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REIMAGINING END-OF-LIFE CARE

BRIDGING SYSTEM GAPS IN HOSPITALS AND INTENSIVE CARE UNITS (ICU) TO REDESIGN THE EXPERIENCE OF DYING

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ABSTRACT

This Major Research Project explores how end-of-life care in Intensive Care Units (ICUs) can be reimagined to ensure the dying's dignity, autonomy, and emotional well-being. Despite the curative focus of acute hospital care, a significant proportion of patients die in ICUs—often surrounded by invasive technologies, under stress, and without adequate emotional, spiritual, or relational support. The guiding research question asks: How might we redesign the ICU experience to ensure all patients achieve a “good death” that reflects their values, minimizes suffering, and incorporates patient-centered design, spirituality, dignity, and cultural dimensions into the dying process?

Employing a human-centered design and strategic foresight approach, the study draws on qualitative interviews with palliative care physicians, policy advisors, and interdisciplinary practitioners and a survey of loved ones who have firsthand ICU and hospital experience of their loved one’s death. Methodologies include system mapping, speculative interventions, and thematic analysis. Findings reveal critical gaps in current care, including poor communication, lack of continuity of care, and minimal emotional or cultural support for patients and families.

Participants emphasized the need for earlier integration of palliative care, team-based approaches, and a broader definition of the “patient", including loved ones, spiritual care providers, artists, designers and community. The project offers future-oriented recommendations and calls to action to inform more compassionate, inclusive, and relationally grounded ICU design, reframing the experience of dying as a meaningful part of life, rather than a medical failure.

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INTRODUCTION AND CONTEXT

1. Research Question

How can hospital-based end-of-life care in acute settings, such as the Intensive Care Unit (ICU), be redesigned to ensure that all patients achieve a “good death” that reflects their values, minimizes suffering, and incorporates patient-centered design, spirituality, dignity, and cultural dimensions into the dying process?

Sub-Questions

Death Denial and the Medicalization of End-of-Life Care

- How does hospital culture, focusing on curative interventions, shape patient and loved one’s experience at end-of-life?
- How does discomfort with death by patients, physicians, and healthcare workers contribute to a culture of death denial?
- What are the barriers to transitioning from ICU-based dying to palliative and home-based care?

A Good Death: Free of Unnecessary Suffering

- How can hospitals improve early integration of palliative care to reduce unnecessary suffering?
- How can interdisciplinary teams, including death navigators and death doulas, prepare the dying and their loved ones for a less anguished death?
- How does the ICU and hospital environment impact the dying experience for patients and their loved ones?
- How can creative interventions, such as art, music, storytelling, and legacy projects, support patient's and loved one's psychological and spiritual well-being during end-of-life care?
- How do we normalize the experience of dying and conversations around it to prepare us for end-of-life?

Community and Home End-of-Life Care

- What systemic reforms could improve hospital-based end-of-life care?
- How do international palliative and home-based care models compare to current North American hospital practices?
- How can communities and greater home-care infrastructure support the dying and their caregivers?

1.1 Mixed Methods Research Approach

This study employs a mixed-methods research approach to provide a comprehensive understanding of end-of-life care experiences, gaps, and improvement opportunities.

- Secondary Sources: This includes quantitative and qualitative research, including policy reports, system trends, medical journals, and data on the costs of end-of-life care in ICU units, to identify systemic inefficiencies and their economic and psychological impacts.
- Qualitative Analysis: This approach involves subject matter expert (SME) interviews, a tour of a palliative care unit, and a thematic literature review to explore human-centered perspectives on the experience of death and dying. A survey was conducted with 21 loved ones who had supported a family member or friend through end-of-life care, gathering personal insights into experiences with hospital, hospice, and home-based dying.
- Integration of Findings: By combining data collection insights with human experiences, this research ensures a balanced approach to understanding the challenges and opportunities in reimagining hospital-based end-of-life care and where the divergence exists between personal experiences and institutions.

1.2 Context and Significance: Most Deaths are Traumatic

- The disconnect between what patients want—a peaceful, dignified death at home—versus what the system provides ICU-based interventions and medicalization, where a continuum of care is lacking.
- End-of-life care often results in trauma for patients, loved ones, and healthcare workers, complicating grief and leading to post-traumatic stress for loved ones and healthcare workers.
- Hospital culture, design, and policies shape how patients die—but often in ways that do not align with best practices for a death where one feels dignity and autonomy.

1.4 Introduction

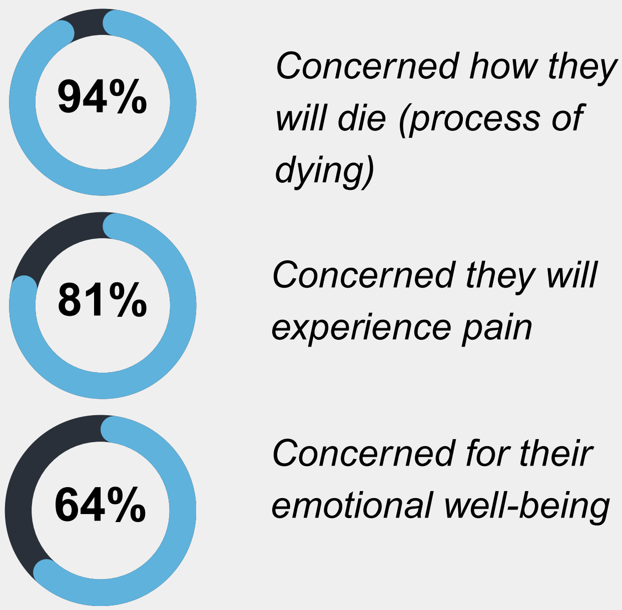
We are all entitled to a “good death” that aligns with our values and wishes—one that is free from unnecessary suffering, surrounded by loved ones, and where our physical, emotional, and spiritual needs are compassionately supported. However, our Western healthcare system presents many barriers to a dignified end-of-life experience. Significant economic and social obstacles can hinder access to quality end-of-life care (Field & Cassel, 1997 and Dosani, 2024). This paper will explore how we can begin to untangle the complexities of end-of-life care and our relationship with death.

In the 15th century, dying was accompanied by accepted customs, and guides to death were widely circulated. People stoically embraced the end of life, facing it with neither fear nor pity (Gawande, 2014). In contrast, today, death is often feared and kept hidden from daily life. In Western healthcare systems, we encounter what many call a “death dilemma”, where aggressive medical interventions are prioritized over acceptance, holistic care, and finding meaning in the end stages of life.

As a researcher, policy advisor, designer, and daughter who witnessed both of my parents die in hospital settings marked by trauma and indignity, this work is profoundly personal to me. It also highlights an emerging ethical dilemma in hospitals, where many people experience a lack of autonomy at the end of life. Once people learned about my research, they often felt compelled to share their own stories of death and grief. This willingness to discuss topics that are often considered sad, and taboo lies at the heart of this project.

According to the study, *Defining a Good Death* (Meir et., al. 2016), core themes that patients stated constituted a good death include their preferences for a specific dying process, pain-free status, emotional well-being, religiosity and spirituality, life completion, treatment preferences, dignity, family, quality of life, and the relationship with their health care provider.

