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**No. 24-1081**

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**In the**  
**United States Court of Appeals**  
**for the Seventh Circuit**

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LAUREN RICHWINE and DEATH DONE DIFFERENTLY LLC,  
*Plaintiffs-Appellees,*

v.

KATHLEEN DIANE MATUSZAK, et al.,  
*Defendants-Appellants.*

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Appeal from the United States District Court  
for the Northern District of Indiana, Fort Wayne Division, No. 1:23-cv-00370-HAB-SLC.  
The Honorable Holly A. Brady, Judge Presiding.

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**BRIEF OF *AMICUS CURIAE* COMPASSION & CHOICES IN  
SUPPORT OF PLAINTIFFS-APPELLEES AND AFFIRMANCE**

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APPEARANCE & CIRCUIT RULE 26.1 DISCLOSURE STATEMENT

Appellate Court No: 24-1081

Short Caption: Lauren Richwine, et al. v. Kathleen Matuszak, et al.

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(5) Provide Debtor information required by FRAP 26.1 (c) 1 & 2:

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## STATEMENT OF INTEREST<sup>1</sup>

*Amicus curiae* Compassion & Choices respectfully submit this brief in support of Appellees Lauren Richwine and Death Done Differently, LLC (collectively, “Richwine”). *Amicus* is a non-profit corporation whose mission is to improve care, expand options, and empower everyone to chart their end-of-life journey. Its services include educating the public about the importance of documenting their end-of-life values and priorities, empowering individuals to control their end-of-life care by providing information about the full-range of available options at the end of life, advocating for expanded end-of-life options and improved medical practices that prioritize patients, and defending existing end-of-life options from efforts to restrict access.

Given its mission and services, Compassion & Choices is uniquely positioned to comment about the importance of death doulas—service providers who support individuals and the relatives of individuals nearing the end of life—and why they should not be regulated as funeral directors. It submits this brief to inform the court that ruling in favor of Defendants will force most, if not all, death doulas out of practice. This will have adverse consequences for the many individuals who benefit from the services and information that death doulas provide. Such a ruling will significantly reduce access to key information for individuals nearing the end of life and their relatives, the control individuals have over their end-of-life and after-

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<sup>1</sup> Both parties have consented to the filing of this brief. No party’s counsel authored any part of this brief nor did any party’s counsel or any other person contribute any money intended to fund this brief.

death care, and their ability to die and have a post-death ritual in accordance with their values and beliefs. The Court should affirm the District Court's conclusion that the State's decision to restrict Richwine's speech warrants a preliminary injunction because Richwine is likely to succeed on the merits and to experience irreparable harm otherwise.

### **SUMMARY OF THE ARGUMENT**

Death doulas are community-based individuals who provide holistic, non-medical support to the dying person and their family members. They do so emotionally, spiritually, and practically. Death doulas also educate these individuals by providing information about end-of-life and after-death care options, such as at-home funerals, cremations, and green burials. In providing these services, death doulas empower individuals to feel confident in making important end-of-life decisions about their care so that individuals can remain true to their values and beliefs as they go through the dying process.

The services that death doulas provide play an important role in furthering patient-directed care at the end of life. They do so in a number of ways. First, they complement traditional end-of-life medical care services by providing non-judgmental emotional, practical, and spiritual support. Second, death doulas fill a void in the healthcare system by acting as patient advocates. They do so by helping individuals make more informed and personalized decisions about their care through education about end-of-life and after-death options. Third, death doulas fill a void in conventional funeral home and funeral director services by assisting

families with the grieving process and by supporting the availability of affordable funeral alternatives through transparent information about those alternatives.

Death doulas should not be subject to the same regulations as funeral homes and funeral directors. Death doulas offer fundamentally different services than funeral homes and funeral directors and do not touch the activities that legislators intended to regulate through the Indiana Code. Moreover, strictly regulating death doulas as funeral directors will effectively put death doulas out of business as many lack the financial resources to comply with the expensive regulations of that industry. This will consequently extinguish their ability to provide information about end-of-life options and will hurt dying individuals and their loved ones by limiting their ability to make informed decisions about their end-of-life and after-death care. Lastly, regulating death doulas as if they were funeral homes or funeral directors infringes on their First Amendment free speech right to provide information about end-of-life and after-death care options and of their clients' rights to receive this information.

In light of this background, *amicus* submits this brief to aid the Court by giving a broader context to the alternative end-of-life movement nationwide, highlight the important gaps in the end-of-life continuum that death doulas fill, and show why protecting these alternatives is so critical to the dying and their loved ones.

## ARGUMENT

### I. DEATH DOULAS ARE COMMUNITY-BASED INDIVIDUALS WHO PROVIDE SUPPORT AND INFORMATION TO EMPOWER PEOPLE AT THE END OF LIFE.

A “doula” is a trained companion who supports others through a significant health-related experience. The term “Doula” is Greek in origin and roughly translates to “a woman who serves.” See Coburn Dukehart, *Doulas: Exploring a Tradition of Support*, NPR (July 14, 2011).<sup>2</sup> Notably, a doula is traditionally a community-based person with no formal medical education. See Marian Krawczyk & Merilynne Rush, *Describing the end-of-life doula role and practice of care: perspectives from four countries*, 14 J. Palliative Care & Soc. Prac. 1, 1 (2020).<sup>3</sup> They do not provide medical support or advice. *Id.* at 8. Rather, doulas provide information, emotional support, and physical comfort during major medical events. *Id.* at 5. While the term “doula” traditionally referred to those who assist individuals giving birth, (See Merriam-Webster (June 10, 2024))<sup>4</sup> the term has expanded to also include those who help guide individuals and their loved ones through the dying process.

