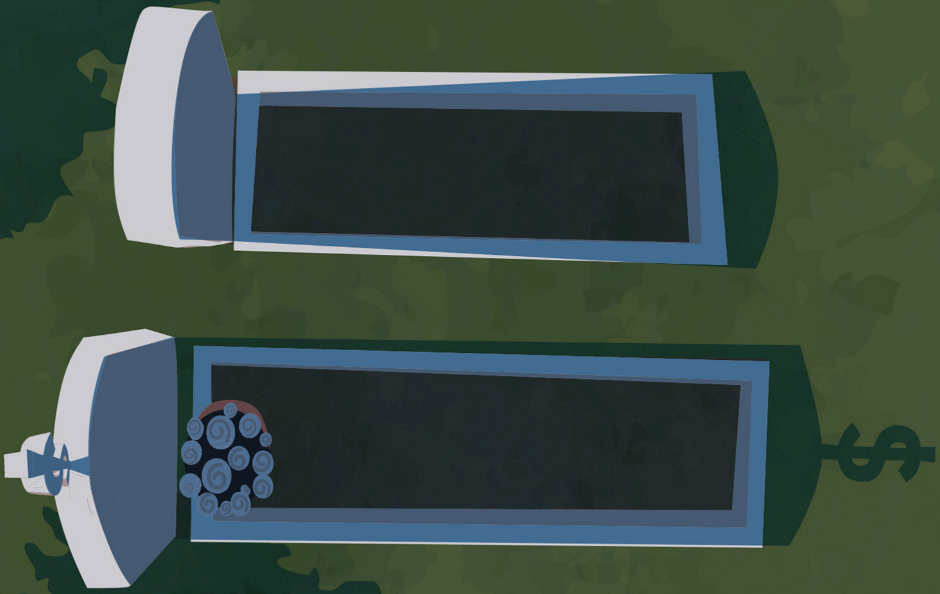
EQUITY at the END

The New American Way of Death



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Equity at the End: The New American Way of Death

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INVESTOR IN PEOPLE

We thank our dads, who we miss, and our moms.

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About the Authors

Staci M. Zavattaro, PhD, is a Professor of Public Administration at the University of Central Florida. Her work focuses on the public management of death, understanding how public servants handle death work. She served as a Durham Collections Fellow at Durham University doing archival research with records from The Cremation Society of Great Britain. She is a certified Disney Adult.

Jennifer L. Wright-Berryman, PhD, MSW, is an Associate Professor of Social Work at the University of Cincinnati. Her work centers on youth suicide prevention and equal deathcare in the United States. She is the Co-founder of Equal Deathcare, a web resource for LGBTQIA+ people and their families, and her work has been featured in academic journals and The Funeral Service Insider (publication and podcast). She lives in the Midwest with her husband.

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Introduction

We became friends in the usual way people do—at a funeral home.

Jennifer arrived first to meet with Tee Rogers, a funeral planning advisor and long-time advocate in the Central Florida community for death care rights for the lesbian, gay, bisexual, queer, intersex, asexual, plus (LGBTQIA+) and secular communities. The funeral home was the site of a Central Florida Foundation Table Talk, which was part of a community-wide effort to bring together leaders on various issues facing the local area and beyond. Tee's Table Talk focused on challenges surrounding death equity, including religious and spiritual needs, LGBTQIA+ rights, legal questions, organ donation, and body disposition options. The idea was to bring people together to identify solutions and resources to make death care more accessible and equitable to LGBTQIA+ and secular communities. When we were introduced, the two of us immediately fell into a deep discussion about how to combine our research efforts to carry this work forward. And here we are now, writing this book.

The meeting room at the Dignity Memorial funeral home was set up with round tables and chairs. The carpet and walls were traditional funeral home mauve, meant to fade into the background as families use the space to think about death planning needs. That day, life was infused into the space as people chatted around tables decorated with rainbow pride flags, promotional materials from participating organizations, and snacks. In attendance were academics, lawyers, death doulas, funeral home employees, loss survivors, and nonprofit organizers. Attendees settled at tables, eager to collectively find ways to create safe spaces for marginalized communities to find and receive the kind of death care they deserved.

Soon after the Table Talk, Jennifer started a coalition to keep the conversation going. Through these conversations, we found that our areas of expertise complemented each other, and if we united our efforts, we would have something comprehensive to offer. Though Jennifer is a social work scholar, and Staci studies public service, our research interests focus similarly on the intersection of the public, nonprofit, and private sectors administering deathcare in the USA.