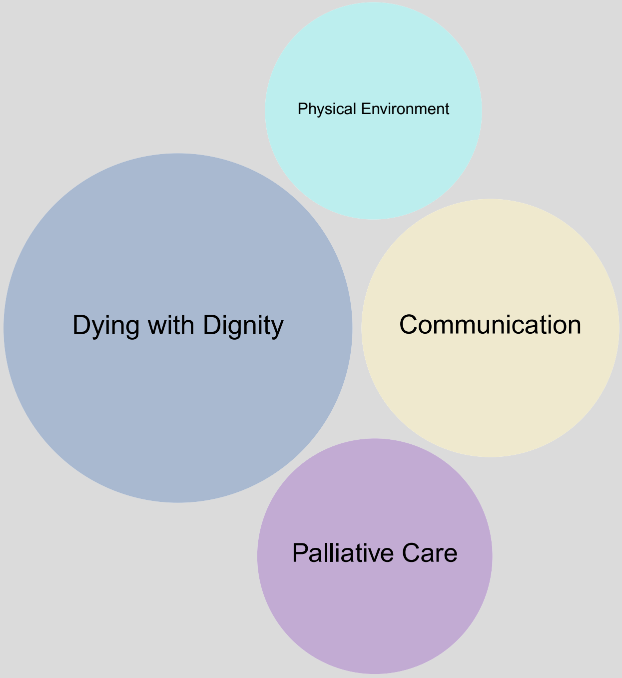
Figure 1: Concerns of the Dying (2016)



Source: Meir et. al., 2016, *Defining a Good Death, The American Journal of Geriatric Psychiatry*

In conversations with subject matter experts including: senior policy advisors, researchers, palliative care physicians, nurses, designers, advocates, and spiritual care providers, recurring themes emerged around how to reimagine end-of-life care. Central to these discussions was the act of dying with dignity—emphasizing autonomy, patient choice, advocacy, and the importance of multidisciplinary teams and spiritual care. Communication was another key concern, particularly how healthcare workers engaged with families, informed consent practices, and the broader lack of preparation and dialogue around death and dying. Access to quality palliative care, including specialized teams, equity, and clearly defined goals of care, also surfaced as critical issues requiring systemic change. As well as, the physical environment—including access to nature, spiritual spaces, privacy, and overall sensory experience—was consistently identified as a significant gap in current end-of-life care (Refer to Figure 2).

Figure 2: Key gaps and opportunities regarding end-of-life care amongst subject matter experts



Sourced: First-person interviews, 2024-2025

Our reliance on hospitals to guide our experiences with death requires a shift in mindset—from viewing death as a medical failure to recognizing it as a profound and natural transition. As writer and palliative care physician Sunita Puri, notes in her book *That Night*, “*Many of my patients feel they’ve barely lived by the time I arrive to help them die comfortably . . . My role is to ease their pain, support their families, and guide them through the emotional, practical, and spiritual challenges of dying*” (Puri, 2019).

This evidence-based paper explores how better design, communication between health care providers, loved ones and the dying, advance care planning, spiritual and emotional support, and creative interventions can restore humanity in end-of-life care. If we begin to talk about death earlier, teach it in schools, prepare for it in policy and practice, and see it not only as loss but as legacy—we can build systems where death cannot be avoided and feared but be faced with grace.

While this research focuses on the emotional, cultural, and systemic redesign of end-of-life care, it is essential to acknowledge that MAID—Medical Assistance in Dying—has profoundly reshaped how we think about autonomy and dying in Canada. MAID raises ethical, legal, and spiritual questions that remain deeply contested, particularly as access may expand to include individuals with mental illness or those seeking advance requests.

As a senior policy advisor for the province of Ontario, working on MAID policies, shared in conversation, *“At baseline, it is contentious. Difficult conversations are not something all providers are prepared to have.”* (Senior policy advisor, personal communication, August 2024) While MAID is a significant contributor to the landscape of end-of-life care and how it is shifting, the complexity of MAID warrants dedicated research and exploration which is beyond the scope of this paper. Yet, I wanted to acknowledge its significance and potential to provide great dignity and autonomy for those who choose it.

This project aims to reimagine how we die—not as a medical emergency but as a collective responsibility that invites community, creativity, and compassion. We are more than ever disconnected from the realities and messiness of dying. This paper seeks to open a dialogue on how we can better care for those who are dying and explore how to humanize the experience of dying in intensive care units and hospitals. Additionally, it will discuss the importance of allowing death to occur more often in our communities and homes.

To move toward a more compassionate future in end-of-life care in the hospital and beyond, we may need to question long-held assumptions about what it means to die well. This paper invites us to reimagine death as a profoundly human and universally shared experience—that calls for presence, and preparation. By engaging with the voices of caregivers, experts, loved ones, and designers, we can begin to design systems that uphold dignity and ensures no one dies feeling alone, unseen, or unheard. What is often missing in end-of-life care is not more medicine but often more meaning.

Intended Audience

In researching end-of-life care, it became evident that it involves multiple systems, and there are decision-makers and policymakers across government, healthcare institutions and advocacy organizations that all contribute to the experience of dying. Therefore, the intended audience includes all those looking to reshape end-of-life care and understand how to improve this experience, from caregivers of the dying to policymakers, to healthcare providers hoping to know how to deliver more compassionate care, and to educators interested in integrating death literacy into public life, and advocates, artists and designers that are looking to reshape our experience of dying. By addressing and speaking to all these audiences, this work aims to promote a shift in how we support the dying.

1.5 Literature Review: Reimagining End-of-Life Care in the ICU and Beyond

Introduction to the Literature Review

The literature review conducted for this research project explores secondary research and first-person accounts of the systemic, cultural, and emotional dimensions that shape current end-of-life care practices, focusing on Intensive Care Units (ICUs). Drawing from palliative care literature and medical journals, ethical debates, news sources, healthcare design, and first-person narratives from healthcare providers and loved ones with personal experiences. This review identifies persistent barriers to a compassionate dying experience. These experiences leave the dying with a restless death experience, loved ones with ongoing trauma and guilt, and healthcare providers suffering from burnout. Literature highlights the potential of reimagined models of care that prioritize dignity, creativity, authentic communication, humanity and early integration of palliative care.

The Medicalization of Death

Modern healthcare has increasingly medicalized the process of dying, often transforming it into a clinical crisis rather than a natural event.

There are dilemmas within the healthcare system and amongst clinicians regarding when it is appropriate to withdraw aggressive medical intervention–calling into question what constitutes one's personhood and what it means to die. Technologies and machines such as ventilators and extracorporeal membrane oxygenation (ECMO) can sustain bodily function long after personhood is lost, contributing to what physician Blair Bigham (2022) refers to as “the death dilemma” This is the gray zone between what it means to be alive and when medical intervention is no longer effective – for instance for one who has an illness that may have progressed past the point of return to being able to live an independent life, or for the elderly whose survival may not entail quality of life. Surgeon and palliative care physician Atul Gawande (2014) emphasizes that the clinical need to treat death as failure leads to patients dying with *"chemo in their veins and tubes in their throats,"* often without adequate conversations about alternatives in care. This medicalization and inability to allow for a peaceful death perpetuates emotional and moral distress for providers and caregivers when making end-of-life decisions for the dying. (Nutik Zitter, 2021)

Death Denial and Lack of Advance Directives

Death denial is the inability to acknowledge we will all die and the importance of understanding what end-of-life care looks like. In our society, this denial leads to poor engagement with advance care planning. Advance care directives provide documentation of the dying person’s wishes for their end-of-life care, including the level of medical intervention they would want. Physician, Jessica Nutik Zitter (2021) critiques informed consent as insufficient when not paired with meaningful conversations about suffering, outcomes, and personal values.

Figure 3 : Percentage of Canadians who have Completed an Advance Directive for End-of-Life

Source: Canadian Hospice Palliative Care Association, 2020, What Canadians Say: A way Forward Survey Report

Defining End-of-Life Care in Hospital: Conflict of Ideology between Loved Ones and Clinicians

Institutional policies often obscure death, both physically and symbolically – which can lead to a culture that prolongs a sub-par quality of life. Northcott and Wilson (2022) in their book *Dying and Death in Canada (Vol.4*), describe how hospitals remove the deceased discreetly, reinforcing social taboos around death. Physician, Atul Gawande (2014) and palliative care physician Jessica Nutik Zitter (2021) write about how hospital culture regarding end-of-life treatment prioritizes heroic intervention over informed, compassionate withdrawal of care. Palliative care physician Sunita Puri (2022) states that families often describe their loved ones as "fighters," which reflects a societal failure to prepare for the realities of the process of dying and an understanding of when interventions may be causing more harm than good.

The Costs of ICU-Based End-of-Life Care

Aggressive end-of-life care comes at a high financial and emotional cost. Canadian bioethicist Kerry Bowman (2022, as cited in Bigham, 2022) critiques “ventilator farms'” in hospitals that sustain biological life without regard for the quality of life.