A death doula, also known as an end-of-life doula, is an emerging form of community-based caregiver whose job is to help individuals nearing the end of life—as well as their loved ones—navigate that experience as peacefully and supportively

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<sup>2</sup> <https://www.npr.org/sections/babyproject/2011/07/14/137827923/doulas-exploring-a-tradition-of-support>.

<sup>3</sup> <https://doi.org/10.1177/2632352420973226>.

<sup>4</sup> <https://www.merriam-webster.com/dictionary/doula>.

as possible. See Krawczyk, *Describing the end-of-life doula role* at 5. The death doula movement is growing (*Id.* at 2), as is the recognition of the unique care and contributions they provide at the end of life. See Hannah Hagemann, *Death Doulas are Becoming Part of the End-of-Life Equation* (January 3, 2020).<sup>5</sup> Since the Covid-19 Pandemic, there has been a significant spike in membership and enrollment of death doulas (See Melissa Chan, *Death Doulas Used to be Rare. The Covid-19 Pandemic Changed That*, Time Magazine (January 19, 2022)<sup>6</sup>, reflecting the increased focus on the quality of life during the end-of-life stage. See Stacey Colino, *Demand for death doulas has soared. Here's how they help patients go with grace*, National Geographic (February 24, 2024).<sup>7</sup>

Consistent with the definition of a traditional doula, death doulas are community-based individuals that have no formal medical training. See Krawczyk, *Describing the end-of-life doula role* at 1. As one California District Court recognized just last year, “[g]enerally, end-of-life doulas do not provide medical treatment or advice, legal advice, or formal counseling or therapy.” *Full Circle of Living and Dying v. Sanchez*, 2023 WL 373681, at \*4 (E.D. Cal. Jan. 24, 2023). Nor do they provide embalming, funeral, or transportation services. See Krawczyk at 8. Rather, death doulas provide “unique services” that are “distinct from those provided by funeral homes or directors.” *Full Circle*, 2023 WL 373681, at \*5 n.6. Four services

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<sup>5</sup> <https://www.npr.org/2020/01/03/793257344/one-way-to-die-hire-an-end-of-life-doula>.

<sup>6</sup> <https://time.com/6128469/death-doulas-covid-19-pandemic/>.

<sup>7</sup> <https://www.nationalgeographic.com/premium/article/death-doula-dignity-end-life-rituals>.

that death doulas provide are especially impactful to those nearing the end of life.

First, death doulas offer non-judgmental emotional, spiritual, and practical support to dying individuals and their loved ones. This support—whether it is holding a dying individual’s hand or keeping an individual’s grieving family company—is immeasurably important to an individual and their loved ones at the end of life. Some doulas continue to provide care after an individual’s death, such as helping the grieving family wash and dress the body or assisting with home funerals. *Id.* at 5-6. Second, death doulas provide education about end-of-life and after-death planning. They may do this on an individual level, speaking directly to a dying individual about their specific priorities and to help them understand their end-of-life and after-death options. Death doulas may also provide education at a community level, hosting community education events and advance care planning workshops, to help remove the stigma from conversations about death and encourage the public to engage in end-of-life planning. *Id.* at 1-2. This education assists individuals in making fully informed end-of-life decisions.

Third, death doulas often act as a patient advocate, helping ensure an individual gets the care they want. Death doulas achieve this by amplifying a patient’s voice and assisting them as they navigate the complexities of obtaining the care they want. For example, death doulas can discuss an individual’s priorities and provide information helpful to an individual as they memorialize their end-of-life wishes in an advance directive or help an individual navigate the complicated statutory requirements of obtaining a medical aid-in-dying prescription. *See Kim*



Callinan, *Medical Aid in Dying: The Role of Death Doulas*, Compassion & Choices (February 1, 2021).<sup>8</sup>

Lastly, death doulas empower an individual to make decisions about their own end-of-life care or assist in the care of a loved one. Krawczyk, *Describing the end-of-life doula role* at 7. A recent empirical study found that death doulas enabled family members to be prepared for death, which led to a sense of empowerment. See Deb Rawlings, *Experiences of engaging a death doula: qualitative interviews with bereaved family members*, Palliat. Care Soc. Pract. (November 8, 2023). This made them feel emotionally supported and enabled the family members to provide personalized deaths and funerals for their loved ones. See *id.* By providing support and information to dying individuals and their loved ones, death doulas help ensure that individuals receive the care that is best for them at the end of life.

Death doulas provide these services in a variety of settings, including at an individual's home, hospice centers, hospitals, and long-term care facilities. See Krawczyk at 6. While some death doulas charge modest fees for their services, many death doulas work on a volunteer basis. See generally Kara Mason, *Embracing End-of-life doulas growing in popularity*, Associated Press (May 15, 2021)<sup>9</sup>; see also Abby Ellin, *'Death Doulas' Provide Aid at the End of Life*, New York Times (June 25, 2021).<sup>10</sup>

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<sup>8</sup> <https://compassionandchoices.org/news/medical-aid-in-dying-the-role-of-death-doulas/>.