The result of our partnership is found in these pages, which can be defined as both an educational tool and a call to action. We have spent years studying deathcare policy and implementation, and the impact of those on equity. Sometimes the public sector (e.g., policymakers and public administrators) takes the lead, while others in the private sector (e.g., funeral providers) drive policy and

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implementation. It is these entanglements that make the American deathcare system startlingly complex. A largely privatized industry that is often mechanized and secretive—confounded by incongruous death management jurisdictions in the country—the focus of the funeral industry, specifically, is profit and fighting regulation. In contrast, the public sector, such as some cemeteries, medical examiners, and coroners, prioritizes policy implementation under resource constraints. What gets lost in these competing agendas, and what we want to bring to light fully, is a focus on death equity at the individual level. What we mean by that is how these policy complications and private sector demands affect various death equity elements for individuals receiving and providing death care services.

Before we dive in, we want to share our stories of how we came to research something many Americans tend to avoid talking about—planning for, and coping with, death. Neither of us started our careers in death scholarship. Yet, we both landed here, having observed the lack of public understanding of this topic and the importance of making this complex system more transparent and accessible.

Staci's Story

I have always loved old cemeteries. I can only explain that cemeteries bring me peace, a sense of calm in a tumultuous world. When I walk into a cemetery, I feel grounded. It has become a running joke that I will absolutely find a cemetery wherever I go. Indeed, *not* finding one would be rarer. To me, cemeteries are the best museums. Buried beneath our feet is a place's history, for better or worse. Cemeteries, though, get neglected, paved over, forgotten. The people, then, become little more than a blip rather than a thriving memory.

In college, I was also swept up in *CSI* fever. The popular, long-running television show had recently premiered, and everyone wanted to become a forensic scientist solving crimes neatly within an hour. I had no idea what I wanted to do, but I wanted to learn more, so I took a forensic anthropology class from one of the country's leading scientists, who is still regularly called in to provide identification during some of the worst disasters. I stocked my bookshelves with titles about death and dying. I was the police reporter for the college newspaper, covering everything from stolen bikes to a state execution. Once I realized the science and math involved in becoming a forensic anything, well, that was the end of the road for me. I was better at telling stories anyway. I became a journalist instead.

After I finished my PhD, my research focused on place branding and marketing, and wanting to know how cities undertook these efforts. I concerned myself with local governments rather than tourism agencies, trying to understand the time, money, resources, and return that went into developing, communicating, and evaluating place branding campaigns. This is a far cry from studying death. But even throughout that time, cemeteries still captured my imagination. I remember being at a conference in Switzerland, and each morning on the train ride into the conference location, I would pass a cemetery in the distance. I had no idea what it was called, but I was determined to find it. One day, on a lunch break, I put the word "cemetery" into my phone's map app and took my lunch there. I like to say I had lunch with Coco Chanel. Sure, it was her place of burial, but it remains a great story to tell. At one conference in Wyoming, I dragged my doctoral student to a cemetery when we needed a break. A conference in Chapel Hill, North Carolina, took place on campus directly across from a cemetery, so clearly my dream came true. If anyone wondered where I went, all they had to do was cross the street to find me sitting on a bench, wondering why this cemetery with some of the city's founders was in the middle of campus.

I never imagined death could become a research interest until I participated in a project studying the aftermath of the Pulse nightclub shooting in 2016, at the time the worst mass fatality shooting event in the country's history. That June evening, a man walked into an LGBTQ+ nightclub in Orlando and murdered 49 people simply wanting to dance. I was part of a four-person research team working with City of Orlando officials to understand the response. With more than 700 pages of interview data and 40 interviewees, 2 people stood out: the city cemetery manager and the county medical examiner. They had to maneuver around politics, resource scarcity, and burial rules to handle the shooting's aftermath. I found this interesting from my disciplinary perspective—do we think of death management as a public sector problem?

Realizing the answer was "not really," I began exploring this line of research. I started with a book about municipal cemetery management. Mostly, my interest was to understand how and why public servants managing city cemeteries do what they do. These deceptively simple questions allowed me to put my journalism training to use, talking to people, learning their stories, and sharing their insights. I began asking cemetery managers how they got into the job, the challenges they faced, what they enjoyed, how they got resources, what they wish they had, and what they want others to know. From there, my research spread into medical examiners, coroners, and other death managers throughout the USA. Some might dismiss my research as too descriptive, yet I have unlocked this often unseen, misunderstood, and vastly vital aspect of public service.