ICU admissions can cost up to $3,000 per day in the U.S. (Reardon et al., 2018). Zitter (2017) and Gawande (2014) note that procedures like intubation or PEG tubes often create prolonged physical suffering. The emotional toll also extends to loved ones, many of whom experience ongoing PTSD from the trauma of the ICU experiences and lack of dignity for their loved ones. (Petrinec & Daly, 2014).

Transitioning from ICU to Palliative Care

According to a palliative care physician and researcher, delays in initiating palliative care stem from provider discomfort and family denial (Palliative care physician and researcher, personal communication, 2024). Physician Jessica Nutik Zitter (2017) describes doctors emotionally distancing themselves from patients and their families once a cure is no longer possible, creating a gap in support during the final stages of the dying process. Medical anthropologist Margaret Lock (as cited in Bigham, 2022) and a retired palliative care nurse (Retired palliative care nurse, personal communication, 2025) speak of how the moral burden is placed on families who must decide to withdraw treatment, often with insufficient support and communication, and with an assumption that palliative care is a form of “giving up”.

Redefining End-of-Life Through Early Palliative Integration

The World Health Organization and provincial and federal Canadian policy frameworks increasingly recognize palliative care as a continuum of care that should start at diagnosis, not just at death's door (Alcalde & Zimmermann, 2022). The "7 C's" of palliative care: comprehensive, compassionate, collaborative, coordinated, continuous, communicative, and culturally competent—offer a patient-centered and values-driven model of care (Western Community College, n.d.). However, only a fraction of Canadian medical students receives palliative training. (Gagnon et al., 2020). This lack of training is especially detrimental because palliative care cannot be accessed without a referral from a physician, many of whom do not understand the full scope of its value or how it can accompany curative care and better prepare one for end-of-life with less pain and suffering.

Spiritual and Emotional Support as Essential Aspects of Care

Spiritual distress often intensifies during dying, regardless of religiosity and belief systems. (Connolly & Quinn, 2023). Physician Sunita Puri (2019) and advocate and palliative care physician Ira Byock (1997) describe death as an existential process that can be fraught or peaceful depending on one’s acceptance and support, which needs acknowledgment of the reality of existential questioning and angst. A shaman practitioner, death doula and Métis physician and educator (personal communications, 2024–2025) state that Indigenous, shamanic, or death doula support needs to be incorporated as valid forms of care to truly address the nuance of an individual’s spiritually pluralist end-of-life care needs. The World Health Organization (WHO) guidance also states that spiritual care is central to palliative medicine. However, spiritual care remains an afterthought in hospital environments.

Hospital Design and the Built Environment

Physical space shapes dying experiences. Natural light, privacy, and access to nature improve dying patients' and their families' quality of life (Sternberg, 2009 and McLaughlan, 2024). Research by Roger Ulrich (1984), a pioneer in “healing architecture”, demonstrates how architectural design, particularly incorporating natural elements and views, can significantly impact patient well-being and recovery, leading to shorter hospital stays and reduced stress. Many die in the ICU environment, which is chaotic, with inadequate accommodations for families who may be camped out at their loved one’s bedside or for the sensory regulation of the patient. (Health Quality Ontario, n.d.)

Creative Interventions in End-of-Life Care

Art therapy, music, storytelling, and rituals can reduce pain, foster emotional expression, and create a legacy during end-of-life care. (Collette et al., 2020 and Warth et al., 2015). Narrative medicine and cultural rituals offer frameworks for dignity and meaning (Edtstadler, 2023). Shaman practitioner and death doula (personal communications, 2024) feel that sound, ritual, and personal items reconnect patients with identity and peace, even amid clinical settings. Surveyed loved ones agreed that creative interventions could offer respite during an emotionally trying time and offer a fond parting memory.

Identified Gaps in Healthcare Systems

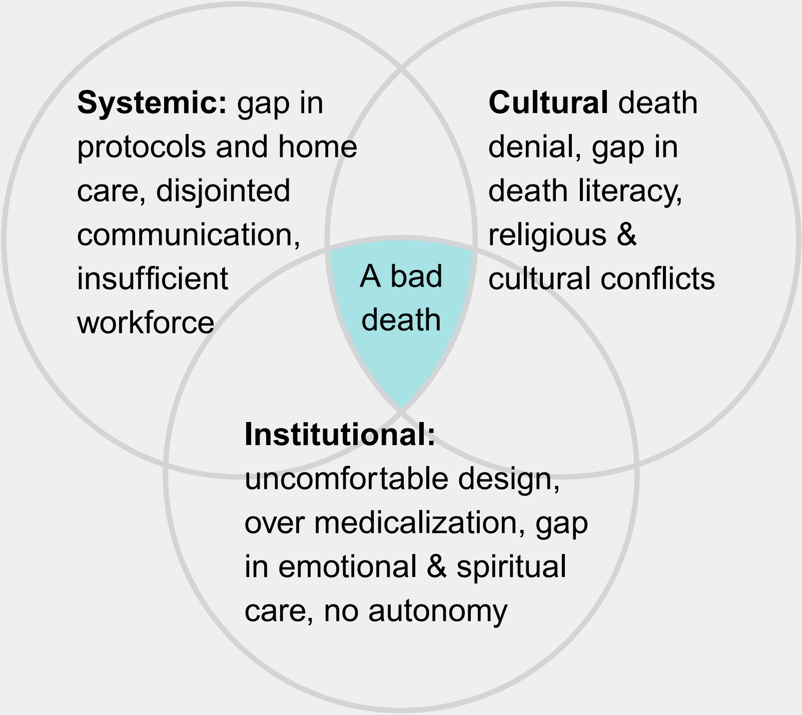
A worldwide pandemic and an aging population have resulted in policy advancements and care frameworks for end of life. However, quality of care is still implemented unevenly despite this growing awareness of the need for end-of-life care. There remains a lack of funding for palliative and hospice end-of-life care, a gap in interpersonal collaboration, and a lack of infrastructure for home and community-based palliative care–potentially limiting people’s options and autonomy in their end-of-life care.

Identity, socio-economic status, and geography all play a part in one’s ability to access dignified end-of-life care. Dr. Naheed Dosani (2023), who offers palliative care to the unhoused, speaks to how palliative care must address the social determinants of health, including housing, food, and cultural safety. Cultural sensitivity remains a key gap in end-of-life care, for not all feel safe navigating the medical system, nor do they have the support, and skills needed.

Summary of Key Themes

The literature consistently demonstrates that death in hospitals is often prolonged, impersonal, and misaligned with patient values and their loved ones. Redesigning end-of-life care requires systemic shifts in education, design, and culture. Quality care is holistic, person-centered integrating palliative care, spiritual support, and creative practice offer a way forward.

Barriers to a Good Death



BARRIERS TO A GOOD DEATH: MEDICALIZATION AND SYSTEMIC GAPS

2.1 The Death Dilemma: Ethical and Emotional Consequences of Medicalized Dying

Death has moved away from being treated as a natural part of living to being an event that takes place in medical institutions and is viewed as something to be cured. In 2021, approximately 68 million people died globally (Ritchie & Mathieu, n.d.). However, despite over a century of medical advancements which were believed to simplify the experience of dying, death has increasingly become one of society's most complex ethical and scientific challenges. The boundaries between life and death have grown increasingly blurred—entangling biological function, consciousness, and cultural interpretation.

Modern life-sustaining technologies have disrupted our once-clear definitions of death. Clinically, physicians distinguish between somatic death (when the heart irreversibly stops) and neurological death (when brain activity ceases permanently). However, technologies like ventilators can maintain breathing and warmth in brain-dead patients, creating the appearance of life. Further complicating this, extracorporeal membrane oxygenation (ECMO) circulates and oxygenates blood outside the body – sustaining life in individuals without a pulse (Bigham, 2022). These medical technologies challenge the conventional criteria for death.

In intensive care units (ICUs), nearly all bodily functions can be artificially supported and prolonged. Ventilators deliver oxygen, medication infusions sustain organ activity, dialysis machines filter blood, and feeding tubes provide nutrition. However, with each technological intervention comes an ethical dilemma: At what point does treatment shift from healing to harm?