<sup>9</sup> <https://apnews.com/article/coronavirus-pandemic-lifestyle-health-business-3b4e6af60889b69fde4f8fc14d01f7af>.

<sup>10</sup> <https://www.nytimes.com/2021/06/24/well/doulas-death-end-of-life.html>.

## II. DEATH DOULAS FILL A VOID IN TRADITIONAL HEALTHCARE AND FUNERAL SERVICES AND ADVANCE PATIENT-DIRECTED CARE.

Medical care is only one aspect of the support an individual needs at the end of life. Death doulas help to make end-of-life care more holistic, focusing on an individual's spiritual, emotional, and practical needs, while also educating and empowering individuals to make the end-of-life and after-death decisions that are best for them. Working with medical professionals, death doulas fill a void in the traditional medical system, helping to ensure an individual's care is self-directed and fits their unique needs.

The medical profession has traditionally been focused on treating patients' illnesses through a physician-directed approach. *See Raman Kumar & Vijay Kumar Chattu, What is in the name? Understanding terminologies of patient-centered, person-centered, and patient-directed care, 7 J. Fam. Med. Prim. Care 487, 487 (2018).*<sup>11</sup> Under this approach, healthcare workers provide care based on evaluating the symptoms presented by a patient, recommending medically indicated courses of treatment, observing and assessing the outcome of that treatment, and then repeating this cycle if necessary. *See id.* While this approach can be effective in curing illness, the patient's individual wants and needs are largely ignored. *See id.* Under this model, physicians, and not patients, are the decision makers. A patient's limited role under this paternalistic method is to trust and comply with the directions of trained medical staff.

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<sup>11</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6069658/>.

To address the shortcomings of physician-directed care, a new healthcare approach coined “patient-directed care” has emerged. *See id.* This form of care offers a more holistic approach tailored to meet a patient’s medical needs *and* individual priorities. *Id.* In the patient-directed care model, the *patient* is the decision maker and has a high level of control in choosing or refusing treatment in accordance with their individual values. *Id.* at 488; *see also* Barbara Coombs Lee, *From Patient-Centered to Patient-Directed Care*, Compassion & Choices (March 1, 2019).<sup>12</sup> This approach thus shifts decision-making power away from healthcare workers, providing patients with greater autonomy to direct their own medical needs. Patient-directed care is especially important at the end of life, allowing an individual’s values and beliefs to guide the kind of care they receive in their final moments of life. *See* Coombs Lee.

Death doulas play an important role in advancing patient-directed care in two ways. First, they assist in ensuring that patients are provided with the full spectrum of care at the end-of-life. Second, they help to fill a void in end-of-life care provided in traditional healthcare settings.

**A. Death doulas further patient-directed care by providing information and services that support an individual’s practical, emotional, and spiritual needs at the end of life.**

Death doulas help to enhance the full spectrum of care by offering the support and education necessary for individuals to feel empowered and make fully-informed end-of-life decisions. The full-spectrum of care at the end of life offers

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<sup>12</sup> <https://compassionandchoices.org/news/from-patient-centered-to-patient-directed-care/>.

comprehensive and holistic treatment to patients nearing the end-of-life, addressing an individual's medical, psychological, social, cultural, and spiritual needs. *See generally* Derek Doyle, *Principles of Palliative Care*, International Association for Hospices and Palliative Care (November 6, 2021).<sup>13</sup> Providing an individual nearing the end of life with the full spectrum of care options helps to manage the discomfort, symptoms, and stress of what they are experiencing and improves the individual's quality of life by ensuring that *all* of their needs are met. *See Palliative care: A spectrum of support*, NIH Medline Plus Magazine (April 24, 2018).<sup>14</sup>

A death doula's services complement the full spectrum of care at the end of life in myriad ways. First, death doulas provide important education to individuals nearing the end of life and to their loved ones that would otherwise be difficult to obtain. For example, death doulas provide information about after-death options, such as at-home funerals and cremation, as well as about the laws that govern a decedent's body. Krawczyk, *Describing the end-of-life doula role and practices of care* at 7. Without the valuable services that death doulas provide, individuals would be forced to rely upon funeral homes and funeral directors for this information—actors that have a vested financial interest in promoting conventional funeral home services—and are thus less likely to learn about alternatives to conventional funerals. *See* Victoria J. Haneman, *Funeral Poverty*, 55 Mich. L. Rev. 387, 405-06 (2021).

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<sup>13</sup> <https://hospicecare.com/what-we-do/publications/getting-started/principles-of-palliative-care/>.

<sup>14</sup> <https://magazine.medlineplus.gov/article/palliative-care-a-spectrum-of-support>.

Second, death doulas work closely with individuals at the end of life to help them better understand their emotions and spiritual beliefs as they navigate their experience. *See* Krawczyk at 7. In doing so, death doulas help individuals and their loved ones cope with the difficult emotions that inevitably arise during the end-of-life process. Understanding these emotions gives individuals a greater sense of control over the process and helps to preserve individual dignity through the end of life. *See* Jennifer A. Woo, Guy Maytal & Theodore A. Stern, *Clinical Challenges to the Delivery of End-of-Life Care*, 8 Prim. Care Companion J. Clin. Psych. 367, 368 (2006).