One question I often get asked is where is my favorite cemetery? That is a difficult question for me to answer, as I have seen so many that are special. I enjoyed visiting the Gettysburg National Cemetery because it began the national cemetery movement in the USA. Mount Auburn Cemetery in Massachusetts was gorgeous, which is not surprising given it was the country's first rural garden cemetery, an idea imported to the USA from Europe. New Orleans cemeteries are always standouts for their beauty and above-ground burial needs. The tiny cemetery in Talkeetna, Alaska, was where a woman invited a friend and I to the Memorial Day potluck at the Veterans of Foreign Wars building. (We could not stay, or we would have missed our bus back to our hotel, and we both still regret not being able to attend.) Anchorage is where I met a cemetery manager whom I interviewed for my research, and he took me on a personal tour of the cemetery many years after we connected via phone. But so far, the most beautiful cemetery I have visited is in Budapest. Kerepesi is the national cemetery, and it is arrestingly gorgeous. Monuments are sprawling, made of the finest marble. Some are destroyed and deteriorated, lending a creepy look. When my friend and I were there, it was a cold December day, and the cemetery was covered in a layer of snow. The gray in the sky and birds screeching overhead brought a haunting quality. We both walked in awe as Kerepesi's memorials got more beautiful by the step.

I have been fortunate in my research to talk with so many dedicated public servants who actively choose to surround their lives with death. I am a conduit to tell those stories, while also keeping mine close to my heart.

Jennifer's Story

During the 2014–2015 school year in my smallish Midwestern hometown, we lost three teens to suicide. Two of them were well-known by my daughter, who was the same age. She pled with me to fix the problem of suicide so that no more kids died. At the time, I was a newly appointed academic at the University of Cincinnati, and my research focused on serious mental health disorders. Feeling my daughter's call to action deeply, I began a grassroots project aimed at reducing teen suicide in my town. This led me to research the topic, which resulted in my becoming a suicidologist.

At a suicidology conference a couple of years later, I overheard two colleagues discussing the lack of death care knowledge in our field. We all studied a stigmatized form of death—suicide—yet we did not know much about how the death care system worked for those lost to suicide. How were they remembered? How well did the death care system understand these deaths? Did we educate our young people on death care? How well do adults who lost a loved one to suicide navigate the death care system? My curiosity drove me to find the answers, and I went on a journey to discover as much about the USA death care system as I could.

During this time, I noticed a stark absence of LGBTQIA+ voices in the death care research literature. As an advocate and member-ally of the LGBTQIA+ community, I discovered that although there are unique death care needs for sexual and gender minorities and their families (and chosen families), there was no research exploring the barriers and solutions to equitable death care for this marginalized community. I sought to fix that and recently completed a three-year study investigating equitable death care marketing, policy, and practice in the USA.

The Goal of the Book

Although our death care research origin stories are different, we have the same goal: to shed light on disparities in legacy, memorial, and body disposition because everyone, everywhere, deserves a send-off that aligns with their life and their story. We also aim to educate readers on the vastness of the deathcare industry in the USA, from the public, nonprofit, and private sectors. We want readers to walk away with an idea about the equity issues that pervade so many aspects of death, burial, and mourning in the USA. Some might be clear, while others might be new to readers. Armed with this information, readers ideally can make informed choices for themselves and others when it comes to their own definition of a "good" death.

A quick note on terms before we continue. We use the word/phrase deathcare and death care not interchangeably throughout the manuscript. When we write deathcare as one word, we are referring to the infrastructure, rules, policies, and procedures surrounding the administration of death and dying. When death care is two words, we mean the people, items, and resources needed when it comes to end-of-life planning and care. The two are naturally intertwined, as some of the deathcare mechanisms and limits affect those providing and seeking death care.

Moreover, chapters throughout the book draw on our personal research from our disciplinary perspectives. Staci's research includes interviews with more than 50 deathcare public servants at the federal, state, and local government levels. Jennifer's work includes studies examining the inclusivity of funeral home marketing, deathcare policy, and funeral home services (from interviews with 23 death care providers and consumers). Along the way, we both have also had numerous conversations, observations, and personal experiences adjacent to our research. We will share some of these as well.

Chapter 1 sets the foundation for the book by explaining the landscape and complexities of the American deathcare system that is beholden to federal, state, and local laws. We also draw on Jessica Mitford's classic book *American Way of Death* to explore the historical changes and current intersections of private-sector funeral and death care provision rife with implementation barriers stemming from confusing policies.

In Chapter 2, we define death equity, the major contribution of this volume, and where our research interests intersect. We draw from and build on definitions of health equity to develop a definition of death equity:

> *Access to a person's death care preferences regardless of gender identity, sexual orientation, religion, socioeconomic status, or geographic and environmental location.*

Throughout the book, we dive into various social equity challenges that come with death and dying in the USA as we write this book. Admittedly, those conditions are changing rapidly with the erasure of many diversity, equity, and inclusion policies, along with dwindling social safety nets. That is why this book and view are important, so people can consider all the ways in which equity issues mount when it comes to death and dying. Some issues might be expected, like the cost or personal burial preferences. But we hope readers might not know much about deathbots, or green burial narratives, or rights when it comes to embalming, or state policies affecting alternative body disposition.