Despite efforts to standardize definitions of death—such as Harvard Medical School's criteria for for irreversible coma or the *Uniform Determination of Death Act* (1981) in the U.S.—there is still no clear cultural or legal consensus. In Canada, definitions of death are determined provincially, contributing to inconsistencies in how death is recognized and managed (Bigham, 2022; Uniform Law Commissioners, 2001).

As emergency physician Blair Bigham writes in his book *Death Interrupted*, *"The death dilemma is, to some extent, a result of our often-indiscriminate application of technology… patients have ended up tethered to machines, unable to die, as their doctors stare at computer screens far away from their bedside"* (Bigham, 2022).

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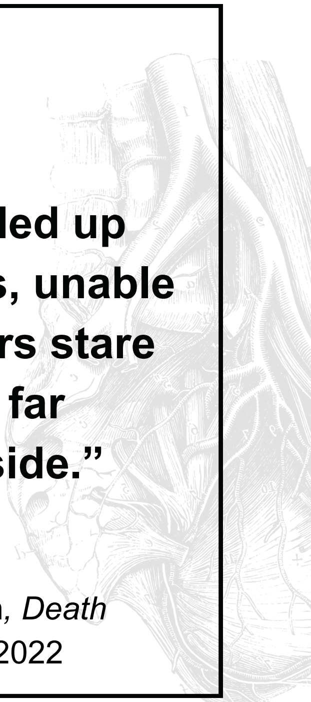
Dr. Blair Bigham*, Death Interrupted,* 2022



A Toronto-based palliative care physician emphasizes the emotional weight of end-of-life care decisions, and the unnecessary suffering aggressive medical intervention can cause.

“Every medical intervention has some amount of pain attached to it. Is it worth suffering to feel better after? Medical treatment should help you live better. ICU and intubation are traumatic, but they’re amazing if you can recover. To make an informed decision, you need to know the consequences” (Palliative care physician, personal communication, December 2024).

Loved ones and family members of the dying, too, often lack a full understanding of what care options are available due to gaps in communication between themselves and healthcare providers – leading to confusion regarding how to serve their loved one best. They believe medical intervention is the only path forward. “*There was little decision-making, but in hindsight, maybe there could have been questions. But no one asked us, so we did not know what options we had”* (Loved One Survey, February 2025). Often, death comes more quickly than the family imagines it will, and they are left to decide things in constrained circumstances, *“Her condition deteriorated quickly, her pain was not well addressed, and the whole ‘what is happening’ conversation was not well tended”* (Loved One Survey, February 2025).

Better training for bedside nurses, often closest to patients and families, is critical in normalizing the dying process by recognizing predictable signs, offering appropriate medications, and avoiding unnecessary interventions like routine vitals. Their ability to educate and comfort families through these changes can significantly reduce fear and support dignity in the final days. A shift in provider attitudes, language, and training is needed to help patients and families feel supported immediately—not just at the end (Palliative care doctor, personal communication, December 2024).

Ultimately, this uncertainty fuels a system-wide dilemma. Loved ones and physicians are left navigating medical gray zones and moral distress in a hospital landscape where machines can preserve bodily function long after personhood may be lost. The death dilemma, then, is not just about technology and prolonging life; it is about determining what it truly means to die.

2.2 Death Denial in Society: Lack of Advance Directives

Despite the inevitability of death, many people avoid planning for it—leaving families and clinicians to make complex decisions in moments of crisis. In Western medicine, the prevailing emphasis on prolonging life can overshadow meaningful conversations about dying. This reluctance to think and plan for death reinforces a cycle of avoidance and default medical interventions that may not reflect a person’s values or wishes.

A 2024 Canadian Hospice Palliative Care Association survey found that although 93% of Canadians believe it is essential to discuss their wishes for care with loved ones, very few have completed an advance care plan. More than half have never discussed their preferences at all for their end-of-life care. Advance care planning is crucial because serious illness or sudden decline can occur unexpectedly (Canadian Hospice Palliative Care Association, 2020). Without documentation, care often defaults to invasive treatment—even when it may not be what the person would have chosen.

Research shows that early end-of-life planning improves patient-centered outcomes and reduces family stress. In one Wisconsin study, 85% of deceased individuals had advance directives after a community-wide death education initiative, and of those who were educated on end-of-life, only 2% opted for aggressive medical intervention—the vast majority preferred a peaceful, natural death (Bigham, 2022).

Experienced end-of-life healthcare providers agree that there are benefits to early advance care planning, as stated by a palliative care unit manager based in a Toronto hospital, who has seen many come to their unit without documentation of their care goals. *"It shouldn't start when you're 60 or 65. I would love to see it in the education system. Everyone expects to have time, but it should be at the age of 35 that people are documenting their end-of-life wants"* (Palliative care unit manager, personal communication, January 2025).

A palliative nurse of 30 years, now retired, shared how, in the emotionally trying times of end-of-life, loved ones and the dying need to be genuinely seen and communicated with clearly on their care options.

"Going all out to save someone is not always the valiant and appropriate way to go. Not being heard, be it the patient, family member, or visitor, can take the sun out of their eyes. If you are not heard, it stays very deep and contributes to a restless dying" (Retired palliative care nurse, personal communication, February 2025).

"If you are not heard, it stays very deep and contributes to a restless dying."

Retired palliative care nurse, personal communication, 2025

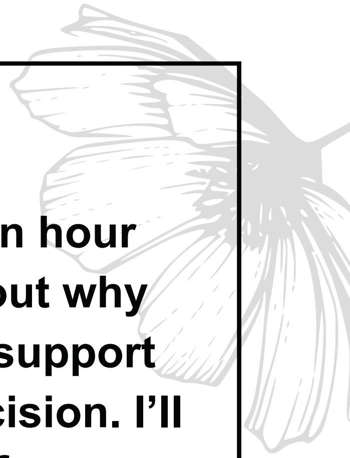
Loved ones, when surveyed, spoke of feeling as though the wishes of their loved one were not acknowledged by medical staff, emphasizing the need for clear and documented advance directives to ensure their wishes are known. *"They talked to us (the family), but not to our loved one. It felt like their voice was missing in the conversation"* (Loved One Survey, February 2025).

"They talked to us (the family), but not to our loved one. It felt like their voice was missing in the conversation."

Loved One Survey, 2025

By contrast, those with compassionate support or advance directives described far more peaceful and aligned care, providing a great deal of comfort. *"A nurse spent an hour talking to me about why withdrawing life support was the right decision. I'll never forget her for my whole life"* (Loved One, personal communication, February 2025). A daughter who knew of her father's end-of-life wishes speaks of the peace this afforded her, *"My father wanted the pain to end and to go privately. He got those wishes—and I experienced less guilt because of it."* (Loved One, personal communication, February 2025)

> **"My father wanted the pain to end and to go privately. He got those wishes."**
>
> Loved One, personal communication, 2025



> **"A nurse spent an hour talking to me about why withdrawing life support was the right decision. I'll never forget her for my whole life."**
>
> Loved One, personal communication, 2025

Normalizing advance care planning requires more than policy shifts—it demands a cultural reimagining of death itself and more opportunities across institutions, including healthcare settings, to discuss options for end-of-life care. The Canadian Hospice Palliative Care Association recommends integrating advance care planning into our legal and financial systems, improving the ease of documentation and sharing, and ensuring those wishes are respected across care settings.

Research shows that advance care planning enhances communication, reduces unnecessary interventions, and relieves the moral burden on families and healthcare teams. (Health Canada, 2023) Early and ongoing planning of wishes and care goals while dying allows individuals to maintain autonomy, reduces fear, and ensures that end-of-life care is compassionate, values-driven, and aligned with what matters most to patients and their loved ones. Without documented end-of-life care options, the dying person's last wishes for their care are unknown, making final decisions on when to withdraw medical interventions fraught and difficult for families and medical staff.

2.3 When to Withdraw Curative Care: Medical Intervention

Advancements in medical technology have significantly extended life expectancy. However, they have also complicated the distinction between effective treatment and prolonged suffering, making it increasingly difficult to decide when to withdraw curative care at the end of life. In Canada, a large percentage of deaths occur in hospital settings. According to Statistics Canada, in 2022, approximately 58.9% of all deaths—167,464 out of 284,082—occurred in hospitals.