Lastly, because death doulas are able to spend a significant amount of time with their clients, they have a greater capacity to be present with individuals nearing the end of life than traditional healthcare workers. A lack of time due to competing demands, such as being interrupted by pagers or calls, is a major barrier to end-of life conversations for clinicians, affecting their quality of communication and ability to build relationships with families of the dying. *See* Brett Scholz, et. Al., *Clinicians' Accounts of Communication with Patients in End-of-Life Care Contexts: A Systematic Review*, Patient Education and Counseling Volume 103, Issue 10 (October 2020). The flexibility of death doulas allows them to be more responsive to the client's supportive needs as they arise than traditional healthcare workers.

By providing individuals nearing the end of life with valuable information and services that advance the full spectrum of care, death doulas help enhance

individual-directed care by empowering them to dictate the terms of their care at the end of life and after death.

**B. Death doulas fill a void in the healthcare system by bolstering informed consent and by complementing care from hospices, hospitals, and senior care facilities.**

Traditional healthcare systems—such as hospice care, palliative care, nursing homes, and senior-care facilities—are primarily concerned with the medical aspect of end-of-life care, focusing on controlling pain and other symptoms to provide maximum comfort to a dying patient. *See NCI Dictionaries*, National Cancer Institute (June 10, 2024).<sup>15</sup> These traditional healthcare providers, however, are generally unable to exclusively focus on the emotional, spiritual, or practical needs of an individual or their loved ones at the end of life.

One reason for this is that healthcare workers often lack resources to assist with a patient's full range of end-of-life needs. Woo, et al., *Clinical Challenges to the Delivery of End-of-Life Care* at 369. In 2003, a poll of 1,455 medical students and 296 residents affiliated with 62 accredited U.S. medical schools found that only 18% of participants had received any formal training in end-of-life care. *See* Amy M. Sullivan, Matthew D. Lakoma & Susan D. Block, *The Status of Medical Education in End-of-life Care*, 18 J. Gen. Intern. Med. 685, 685 (2013).<sup>16</sup> In addition to a lack of training in delivering difficult news to patients, traditional healthcare workers often lack the resources to provide healthcare that is individually tailored to the needs of the patient given the burdensome demands of caring for multiple patients,

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<sup>15</sup> <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/end-of-life-care>.

<sup>16</sup> [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1494921/pdf/jgi\\_21215.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1494921/pdf/jgi_21215.pdf).

even though they may want to. Because of these inadequacies, patients nearing the end of life frequently lack holistic support from traditional healthcare workers.

Another reason is that healthcare workers are often uncomfortable in talking about death with patients or with that person's family members. This discomfort may be partly driven by a generational shift in perspective about death. This shift has morphed death from an ordinary part of life into a taboo that should be seldom spoken about. *See Haneman, Funeral Poverty* at 390; *see also* Lee Webster, *Why Caring For Our Own Dead Is An Act of Social Justice*, 8 Wake Forest J. L. & Pol'y 125, 127 (2018). Furthermore, end-of-life healthcare workers are often undercompensated as compared to other healthcare workers and are thus disincentivized from more meaningfully connecting with their patients. *See Woo, et al., Clinical Challenges to the Delivery of End-of-Life Care* at 369-70.

On top of the challenges presented by the inadequacies of traditional end-of-life healthcare offerings, many patients nearing the end of life often have limited access to these options. Michael Ollove, *Why Some Patients Aren't Getting Palliative Care*, Pew Charitable Trusts (July 10, 2017).<sup>17</sup> This stems partly from restrictive definitions of who qualifies for end-of-life treatment. *Id.* For example, some health insurance plans only cover individuals who are hospitalized or in hospice. *Id.* Consequently, these services typically do not cover individuals who are expected to live fewer than six months or who cease curative treatment, forcing patients into

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<sup>17</sup> <https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2017/07/10/why-some-patients-arent-getting-palliative-care>.

the uncomfortable dilemma of either continuing treatment and fighting to stay alive or foregoing treatment and accessing end-of-life care. *Id.* Moreover, even when insurance plans do cover end-of-life care, they rarely cover home visits. *Id.* This lack of coverage is all compounded by a lack of awareness about the availability of robust end-of-life care, like palliative care, with one recent survey indicating that fewer than 30% of participants knew about palliative care. Signe Peterson Fliieger, Kenneth Chui & Susan Koch-Weser, *Lack of Awareness and Common Misconceptions About Palliative Care Among Adults: Insights from a National Survey*, 35 J. Gen. Intern. Med. 2059, 2059 (2020).<sup>18</sup>

Death doulas help address these healthcare shortcomings in several ways. First, because dealing with death is an everyday part of their job, death doulas are well equipped to provide non-medical support to help individuals nearing death navigate that experience. Death doulas do not shy away from death; they embrace it. See John Leland, *The Positive Death Movement Comes to Life*, New York Times (June 22, 2018).<sup>19</sup> Death doulas can engage in meaningful dialogue with clients about their end-of-life experiences, help individuals create an end-of-life plan, advocate for an individual's end-of-life needs, and provide the non-judgmental emotional, practical, and spiritual support that these patients often lack.

Second, death doulas help provide affordable end-of-life care to individuals who may not be able to access expensive, traditional end-of-life care options. This is

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<sup>18</sup> <https://link.springer.com/content/pdf/10.1007/s11606-020-05730-4.pdf>.

