensive Care Unit, unresponsive and unable to participate in the discussion. His health had declined sharply and this was his second intubation in three months. During this critical illness in his eighth decade of life, when no longer able to care for himself, Mr. H had come out to his daughter as a transgender man.

According to SAGE and the National Resource Center on LGBT Aging, there are greater than three million LGBTQIA+ adults over age 50 in the United States. These elders are twice as likely to be single and live alone, and four times less likely to have children. They are more likely to face poverty and homelessness, and to have poor physical and mental health.¹ LGBTQIA+ older adults face several unique health challenges, particularly as they encounter serious illness.

Legal Surrogates for Decision-Making

Mr. H’s decision-making defaulted to his daughter as legal surrogate.

If a Delaware adult has neither medical decision-making capacity, nor a valid advance directive designating a power of attorney (POA) for healthcare, decision-making defaults to the legal surrogate per Delaware Code Title 16 Chapter 25. Until September 30, 2025, the Delaware surrogate hierarchy recognizes relatives by marriage or blood.² This can adversely impact LGBTQIA+ older adults by granting decision-making rights to family of origin who may not be as close as chosen support network. For those elders who are unmarried and childless, this hierarchy may allow more distant biological family members to make decisions, rather than unmarried partners, roommates, and close personal friends. After September 30, 2025, Delaware will adopt the Uniform Health Care Decisions Act (UHCDA) which updates the surrogate hierarchy. Additional parties recognized include any adult the individual has identified, cohabitants, adults who have exhibited special care and concern for the individual and are familiar with their personal values.² While imperfect, the updated surrogacy hierarchy is more inclusive of varying support structures.

Advance Care Planning

Mr. H did not have a completed advance directive or a DMOST form. He had never talked to his daughter or his healthcare team about his wishes.

Advance Care Planning (ACP) is “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.”³ Given the nuances of legal surrogate law, it is of paramount importance for LGBTQIA+ older adults to engage in ACP. Having high quality conversations about their wishes with loved ones and healthcare providers empowers elders to direct their own care. Advance directives should be offered to all adults; however they are essential to name a medical power of attorney when the preferred decision-maker does not match the state's legal surrogate hierarchy. For LGBTQIA+ patients, this may include unmarried partners, long-time roommates,

close friends, and other chosen family. The upcoming legal change with the UHCDA is more inclusive, however it is still unwise to leave life-or-death decisions to a hierarchy which may not accurately represent one's preferred decision-maker. For LGBTQIA+ adults with serious illness or frailty, a Delaware Medical Orders for Scope of Treatment (DMOST) form is a standing medical order which can be signed to protect their end-of-life wishes across settings.⁴ A DMOST can be signed either by the individual, or by their legal decision-maker if the individual lacks the capacity for medical decision-making.

Long Term Care

Mr. H experienced mistreatment in skilled nursing facilities, misgendered by staff and left exposed in bed, too weak to cover himself up.

Some LGBTQIA+ older adults fear discrimination in long term care settings leading to the erasure of their identities.⁵ Studies repeatedly find that LGBTQIA+ elders experience harassment in long term care, with caregivers refusing to use their preferred name or pronouns. Some LGBTQIA+ elders consider suicide to be preferable over long term care.⁶ Greater staff training, as well as inclusive forms and policies, are needed to address this challenging situation. SAGECare has provided LGBTQ+ culturally sensitive staff development and training to over 1100 long term care facilities, hospices, and other organizations.⁷ As clinicians we can advocate for organizations to earn such credentials and provide better care to LGBTQIA+ older adults.

Gender-Affirming Care

Mr. H continued to receive testosterone injections every two weeks while critically ill, as well as a binder over his chest.

Gender-affirming care is just as important during serious illness and end of life. Typically, gender-affirming hormone therapy is maintained throughout life to provide masculinizing or feminizing effects as desired.⁸ At end-of-life, it may be the person's wish to continue hormones even if the medication poses additional risk. Whenever possible, gender expression preferences of LGBTQIA+ elders should be honored. TRANSforming Choices Healthcare Decisions Starter Guide is an excellent resource for transgender, gender-diverse, and gender-expansive people to make choices about their healthcare including gender-affirming care.⁹ Funeral directives are available to ensure that LGBTQIA+ elders' funeral wishes are followed, including name, pronouns, and presentation of the body.

Conclusion

"We honor your dad's gender identity and acknowledge a lifetime of discrimination." The medical team continued to support Mr. H medically while conducting ongoing discussions with his daughter regarding goals of care. He was unable to be weaned from the ventilator and underwent tracheostomy and gastrostomy tube placement. Mr. H ultimately died several months later with his daughter at his side. Throughout his final critical illness, the medical team endeavored to provide respectful and inclusive care. We honored him as a whole person, a dedicated father, and a proud man in his final chapter of life.

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