Despite hospitals being the primary location for end-of-life care, there is still a lack of attention to the emotional and psychological needs of patients and their families during this critical time. Additionally, there exists an expectation among the dying and their families that physicians possess the ability to save their loved ones' lives, even in the direst of circumstances.

Figure 4 : Loved One Survey on Quality of End-of-Life Care

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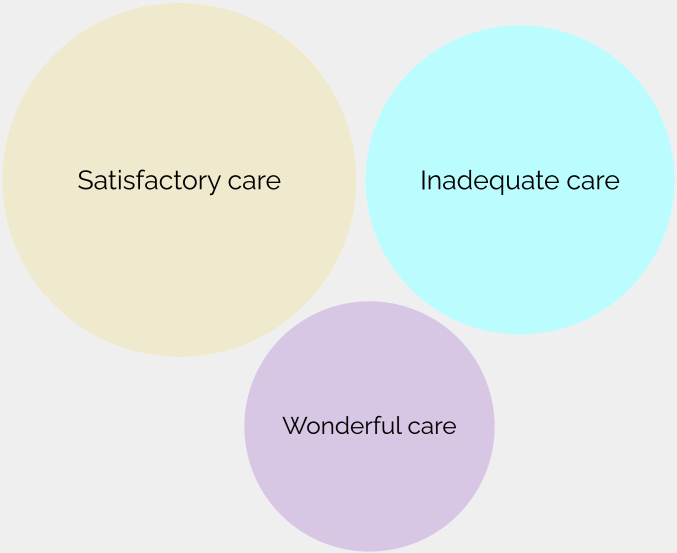
How would you describe your loved one’s end-of-life care in the hospital?



Source: Loved One Survey, 2025

Hospitals are designed to shield staff and patients from the visibility of death. The discreet removal of deceased individuals, following established protocols, reinforces the perception of death as a taboo. These practices are not isolated incidents; instead, they reflect a broader societal discomfort with death. This discomfort treats death as an event to be hidden rather than acknowledged, highlighting the need for open discussions. Such discussions can help us navigate the challenging situation when curative treatments are no longer appropriate (Wilson et. al., 2022 and Cable-Williams et al., as cited in Northcott and Wilson, 2022). The hospital's approach to avoiding and concealing death, coupled with the unpreparedness of dying patients in documenting their wishes and needs, indicates why the complexities of end-of-life care are not always fully considered.

Research indicates that discussions about withdrawing life-sustaining treatment are often inadequately addressed in hospital settings, leading to ethical dilemmas and communication challenges for healthcare providers. A study published in *BMC Palliative Care* found that physicians frequently experience uncertainty and discomfort when deciding to withhold or withdraw life-sustaining treatments. Similarly, a study in the *Journal of Clinical Nursing* revealed that nurses and physicians often face tensions and lack of consensus when navigating the withdrawal of life-sustaining treatment. This demonstrates the complexity and variability in how healthcare workers approach end-of-life decision-making processes (Ketchaikosol et al., 2024 and Hye & Chia-Chin, 2024). Also, there is a need for improved communication, enhanced end-of-life training, and decision-making frameworks for hospital staff on end-of-life practices – enabling greater consistency regarding withdrawal of life-sustaining treatments.

Medical training and hospital culture often encourage aggressive intervention over pausing to consider how end-of-life should look and feel. As medical ethicist Murray Enkin argues, *"Too many people are dying undignified, graceless deaths ... with doctors battling against death way past the humane point"* (Enkin, et al., 2011). The risks of a healthcare culture of death denial can result in prolonged suffering for the dying and their loved ones, forcing them to endure dehumanizing, medicalized deaths.

The bias of end-of-life care toward interventionist medicine extends beyond institutional policies and is embedded into medical education and practice. Within medical training, there is an impulse to view death as a failure. As a palliative care doctor, Jessica Nutik Zitter writes in her book *Extreme Measures* that medical training can foster an illusion of control over death, where physicians believe that through medications and machines, they can restore life and perform a “miracle of modern medicine” (Nutik Zitter, 2017). Journalist and physician Blair Bigham describes the ambiguity of the complex state afforded by advanced medical technology as a "gray zone between life and death" where the decision to continue or stop care is unclear. *"How to achieve a timely death isn't taught in medical schools or spoken about in hospital hallways... it's an agonizing place to be"* (Bigham, 2022).

The expectation that physicians do everything possible to prolong life—even when doing so leads to increased suffering—creates moral and ethical dilemmas in end-of-life care. Intensive care unit physicians are under immense pressure to continue treating dying patients past the point of possible recovery, fearing accusations of negligence if they cease aggressive treatment: *“The pressures, particularly on ICU physicians, to keep treating dying patients until they die. If they don't appear to be struggling at all costs to keep a body alive for as long as technologically possible, they might be suspected of murdering patients”* (Nutik Zitter, MD, 2021).

> **“The pressures, particularly on ICU physicians, to keep treating dying patients until they die... or we might be suspected of murdering patients.”**
>
> Dr. Jessica Nutik Zitter,
> *Extreme Measures,* 2017

Loved ones and families, due to an unfamiliarity with the dying process and unrealistic expectations of what medical interventions can achieve, struggle with decisions of the right time to withdraw aggressive treatments. Also, they are taking the lead of their loved ones, who may describe themselves as “fighters” in their illness. A palliative care physician understands this description of the fight for survival being powerful as a biological instinct (Puri, 2022). However, when the suffering caused by aggressive treatment outweighs the benefits, such interventions can become more harmful than helpful.

A Toronto-based palliative care physician emphasizes the importance of being honest with patients about the realities of ongoing medical treatment: *“Every medical intervention has some* *amount of pain attached to it. Medical treatment should help you live better. These interventions will not lead you to that goal”* (Palliative care physician, personal communication, December 2024).

When medical professionals present aggressive medical interventions as the only viable option, the family members of patients may feel that their loved ones are not being treated with dignity and respect. They may be unaware that other end-of-life care options are available or that they could be increasing their loved ones' suffering. One family member stated, *“When they spoke of withdrawing care, it felt coercive. The doctor said that if we moved to hospice, they would stop providing any fluids. It seemed unnecessarily cruel and hindered my decision-making because I needed to consult with my other brothers before making that choice”* (Loved One Survey, February 2025). A wife also reflected on her experience with her husband, who demonstrated a greater awareness of his approaching end-of-life than the medical staff treating him did. Yet, the medical staff did not acknowledge his wishes regarding his care goals.

“Neil wasn't empowered to decide about his end-of-life care and experience. He wasn't listened to when he said, "I think I only have a few days left.” They were convinced he was getting better, and they wanted the bed, so we had to go. That upset him. He asked directly, "Don't I get to choose?" And sadly, the answer was no” (Loved One Survey, February 2025).

In Western medicine and hospitals, determining when to stop curative treatment presents an ethically challenging dilemma in end-of-life care. As life-sustaining technologies continue to advance, death can be postponed indefinitely, often compromising dignity, clarity, and comfort. Within this framework, withdrawing treatment may be perceived as a failure rather than a compassionate medical decision. Such choices can lead to significant distress for healthcare providers, families, and patients facing the end of their lives. With a strong focus on curative and aggressive medical interventions in end-of-life care, what are the potential costs and impacts on patients and the hospital environments they depend on?

“He asked directly, "Don't I get to choose?” And sadly, the answer was no.”

Loved One Survey, 2025

2.4 The Costs of End-of-Life Care in Intensive Care Units (ICUs)

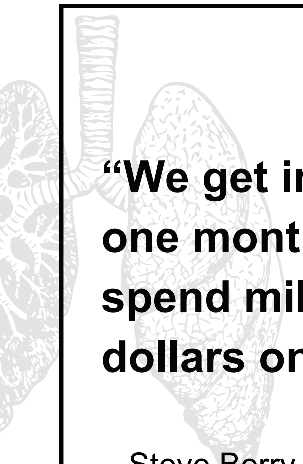
2.4.1 Financial Costs and Systemic Strain

A reluctance to accept death and the pursuit of aggressive, life-prolonging interventions in ICUs come at a high financial cost and can put additional financial strain on our healthcare system. Canadian bioethicist Kerry Bowman critiques the prevalence of “ventilator farms”, which are ICU units that sustain patients through invasive technologies such as feeding tubes, ventilators, and dialysis, even when meaningful recovery is unlikely. These interventions often do not reflect what most people would choose for their end-of-life care (Bowman, as cited in Bigham, 2022).