<sup>19</sup> <https://www.nytimes.com/2018/06/22/nyregion/the-positive-death-movement-comes-to-life.html>.



because unlike traditional end-of-life care providers, many death doulas work on a volunteer or donation basis. Ellin, *'Death Doulas' Provide Aid at the End of Life*. Death doulas therefore serve a segment of the population that would otherwise be without meaningful end-of-life care. A rising number of death doulas have helped combat the racial disparities in end-of life care, where Black people are less likely to get hospice services compared to white people, and more likely to have invasive procedures during their last six months. See Naomi Fedna-Thompson, *'Death Doulas' and the Audacious Act of Dying Well in America*, Boston Globe (January 24, 2024).<sup>20</sup>

Lastly, death doulas provide important information about end-of-life planning options and help raise awareness about traditional healthcare offerings like palliative care of which many patients may be unaware. See Krawczyk, *Describing the end-of-life doula role and practices of care* at 7. In doing so, death doulas help patients navigate complex healthcare systems to get the care that works best for them medically, personally, and financially.

**C. Death doulas fill a void in conventional funeral director services by assisting families with the grieving process and by educating the community about affordable funeral alternatives.**

Death doulas perform a fundamentally different role than that of funeral directors operating out of a funeral home. Death doulas work with dying individuals and their loved ones to help ascertain the after-death ritual that is best for them,

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<sup>20</sup> available at <https://www.bostonglobe.com/2024/01/24/magazine/the-role-of-death-doulas-addressing-racial-disparities-in-end-of-life-care/>.

whether it is a conventional burial, cremation, or home funeral. After an individual dies, death doulas assist their loved ones as they navigate the grieving process and help effectuate an individual's after-death decisions.

By contrast, a conventional funeral director's services are focused on providing logistical and administrative services, not emotional support. According to the Bureau of Labor Statistics Outlook Handbook, a funeral director's typical responsibilities include removing and transporting corpses, confirming signs of death, embalming corpses, planning funerals, preparing obituaries, coordinating burials and cremations, and handling administrative tasks such as obtaining death certificates and notifying the Social Security Administration of a person's death. Bureau of Labor Statistics, *Occupational Outlook Handbook, Funeral Service Occupations*, Department of Labor (*last modified* April 24, 2024).<sup>21</sup> While a funeral director may also provide information and resources on support groups to help the grieving friends and family, most outsource these services rather than provide them themselves. *See id.*

However, many people cannot take advantage of these conventional funeral services because they have become prohibitively expensive. Today, the median funeral costs in Indiana are over *seven thousand dollars*. *Average-Funeral-Cost-by-State*, World Population (2024).<sup>22</sup> And in 2023, the median cost of a traditional adult funeral and burial exceeded nine thousand dollars. *Full Circle*, 2023 WL 373681, at

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<sup>21</sup> <https://www.bls.gov/ooh/personal-care-and-service/funeral-service-occupations.htm#tab-2>.

<sup>22</sup> <https://worldpopulationreview.com/state-rankings/average-funeral-cost-by-state>.

\*3. This is particularly troubling given that a recently conducted survey by the Federal Reserve found that thirty-seven percent of Americans would have to borrow or sell something or would not have been able to cover a \$400 emergency expense. *See Board of Governors of the Federal Reserve System, Report on the Economic Well-Being of U.S. Households in 2023 (2023).*<sup>23</sup> Death doulas help fill the gaps in conventional funeral services by providing services not usually offered by funeral directors and by shedding light on more affordable alternatives.

First, while most funeral directors do not offer grief support to a decedent's family members, grief support is an integral part of a death doula's responsibilities. This includes providing emotional and spiritual support to a decedent's friends and loved ones to help them navigate the grief associated with death and the dying process. Death doulas enable bereaved family members to be prepared for death, which leads to a sense of empowerment. *See Rawlings, Experiences of engaging a death doula.* Beyond this, death doulas offer emotional support to dying individuals throughout the entire process, and sometimes long before, unlike funeral directors who typically become involved only after a person's death.

Second, death doulas help educate consumers in a transparent manner about the full range of after-death options, including alternatives to expensive, conventional funeral home services, so that individuals can meaningfully select between those options. For example, death doulas regularly inform individuals

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<sup>23</sup> <https://www.federalreserve.gov/publications/files/2023-report-economic-well-being-us-households-202405.pdf>.

about at-home funerals, cremations, and green burials as part of their after-death care-planning sessions. These options all cost substantially less than a conventional funeral service (See Haneman, *Funeral Poverty* at 429-30), and may better align with an individual's cultural, spiritual, or environmental beliefs. In providing these educational services, death doulas help ensure that individuals are informed about *all* after-death options, including conventional funerals and funeral alternatives. Individuals may still decide that a conventional funeral best suits their needs. A death doula's job is not to dissuade them from that decision. It is simply to ensure that individuals know their full-range of options before they make *any* decision—conventional and at-home funeral alike.

### **III. DEATH DOULAS SHOULD NOT BE SUBJECT TO THE SAME REGULATIONS AS A CONVENTIONAL FUNERAL HOME OR FUNERAL DIRECTOR.**

Death doulas should not be regulated as funeral directors for several reasons. First, death doulas are community-based individuals who do not provide funeral director services. Second, regulating death doulas as funeral directors will force most out of existence, undermining patient-directed care and reducing options for end-of-life care. Third, the strict regulation of death doulas as funeral directors violates death doulas' rights to provide such information and the rights of patients and their loved ones to receive it.