We describe how a person's personal characteristics and geography can be stigmatized or marginalized, such as being poor in rural USA. We expand on broader social equity concerns and why these concerns are important factors related to death management. This chapter is an overview in which we outline these challenges briefly before devoting the book's remaining chapters to explaining them in greater detail. Each chapter draws out some of the equity concerns surrounding deathcare and death care found in our definition.

Chapter 3 reflects on the barriers to a "good death:" when someone's end-of-life and death care matches their preferences and pre-arrangements. Equity concerns, however, often limit these best-laid plans. Throughout the chapter, we trace the evolution of body disposing practices in the USA, starting with the medicalization of death, to the shift of death and dying from the home to today's funerals, then to more recent variations on body disposing methods, such as cremation, green burial, and aquamation (also known as water cremation or alkaline hydrolysis). Although we spend a great deal of time on the barriers to a good death, we will also offer some solutions.

Chapter 4 focuses on barriers and solutions to equitable death care for sexual, gender, and religious minorities. In reminiscing about our first encounter at the funeral home, we were reminded how funeral homes may feel unwelcoming to those who do not align with a "normative" gender, sexual, or religious identity. Many funeral homes explicitly display Christian symbols and iconography. This could feel exclusionary to anyone outside of Christianity or to anyone who might have been psychologically wounded by religion. In this chapter, we explore how death care settings and professionals inadvertently (or intentionally) turn people away and the policy protections for marginalized communities. We describe death care safe spaces and how people from LGBTQIA+ and secular communities can take steps to arrange and protect their preferred death care plans.

In Chapter 5, we explore equity concerns surrounding the cost of death and body disposition in the US funeral poverty is rampant because burying or cremating a loved one is expensive. What happens when people cannot afford to bury or cremate a loved one? Sometimes, government agencies can step in as was the case during COVID-19 with federally funded funeral assistance. Other times, the public sector's hands are tied. Yet, many bodies go unclaimed and are left for the publicly funded death care service providers to handle. In this chapter, we detail some of these challenges and debunk myths of body dispositions for the poor.

Chapter 6 provides a picture of environmentally friendly death care options, calling attention to how even in death, the body can become a political tool for environmental justice. We detail how cemeteries can be environmentally *unfriendly*, yet the increase in cremation has caused concerns about pollution. Not surprisingly, there also is often resistance to setting up official green burial spaces, as bodies are not buried in traditional caskets but are placed in shrouds (sometimes) close to ground level. We focus on the corpse as a politicized entity, the dead turned into a symbol of the struggles of the living.

In Chapter 7, we highlight the death care barriers of stigmatized and underrepresented populations, such as those living with mental illness, those who die by suicide, the poor, the unhoused, and those society has otherwise ousted. This chapter demonstrates how death care remains largely inaccessible for these underserved populations. Chapter 8 explains the challenges those providing death care face. Specifically, we draw on concepts of "dirty work" and emotional labor to understand the difficulties death care providers face when doing their jobs. We evaluate the disparities in resources between public servants (who are often resource constrained) and private providers (who may thrive or suffer in a capitalist market economy). We detail how private funeral providers are faced with leaving traditions behind to respond to today's changing and dynamic death care landscape.

Death care providers are themselves stigmatized, and this chapter offers stories about struggling and coping.

Chapter 9 centers on expanding death literacy. As we noted earlier, Americans are often reluctant to think about, talk about, or plan for death. Death literacy is one mechanism to overcome this challenge. We offer the following ways to think about death literacy: (1) making deathcare part of health care; (2) autopsy training and access in medical school; (3) including death managers in strategic planning; (4) increasing transparency in funeral and body disposal costs; (5) training burial providers on cultural competency; and (6) expanding clinical training to include death care and death care equity. Chapter 10 expands on these suggestions, and our prior chapters, by offering teaching resources such as case studies drawn from our research. We envision instructors in university, clinical, and practical settings can use these case studies to think about the various intersecting equity concerns and how to address them.

Why This Book?

The timeliness of this book cannot be overstated. We passionately believe that because death comes for all of us, and its expense is personal and financial, the issues of equity and equitability in death care require immediate attention. Like weddings, buying a house, furthering education, or learning a trade, death is a major life event, and if ignored, could result in lasting consequences for a person's legacy and the well-being of those left behind.

We draw attention to our title. We purposefully return to Jessica Mitford's phrasing to showcase how the new American way of death is surrounded by equity issues. Her book focused on some of those challenges, and we draw out more in contemporary times. We know readers might be familiar with some of those concerns, while others might be new to readers.

We do not have a crystal ball. We do not know when we will die. Preparing for death care does not require preparing psychologically for death (although we would argue we should, but that is a challenge for another book, so please see our references and reading list for more information on this). We have written this book so that those in all areas of public and private service might spread relevant and essential information to people who need it. Which, in our estimation, is everyone.