A large amount of healthcare spending is concentrated in the final months of life. Death historian Steve Berry notes that approximately 25% of all healthcare dollars are spent in the last six months of life. “*We get in this heroic one month where we spend millions of dollars on ICU care. If we would go quieter in that good night, it would be a lot easier”* (Berry, as cited in Bigham, 2022).

In the U.S., ICU care costs roughly $3,000 per day, accounting for 13% of hospital costs and 4% of national health expenditures—about 1% of GDP (Reardon et al., 2018). In Europe, daily ICU costs range between $1,300 and $2,700 (Checkley, 2012). Yet such expenditures do not guarantee recovery or quality of life, mainly when used to prolong biological function without the prospect of meaningful consciousness.

Such was the case for the parents of Taquisha McKitty, a young woman who was declared neurologically dead after a drug overdose and who remained on life support. At the same time, her family challenged the hospital in court because they believed that her heartbeat meant she was still alive. Her continued ICU stay reportedly cost the system over $1.5 million (Janus, 2018).



“We get in this heroic one month where we spend millions of dollars on ICU care.”

Steve Berry, death historian, 2022

Prolonged stays on medical machines, way past the point of any potential recovery for the patient, resulting in high financial strain on our healthcare system and hospitals—often for benefits that are unclear. These resource-intensive interventions can overshadow more holistic, compassionate forms of care, leaving families and providers emotionally exhausted and morally conflicted. As healthcare systems absorb the rising costs of futile treatments, we should also consider: what is the emotional and psychological price paid by those forced to witness prolonged dying in environments not designed for peace or closure?

2.4.2 Psychological and Emotional Toll of ICU on Loved Ones and Healthcare Providers

The emotional and psychological costs of ICU-based interventions during end-of-life can have traumatic impacts on families, the dying and those caring for them. As palliative care doctor Jessica Nutik Zitter writes, once patients are attached to machines, it becomes nearly impossible for them to return home or avoid further invasive care. *“These tubes, once inserted into dying patients, tend to remain in place until death,”* she explains, describing the loss of independence, autonomy and dignity (Nutik Zitter, 2017).

Doctor Nutik Zitter goes on to speak of the unintentional abandonment patients and families feel when it becomes clear that medical interventions are not working. Clinicians often lack the skills and time to communicate clearly and compassionately with families and loved ones that their loved one is going to die. These difficult end-of-life conversations require psychological and emotional energy that the care provider may not have the time and ability to provide. *"Once it is undeniable that death is inevitable and imminent … tension and frustration begin to bubble up from the patient.*

Rather than confront our discomfort or sense of failure, we move on to the next patient: 'They're a difficult family. They want everything done.' Phrases like this are often heard as patients begin to die on their machines, their families baffled as to how this was happening when it seemed there were still options to try. We physicians become numb to those we came to help" (Nutik Zitter, 2017).

> **"We physicians become numb to those we came to help."**
>
> Dr. Jessica Nutik Zitter,
> *Extreme Measures,* 2017

Research has found that relatives of ICU patients are at increased risk for long-term post-traumatic stress disorder. In these acute care settings, families experience high emotional stress, poor communication from healthcare providers on what to expect in the dying process, and exposure to the extreme suffering of their loved ones. (Petrinec & Daly, 2014). One loved one surveyed described the experience of their loved one's end of life as "chaotic and jarring," especially when the family had to make rushed DNR decisions with little context or support (Loved One Survey, 2025).

Physicians and ICU staff experience psychological strain from end-of-life care taking place in the ICU. A family physician in Toronto who works in hospital settings describes how the emotional toll on staff is often overlooked, and many ICUs lack wellness infrastructure and support for frontline staff who can experience not only the trauma of dying patients but also volatile behaviour from family and patients. There is also a lack of continuity of care from healthcare providers in ICU settings, a continuity which would allow staff to form relationships with families and patients, contributing to greater well-being for all (Family physician, personal communication, September 2024).

A key complaint from families and loved ones surveyed that hindered their ability to attend to the wishes of their loved ones was a lack of continuity care. Healthcare providers, whom they may have trusted and connected with, were not consistently available to help families navigate difficult decisions they may not have felt equipped to handle. Families often describe the feeling of being unheard and dismissed (Loved One Survey, February 2025).

Figure 5 : Loved One Survey on Quality of Communication by Healthcare Providers

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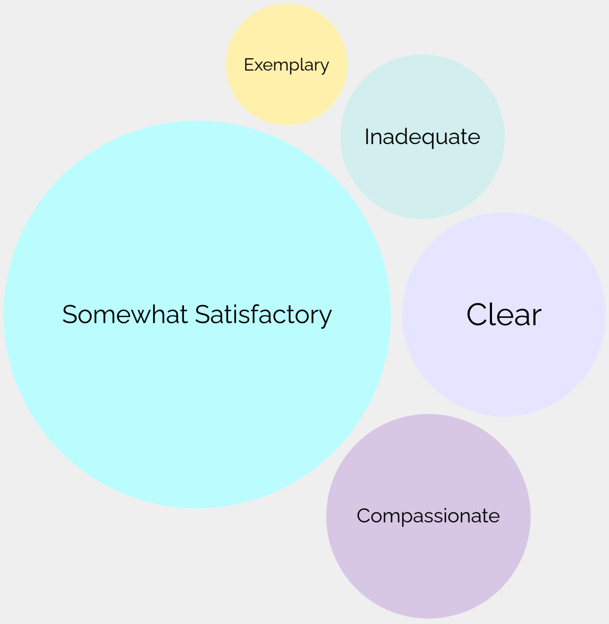
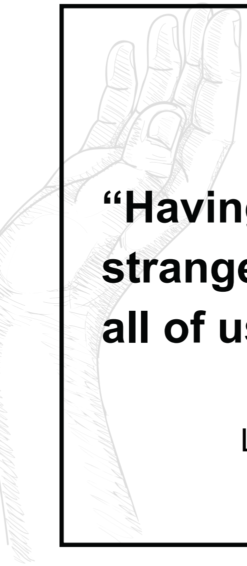
How would you rate the communication from healthcare providers regarding your loved one's condition and care plan?



Source: Loved One's Surveys, 2025

Families craved compassionate care and familiarity from healthcare providers as they were going through something complex and profound, *“We couldn’t stop the many visits and insensitive questionnaires from various professionals”* (Loved One Survey, February 2025). One daughter spoke of the desire for care from people who truly saw her mother, emphasizing the desire and need for personhood as part of end-of-life care, which is not always possible in the ICU setting, *“My mum bonded with a few of the nurses. She wished she could have been cared for by the ones who were the most compassionate and loving. Having a rotation of strangers was hard on all of us”* (Loved One Survey, February 2025).



“Having a rotation of strangers was hard on all of us.”

Loved One Survey, 2025

The emotional and economic burdens associated with dying in the ICU illuminate the necessity for earlier discussions about what it means to die well and what to expect during the dying process. Additionally, these social and psychological challenges highlight systemic deficiencies in providing adequate support for families, clinicians, and patients to make decisions that prioritize not only the dying individual but also their loved ones.

What would comprehensive and holistic end-of-life care entail, and how can we transition patients out of the ICU to ensure they receive quality care?

2.5 Transition From ICU to Palliative Care

The transition from the intensive care unit (ICU) to palliative care is one of the most complex changes in healthcare. This shift involves moving away from aggressive, life-prolonging interventions to a care model that prioritizes comfort, symptom management, and quality of life. Palliative care is a relatively young field that gained prominence in the 1960s. Its roots can be traced back to the modern hospice movement, which was initiated by Dame Cicely Saunders, who established St. Christopher's Hospice in London in 1967 (Alcalde & Zimmermann, 2022). Unlike other branches of medicine that focus on curing diseases, palliative care is designed to address the physical, emotional, and spiritual needs of patients facing serious illnesses, and its role within healthcare systems continues to expand.