#### **A. Death doulas do not offer services that touch the operations of funeral homes or funeral directors and should not be regulated as such.**

Unless exempted, Indiana Code Section 25-15-8-24 makes it a Class B infraction for a person to engage in the practice of funeral service without a license

and for a person to operate a funeral home without a funeral home license. Ind. Code Ann. § 25-15-8-24 (West). But subjecting death doulas to the same standards that govern funeral homes or funeral directors is unnecessary—death doulas offer fundamentally different services that are entirely “distinct from those provided by funeral homes or directors.” *Full Circle*, 2023 WL 373681, at \*3 n.6.

As discussed previously, a key part of a funeral director’s responsibilities include confirming signs of death, obtaining death certificates, and transporting, disinfecting, embalming, and disposing of corpses through either burial or cremation. Bureau of Labor Statistics, *Occupational Outlook Handbook, Funeral Service Occupations*. Carrying out these responsibilities involves the exercise of technical skill. For example, the embalming process consists of making incisions in a corpse, removing the blood and bodily fluids, and replacing those fluids with disinfecting solutions such as formaldehyde. Erich Brenner, *Human body preservation – old and new techniques*, 224 *J. Anatomy*, 316, 319 (2014).<sup>24</sup> It also involves handling potential disease vectors, as blood-borne viruses can be transmitted by coming into contact with the blood or bodily fluids of another—a fundamental part of the embalming process. Nelson Marlborough District Health Board, *The Infectious Hazards of Dead Bodies* (September 28, 2020).<sup>25</sup> Given the

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<sup>24</sup> <https://doi.org/10.1111/joa.12160>.

<sup>25</sup> <https://www.nmdhb.govt.nz/dmsdocument/61-the-infectious-hazards-of-dead-bodies> (“Hepatitis B and C viruses, and HIV pose a particular risk for those in contact with the blood of the deceased. [E]mbalmers, emergency service workers, and forensic scientists are the occupations most at risk.”).

nature of their services and their proximity to potential disease vectors, regulation of funeral directors is appropriate to protect the public health and safety.

Moreover, regulations imposed on funeral homes and funeral directors were responsive to the funeral home industry's history of exploiting vulnerable consumers. For example, in the 1980's, the Federal Trade Commission enacted the "Funeral Rule"—regulations intended to curb deceptive and unfair pricing practices engaged in by funeral providers. *St. Joseph v. Castille*, 712 F.3d 215, 218 (5th Cir. 2013). These practices included failing to disclose price information and "bundling" products and services to force consumers into buying products and services that they did not need. *Id.* The Funeral Rule now requires funeral directors to provide consumers with itemized price lists so that they are no longer forced into buying such services. *Id.* Indiana went a step further by enacting Indiana Code Section 25-15-8-4(2), a law that requires a practitioner offering to sell funeral goods or funeral services to a consumer to disclose prices related to arranging a funeral.

Unlike funeral directors, however, death doulas are informally trained, community-based individuals who do not offer the services of funeral homes and funeral directors. *See Full Circle*, 2023 WL 373681, at \*3 n.6; *see also* Krawczyk, *Describing the end-of-life doula role and practices of care* at 1. Nor do they handle corpses to the same intimate and invasive degree as funeral directors. *See id.* at 7. They do not offer embalming services, confirm signs of death, or obtain death certificates. Rather, death doulas provide emotional, spiritual, and practical support as well as education about the dying process so that individuals at the end of life

feel empowered to make decisions about their care. *See id.* And while death doulas may sometimes interact with corpses as part of at-home funerals, these interactions do not expose them to potential disease vectors since corpses do not generally pose a public health risk. Webster, *Why Caring For Our Own Dead Is An Act of Social Justice* at 129; *see also Risks posed by dead bodies after disasters*, World Health Organization (February 6, 2013).<sup>26</sup> As such, a death doula's services do not threaten the public health and safety, and consequently do not undermine the legislature's intent in protecting consumers in this regard.

Nor do death doulas pose a threat to consumer protection. Unlike funeral directors, most death doulas work on a volunteer or donation basis. *See* Ellin, *Death Doulas' Provide Aid at the End of Life*. Thus, unlike funeral directors, death doulas do not have a financial incentive to withhold information from patients and their relatives. On the contrary, death doulas further the interest of consumer protection by providing patients with information about end-of-life services in a transparent manner, which allows patients and their relatives to make informed decisions about after-death care. *See* Haneman, *Funeral Poverty* at 406-07, 418-19. Death doula services, therefore, do not threaten consumer protection and do not undermine the public health.

Because death doulas do not touch on the traditional functions of funeral homes or funeral directors, they should not be regulated in the same manner.

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<sup>26</sup> <https://www.who.int/publications/m/item/risks-posed-by-dead-bodies-after-disasters> ("Human remains only pose a substantial risk to health in a few special cases, such as deaths from cholera or hemorrhagic fevers.").

