



Legislative Testimony  
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**Written Testimony Supporting Senate Bill 1075, An Act Concerning Hospice and Palliative Care**

Senator Anwar, Representative McCarthy-Vahey, Ranking Members Somers and Klarides Ditria, and distinguished members of the Public Health Committee:

My name is Jess Zaccagnino, and I am the policy counsel for the American Civil Liberties Union of Connecticut (ACLU-CT). I am writing to testify in support of Senate Bill 1075, An Act Concerning Hospice and Palliative Care.

The ACLU-CT believes all people deserve equal access to quality end of life care. Every person should have access to hospice and palliative care, regardless of income. But individual and systemic discrimination disproportionately prevents people from receiving end of life care. Palliative care “has been shown to improve the quality of life for seriously ill patients and their families, save money, and even extend a patient’s life.”<sup>1</sup>

A 2019 study of people with particular kinds of cancer who were being treated at hospitals that serve the highest shares of Black and brown people were 33 percent less likely to receive palliative care than patients in other hospitals.<sup>2</sup> Another study found that Black patients were significantly less likely to have access to hospice care during the end of their lives compared to white patients.<sup>3</sup> As a result, Black people experience more intensive and traumatic care, like hospitalizations, emergency

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<sup>1</sup> Diane E. Meier, *Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care*, 89 MILBANK Q. 343 (2011), <https://pubmed.ncbi.nlm.nih.gov/21933272/>.

<sup>2</sup> Alexandra P. Cole, et al., *Association of Care at Minority-Serving vs. Non-Minority-Serving Hospitals With Use of Palliative Care Among Racial/Ethnic Minorities With Metastatic Cancer in the United States*, JAMA (2019), <https://pubmed.ncbi.nlm.nih.gov/30707230/>.

<sup>3</sup> Katherine A. Ornstein, *Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the REGARDS Cohort*, JAMA (2020), <https://pubmed.ncbi.nlm.nih.gov/30707230/>.

department visits, and aggressive treatments.<sup>4</sup> Another disparity that acutely harms Black and Latinx people is that hospice care is typically provided to people dying from cancer, but not people dying from end-stage kidney disease, which affects Black and Latinx people at significantly higher rates.<sup>5</sup> Racial disparities in access to hospice care create poorer end-of-life experiences: more pain, more financial harm, a greater caregiver burden, especially among women, and more traumatic family experiences with death.<sup>6</sup>

These disparities are also magnified when patients are living in poverty. Income will affect a person's eligibility for hospice care and access to particular pain prescriptions.<sup>7</sup> Older LGBTQ+ adults also experience discrimination and stigmatization in hospice care.<sup>8</sup> A survey found that 80 percent of older LGBTQ+ people hid their sexual orientation when obtaining long-term care.<sup>9</sup> Many others were anxious to let caregivers in their home because of their sexual orientation.<sup>10</sup> Expanding access to telehealth hospice care is one way to ease this very real concern.

It is imperative that we make palliative care and hospice treatment available and accessible to all. That means both expanding the availability of hospice and palliative care in underserved hospitals and communities and ensuring equal coverage of telehealth and home hospice options alongside inpatient treatment. When there is a lack of inpatient care or other hospice services in rural areas of the state, telemedicine

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<sup>4</sup> Laura M. Perry, *Racial Disparities in End-of-Life Care Between Black and White Adults with Metastatic Cancer*, 61 J. PAIN SYMPTOM MGMT. 342 (2020), <https://pubmed.ncbi.nlm.nih.gov/32947018/>.

<sup>5</sup> Melissa W. Wachterman, *Quality of End-of-Life Care Provided to Patients With Serious Illnesses*, 176 JAMA INTERNAL MED. 1095 (2016), <https://pubmed.ncbi.nlm.nih.gov/27367547/>.

<sup>6</sup> See, e.g., Melissa W. Wachterman & Benjamin D. Sommers, *Dying Poor in the US-Disparities in End-of-Life Care*, 325 JAMA 423 (2021), <https://pubmed.ncbi.nlm.nih.gov/33528526/>; Arif H. Kamal, et al., *Unmet Needs of African Americans and Whites at the Time of Palliative Care Consultation*, 34 AM. J. HOSP. PALLIATIVE CARE 461 (2017), <https://pubmed.ncbi.nlm.nih.gov/26888883/>; Reginald D. Tucker-Seeley, et al., *Financial Hardship and the Intensity of Medical Care*, 24 PSYCHO-ONCOLOGY 572 (2015), <https://pubmed.ncbi.nlm.nih.gov/25052138/>.

<sup>7</sup> Katie E. Nelson, *Socioeconomic Disparities in Access to Hospice and Palliative Care: An Integrative Review*, 38 AM. J. HOSPICE & PALLIATIVE MED. (2021), <https://journals.sagepub.com/doi/10.1177/1049909120985419>.

<sup>8</sup> Marie Curie, *Hiding Who I Am: The Reality of End of Life Care for LGBT People*, KINGS COLLEGE LONDON & UNIV. NOTTINGHAM (2016), <https://www.scie-socialcareonline.org.uk/hiding-who-i-am-the-reality-of-end-of-life-care-for-lgbt-people/r/a11G000000G68YNIAZ>.

<sup>9</sup> *For LGBTQ+ Elders, Palliative Care Can Alleviate Aging's Obstacles*, SAGE (Aug. 29, 2019), <https://www.sageusa.org/news-posts/for-lgbtq-elders-palliative-care-can-alleviate-aging-obstacles/>.

<sup>10</sup> *Id.*

coverage is especially important. The ACLU-CT supports legislation like Senate Bill 1075 that works to ensure quality end-of-life care is accessible to all, and encourages this Committee to do the same.