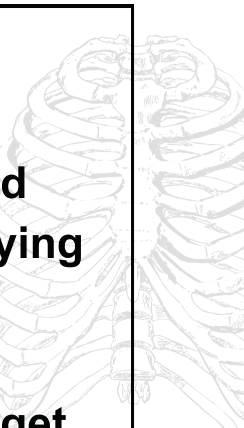
Despite the benefits of early palliative care integration, this transition remains fraught with challenges due to delayed conversations, a hospital culture focused on cures, and a lack of awareness about end-of-life options. Patients and families often struggle with the emotional weight of these decisions. At the same time, healthcare providers may hesitate to initiate discussions about withdrawing treatment, fearing that it signals giving up–largely due to inadequate training in palliative models of care in how it can complement curative care. An Ottawa-based palliative care physician observes that even patients with serious illnesses often never see a palliative care specialist—highlighting how avoidance and stigma around death manifests in healthcare settings manifests.

“*Nobody tells people what happens at the end of the day. People are not seeing palliative care doctors, even those who have cancer”* (Hospice palliative care doctor, personal communication, August 2024).

Individuals facing life-limiting illnesses have priorities that extend beyond merely prolonging their lives. Surveys consistently reveal that their most pressing concerns include avoiding suffering, strengthening relationships, maintaining mental clarity, not being a burden to their loved ones, and achieving a sense of closure. (Canadian Hospice Palliative Care Association, 2013) However, as leading palliative care physician and writer Atul Gawande (2014) points out in his book *Being Mortal*, the current medical system often fails to address these needs, placing greater emphasis on technological interventions rather than on the deeply personal aspects of dying. To better support those at the end of life, its important to find ways to accommodate their wishes and acknowledge their personhood. The challenge is not only about how we can afford these expensive treatments but also about how we can develop a healthcare system that aligns more closely with what matters most to patients throughout their care journey.

The hierarchical nature of ICU decision-making further complicates this transition, as all data is funnelled to an attending physician who must make rapid, high-stakes decisions, often without space for nuanced discussions about goals of care. Medical anthropologist Margaret Locke highlights how families, who are usually responsible for deciding whether to withdraw life-prolonging care, can become torn apart over these decisions as they struggle to balance personal, cultural, and ethical beliefs.

“These dramas would act out literally around the dying person. Time and time again. The family would dither, the medical team would get frustrated, and getting a feel for what would be possible would be difficult" (Locke, as cited in Bigham, 2022).



> **“These dramas would act out around the dying person. The family would dither, the medical team would get frustrated.”**
>
> Margaret Locke, medical anthropologist, 2022

A retired palliative care nurse of over 30 years, has witnessed again and again the turmoil families and loved ones face because they are ill-prepared and uninformed about the benefits of palliative care, so much so that they are unable to navigate end-of-life decisions for their loved ones. She addresses how important it is to establish relationships and trust with caregivers and patients. Many arrive at the palliative care unit confused and lacking clear information about what to expect in their loved one’s dying experience. She speaks of the need to remain emotionally present for the family and the patient during this transition in care to garner trust (Retired palliative nurse, personal communication, February 2025).

A manager of a Toronto hospital’s palliative care unit emphasizes the difficulty of transitioning to palliative care when families and patients still believe their incurable illnesses will get better. Palliative care unit staff reassure families by letting them know that it is not “giving up” to move their family to a palliative care unit. Many are unaware of palliative care's nuance and gray areas; for instance, an IV can be kept running and feeding the patient. Palliative care staff are also well versed in communicating with family and patients. To provide them with the comfort and clarity patients need, these staff are trained via Pallium Canada, the largest provider of palliative care education in Canada – to understand how to guide families through end-of-life care (Palliative care unit manager, personal communication, January 2025).

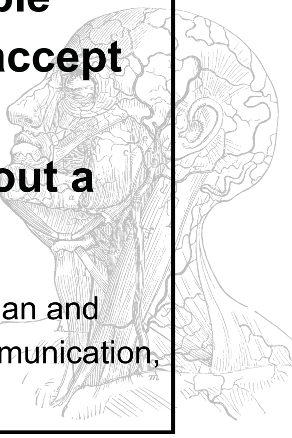
Yet, palliative care remains a specialty and depends on a doctor’s referral – and many physicians still do not see the value of this modality of care in providing quality of life. Thus, many terminally ill patients do not access palliative care in a timely fashion due to delayed referrals.

"*Once we can bring them up here, there is no flip-flopping back and forth. One of the barriers in the outpatient world is that many doctors and specialty services feel like they are giving up. But we can offer them more comfort in the interim, and if they are end-of-life, we can step up"* (Palliative care unit manager, personal communication, January 2025).

A leading palliative care physician, professor and researcher, explains that one of the greatest dilemmas in end-of-life care is when patients or their families demand treatments that will keep them alive, yet do not comprehend that these treatments offer no real benefit. *“It takes a remarkable amount of trust to accept such a dire pronouncement about a loved one. "doctors made these decisions, but today, families, which makes it even more complicated"* (Palliative care physician and researcher, personal communication, September 2024).

“It takes a remarkable amount of trust to accept such a dire pronouncement about a loved one.”

Palliative care physician and researcher, personal communication, 2024



Families who experience a transition from ICU to palliative care often describe a stark difference in care philosophy. The ICU can feel chaotic and impersonal, and those who received palliative care support reported a more compassionate and reassuring experience. *"The palliative care team was the most helpful. Their compassion, patience, and reassurance changed the feeling of the space”* (Loved One Survey, February 2025).

Transitioning from ICU to palliative care is not just a medical shift—it is a profoundly emotional and ethical challenge that requires better communication, earlier integration of palliative teams, and a cultural shift in how we approach death within the healthcare system. Without these changes, many patients will continue to endure aggressive, unwanted interventions, while families will be left navigating painful decisions with little guidance or support. Given the power of palliative care to provide greater comfort and peace at end of life to the dying, how can this be integrated earlier into one's healthcare experience?

3.1 Early Integration of Palliative Care in the Health Journey

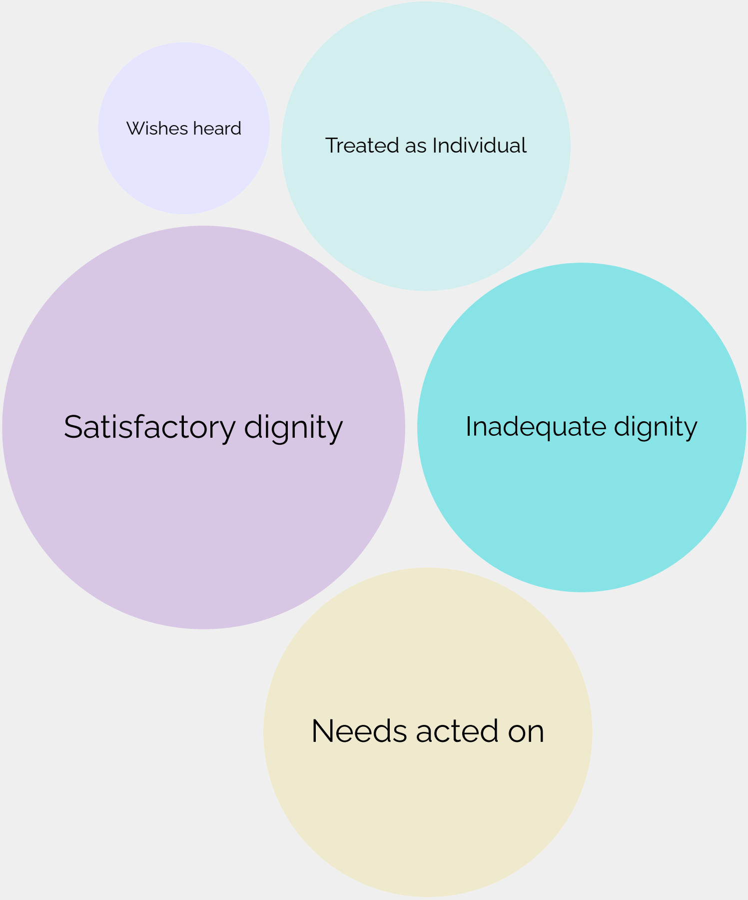
Palliative care has evolved from its early conception as a service reserved for terminally ill patients to a broader model that supports individuals throughout serious illnesses. The World Health Organization (WHO) originally defined palliative care as the active total care of patients whose disease is not responsive to a curative treatment to achieve the best possible quality of life. As research demonstrates palliative care has benefits across the entire illness trajectory. A palliative care definition was expanded in the medical community to include early identification, symptom management, psychosocial and spiritual support, and curative treatments (Alcalde & Zimmermann, 2022). Despite this shift in understanding, palliative care is predominantly introduced only when curative treatments are no longer effective, rather than being integrated earlier in disease care.