**B. Regulation of death doulas will severely restrict their ability to provide information about end-of-life options and will hurt patients.**

The regulation of death doulas as funeral directors will prevent most from offering their services at all, undermining patient-directed care. Complying with the regulations that govern funeral directors in Indiana is expensive. A funeral director must complete a course of education consisting of either (i) thirty semester hours or forty-five quarter hours of college-level work in a regionally accredited postsecondary educational institution that apply toward a baccalaureate degree and four academic quarters or the equivalent in an accredited college, school, or department of mortuary science; or (ii) complete a twenty-one month program in an accredited college, school, or department of mortuary science approved by the board. Ind. Code Ann. § 25-15-4-3 (West). Additionally, a funeral director must pass the examination required by the board, have at least one year of continuous experience in the practice of funeral service under the direct supervision of a funeral director licensee, and pay the licensing fee set by the board for a funeral director license. *Id.*

To qualify for a funeral home license, an applicant must operate a funeral home that complies with the rules of the board and pay a licensing fee. *Id.* § 25-15-4-1. This requires a physical structure with a fully functioning embalming room. *Id.*

Most death doulas operate on a volunteer basis or charge very modest fees. Because of this, many have very small budgets and would be financially unable to comply with these requirements. Regulating death doulas as funeral directors will, therefore, decrease the availability of emotional and practical support as death doulas are forced out of practice. Accordingly, dying individuals and their loved ones



will be forced to turn to traditional healthcare workers that are ill-equipped to provide the full range of support that patients at the end of life require and to conventional funeral homes and funeral directors who offer limited services and options. *See Woo, et al., Clinical Challenges to the Delivery of End-of-Life Care at 369; see also Bureau of Labor Statistics, Occupational Outlook Handbook, Funeral Service Operations.*

At the same time, regulating death doulas as funeral directors will reduce the availability of information about the full range of after-death options to individuals. This may not have been an issue when conventional funerals were the norm, but individual after-death preferences have changed and continue to change. Tanya D. Marsh, *Rethinking the Law of the Dead*, 48 Wake Forest L. Rev. 1327, 1340 (2013). Today, a growing number of individuals want access to conventional funeral alternatives for emotional, cultural, spiritual, and environmental reasons. *Id.* A lack of information about the full range of after-death options will impair an individual's ability to select the after-death option that best fits their values and make it more difficult for individuals to make empowered and informed decisions about what happens to their body after death. *See Woo, et al., at 368.* Doing so will undermine informed consent and patient-directed care by depriving individuals of the opportunity to decide the after-death option that is best aligned with their individual needs and beliefs.

Relatedly, regulating death doulas as funeral directors will reduce the accessibility of information about affordable after-death options. This will

disproportionately affect lower-income populations because they are often most dependent on funeral directors for advice after the death of a loved one. *See* Haneman, *Funeral Poverty* at 406-07, 412-13. To pay for the expensive funerals these vulnerable individuals are advised that they need, many must turn to loans with expensive interest rates. *Id.* at 402-03. Depriving consumers of access to information that death doulas provide on affordable funeral alternatives will further encourage these practices.

**C. Death doulas have a First Amendment right to provide information about end-of-life options and individuals have a right to receive this information.**

The First Amendment, as applied to the States via the Fourteenth Amendment, prohibits the government from passing laws that restrict speech. *Nat'l Inst. of Fam. and Life Advoc. v. Becerra*, 138 S. Ct. 2361, 2371 (2018). A law that targets speech based on its content is presumptively unconstitutional unless the government shows that the law is “narrowly tailored to serve compelling state interests.” *Id.*

As a threshold matter, death doula speech is subject to First Amendment protection because it is constitutionally protected “pure speech.” Death doulas educate their clients about after-death care services so that they can make fully informed decisions as they near death that align with their personal values, beliefs, and desires. Part of this education includes offering information about services that compete with conventional funeral home services like at-home funerals, green burials, and cremations. Providing this education involves disseminating factual information to clients both verbally and in writing, an activity that the Supreme

Court has recognized is protected by the First Amendment. *See Bartnicki v. Vopper*, 532 U.S. 514, 527 (2001) (recognizing that “if the acts of disclosing and publishing information do not constitute speech, it is hard to imagine what does fall within that category . . . .” (some internal quotation marks omitted); *see also Lovell v. City of Griffin, Ga.*, 303 U.S. 444, 452 (1938) (recognizing that “[the] liberty of circulating [information] is as essential . . . as [the] liberty of publishing [it].”). And, a death doula’s clients have a right to receive this information. *See Martin v. City of Struthers, Ohio*, 319 U.S. 141, 143 (1943) (holding that the First Amendment protects the right to distribute *and* receive literature); *see also Stanley v. Georgia*, 394 U.S. 557, 564 (recognizing that “the Constitution protects the right to receive information and ideas.”).

To the extent that the information death doulas provide is factual and not intended to solicit or advertise a commercial transaction, their speech is not commercial in nature. *See Bolger v. Youngs Drug Products Corp.*, 463 U.S. 60, 66 (1983) (explaining that commercial speech is “speech which does no more than propose a commercial transaction”) (some internal quotations omitted). But even if this death doula speech is considered commercial in nature, it is still entitled to First Amendment protection. The Supreme Court has long held that commercial speech enjoys First Amendment protection if it concerns lawful activity and is not misleading. *Central Hudson Gas & Elec. Corp. v. Pub. Serv. Comm’n of N.Y.*, 447 U.S. 557, 566 (1980) (holding that “for commercial speech to come under [First Amendment] protection, it at least must concern lawful activity and not be

misleading.”). Death doula speech is protected, even if commercial in nature, because it concerns lawful activity—namely, disseminating information about legal, conventional funeral alternatives like at-home funerals. *See Krawczyk, Describing the end-of-life doula role and practices of care* at 7. It is also not misleading because death doulas do not represent themselves as funeral directors or medical professionals. On the contrary, they represent themselves as individuals who have no specialized training or skills. *See id.* at 1.

Moreover, requiring death doulas to be licensed as funeral directors simply because they provide information about affordable funeral alternatives is a content-based restriction on speech. *See Nat’l Inst. Of Fam. And Life Advoc.*, 138 S. Ct. at 2371 (stating that content-based discrimination “target[s] speech based on its communicative content.”). But the government does not have a compelling interest to justify this content-based restriction. Death doulas do not provide services that undermine public health and safety since, unlike funeral directors, they do not offer embalming services and do not handle corpses to the same invasive extent. *See Krawczyk* at 7. Even if the government had a compelling interest in treating death doulas as funeral directors, requiring *every* death doula to be licensed as one is not the least restrictive means of achieving the state’s alleged compelling purpose. Treating death doulas as funeral directors would require them to invest in facilities to store and embalm corpses, even though they do not offer these services—the cost of such a facility alone would force most death doulas out of practice. It would also prohibit death doulas from providing *any* information or services (even information

and services that have no bearing on the government's alleged public safety or consumer protection interests) without being licensed.

That death doulas view themselves as “professionals”<sup>27</sup> does not diminish their First Amendment right to inform their clients. The Supreme Court has held that professionals have equally as strong First Amendment protections in their communications as non-professionals. In *National Institute of Family and Life*, pro-life organizations challenged the California Reproductive Freedom, Accountability, Comprehensive Care, and Transparency Act arguing that it violated the First Amendment. 138 S. Ct. at 2370. The Act required pro-life centers in California to post flyers in their clinics notifying women of free or low-cost abortion services as well as contact information for obtaining those services. *Id.* at 2369. The Ninth Circuit held that the organizations' speech enjoyed lessened First Amendment protection because it was professional speech. *Id.* at 2371. The Supreme Court disagreed, stressing that speech is not subject to lesser protection merely because it is “professional.” *Id.* at 2371-72. Given this holding, it is clear that death doula

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<sup>27</sup> “Professional” was a legal term used by some Courts of Appeal in performing a First Amendment analysis justifying lessened First Amendment protections for “professional speech.” See *Nat'l Institute of Family and Life Advocates v. Becerra*, 138 S. Ct. 2361, 2371 (2018). Those courts defined “professionals” as individuals who provided personalized services to clients and who were subject to a generally applicable licensing and regulatory regime. *Id.* Though death doulas view themselves as professionals in the sense that they conduct themselves in a courteous, conscientious, and businesslike manner, they are not subject to a generally applicable licensing regime and are therefore not “professionals” for purposes of a First Amendment analysis. See *Id.* at 2372.

speech is subject to the same First Amendment protection as non-professionals even if their communications can be classified as professional.

Because regulating death doulas as funeral directors would infringe on their First Amendment rights and the rights of their clients, they should not be regulated as such.

## CONCLUSION

Restricting the speech of death doulas does not advance any compelling governmental interest. Death doulas are individuals who provide holistic, non-medical support and information to empower the dying and their loved ones at the end of life. They fill a void in traditional healthcare and funeral services and advance patient-directed care. Finally, death doulas should not be subject to the same regulations as a conventional funeral home or funeral director. They do not offer services that touch the operations of funeral homes or funeral directors. Regulation of death doulas will severely restrict their ability to provide information about end-of-life options and will hurt patients. And death doulas have a First Amendment right to provide information about end-of-life options and individuals have a right to receive this information. For these reasons, *amicus* urges the Court to rely upon the accumulated experience and knowledge of experts around the nation who have concluded that death doulas fill an important gap in the end-of-life continuum and why they are so critical to the dying and their families. For the foregoing reasons, we respectfully request that the Court affirm Chief Judge

Brady's conclusion that a preliminary injunction preventing the State from restricting the speech of Richwine is warranted.

Respectfully submitted,

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**CERTIFICATE OF COMPLIANCE**

Pursuant to Federal Rule of Appellate Procedure 32(g), I hereby certify that the foregoing brief of Compassion & Choices as *Amici Curiae* in Support of Plaintiffs-Appellees complies with (1) the typeface requirements of Federal Rule of Appellate Procedure 32(a)(5)-(6) and Cir. R. 32(b) because it was written in Century Schoolbook, 12-point font, and (2) the type-volume limitations contained in Cir. R. 29, because it contains 6,981 words, excluding those parts of the brief excluded from the word count under Federal Rule of Appellate Procedure 32(f).

Dated: July 3, 2024

*/s/ John Kappos*

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John Kappos



**CERTIFICATE OF SERVICE**

I hereby certify that a true and correct copy of the foregoing brief of Compassion & Choices as *amici curiae* in support of Plaintiffs-Appellees was electronically filed with the Clerk of the Court for the United States Court of Appeals for the Seventh Circuit on July 3, 2024 using this Court's CM/ECF system, and service was accomplished on counsel of record by that means.

*/s/ John Kappos*

John Kappos