The “7 C's” of palliative care are foundational principles designed to enhance the quality of life for individuals facing serious illnesses. These principles are widely recognized and taught in various educational institutions, including Western Community College in Canada. The “C’s” strive for comprehensive, compassionate, collaborative, coordinated, continuous, communicative, and culturally competent care, which forms a holistic framework for delivering high-quality care to individuals with serious illnesses. These principles emphasize whole-person care, clear communication, interdisciplinary collaboration, and respect for cultural values (Western Community College, n.d.). Together, they support a patient- and family-centered approach that enhances quality of life and ensures care is consistent, respectful, and responsive across all settings.

According to palliative care specialists, to be most effective, palliative care needs to guide patients through their illnesses rather than being called in at the last second to hold a dying patient’s hand and deliver morphine. Palliative care can be a key component of the care journey.

Figure 6: Loved One Survey on Level of Dignity in End-of-Life-Care

How would you rate the dignity (recognized personhood and needs and wishes heard and met) of your loved one experiences during their end-of-life care?



Source: Loved One’s Survey, 2025

“Now, palliative care teams aim to meet patients much earlier in the illness trajectory and provide them with a coach or person who can guide them through their journey and explore their values, what brings joy to their lives and what things they wouldn't find acceptable” (Blake, as cited in Bigham, 2022).

> **“... a coach or person who can guide them through their journey and explore their values, what brings joy to their lives.”**
>
> Chris Blake, palliative care doctor, 2022

Patients and their families often remain unaware of how varied their end-of-life care options are, and healthcare systems continue to treat palliative care as a last resort rather than an essential component of comprehensive, patient-centered care. In 2021–2022, 58% of those who died in Canada (89,000 people) were described as palliative and received some form of palliative care. Among those who received some form of palliative care, 61% had palliative care in hospital only (Canadian Institute for Health Information, 2023). These statistics exemplify that many patients die without accessing end-of-life care that is focused on reducing suffering and supporting their psychosocial well-being, likely leading to traumatic dying experiences. A senior policy advisor for the provincial government of Ontario on reimagining home-based palliative care, states there is a need for stronger foundational knowledge to ensure that patients receive appropriate support from the beginning of their illness care rather than only at the end. Physicians, especially, should be equipped with the knowledge and resources to guide patients through palliative care options that attend to all their needs, ensuring they receive continuous support rather than being left without care when curative treatments are no longer effective. *“Break down barriers through clinical coaching, education, and earlier education in a palliative approach to care. It is essential to have those supports before it gets to the last minute”* (Senior policy advisor, homecare, personal communication, February 2025).

An assistant deputy minister of long-term care who formerly worked at a hospital spoke about how *Ontario's Compassionate Care Act* of 2020 is a framework developed to ensure that every Ontarian has access to quality palliative care, yet full implementation remains difficult.

“The Compassionate Care Act (2020) laid the groundwork for a provincial palliative care framework, but the challenge remains in implementation. It was introduced during COVID-19 to normalize conversations about goals of care, asking people what they want for their treatment. The goal is to destigmatize these discussions and ensure that palliative care is integrated earlier, not just left to specialists” (Long-term care, assistant deputy minister, personal communication, September 2024).

A multidisciplinary team is essential to the early integration of quality palliative care, for each team member can attend to various aspects of the patient's care needs. A team-based approach ensures that patients receive comprehensive care beyond medical treatment and that healthcare providers also receive needed support from their colleagues to provide the best care possible. A best practices team-based approach includes physicians, nurses, social workers, spiritual care providers, and psychologists, allowing for coordinated care that addresses physical symptoms and emotional, psychological, and spiritual needs. The manager of a palliative care unit in a hospital in Toronto describes their best practice model of care as including a dedicated social worker, spiritual care, a clinical nurse and family physicians specializing in palliative care (Palliative care unit manager, personal communication, January 2025).

Fifteen years after her father's death, a woman reflected on the value of the multidisciplinary team, which was able to accommodate his advance care directives. *"... the care was respectful and attentive to his wishes. They encouraged us to guide the process and involved us in key decisions."* (Loved one, personal communication, February 2025).

Many surveyed loved ones desired earlier and more consistent access to palliative care staff and multidisciplinary teams to facilitate goals-of-care discussions and eliminate unnecessary suffering, improving their loved ones' dying experience. *"Bring in the palliative teams earlier. They are gifted at helping families understand where things stand and prepare for what lies ahead"* (Loved One Survey, February 2025).

> **"Bring in the palliative teams earlier. They are gifted at helping families understand where things stand and prepare for what lies ahead."**
>
> Loved One Survey, 2025

Others surveyed spoke of how a palliative care team would be a "game-changer" in the quality of care their loved one received. *"We didn't get enough time with the palliative team–there needs to be a continuity of care to help patients and families understand what unfolds"* (Loved One Survey, February 2025).

Palliative care has demonstrated significant benefits when integrated early in a patient's illness, yet many patients and families struggle to access it in a timely and consistent manner. While best practices emphasize a multidisciplinary approach, gaps in awareness and availability often leave patients without these critical supports. Holistic end-of-life care has the potential to support and guide decision-making as patients and caregivers face the trajectory of a serious illness.

Studies indicate that those who receive palliative care earlier in their diagnosis feel more supported in navigating the healthcare system and managing their symptoms (Hannon et al., 2016). Despite these demonstrated benefits, many patients only receive palliative care in the final stages of their illness. Considering many dying patients' inability to access comprehensive palliative modalities of care, how well-attended are their emotional, psychological and spiritual needs during end of life?

3.2 Dying With Dignity: Emotional and Spiritual Support in Dying

Although the World Health Organization recognizes spiritual care as an essential domain of palliative care, it is still one of the most neglected components of the healthcare system. During the twentieth century, the influence of religion on dying and death declined considerably; in the past, religion was essential to many people as healthcare could do little to prevent death, but scientific advances radically changed this. These advancements quickly led to the rising significance of hospitals and physicians in Canadian society. A survey of Canadians in 2011 revealed that 24% had no religious affiliations (Northcott, Wilson, 2022 and Statistics Canada 2014a as cited in Northcott, Wilson, 2022). The increased success and prominence of healthcare tended to overshadow religious conventions regarding dying and death.

However, spirituality encompasses more than religious affiliation. An individual's search for meaning, purpose, and connection becomes particularly significant during end-of-life care. Patients often experience spiritual distress, characterized by profound inner and existential questioning (Connolly, Quinn, 2023). Therefore, palliative care needs to extend beyond physical symptom management to include spiritual support, ensuring a holistic approach honouring the patient's entire being.

Hospitals struggle to adequately accommodate the diverse spiritual and religious needs of dying patients and their families. While many Canadian hospitals offer some form of spiritual care—primarily led by Christian chaplains—this support is not always culturally or religiously inclusive (Canadian Hospice Palliative Care Association, 2022). For instance, Muslim patients may require the body to be positioned toward Mecca and seek swift burial rituals, while Hindu patients often request time for the soul to transition and for family members to chant mantras or bathe the body (Puchalski et al., 2009 and Koenig, 2004). Buddhist traditions emphasize a peaceful environment free from sedatives to support conscious dying, and Jewish families may require rabbinical guidance and expedited burial practices that conflict with hospital protocols (Schlesinger Institute n.d. and Ratanakul, 2007). Despite these varying needs, research shows that spiritual needs and potential distress at the end of life are often overlooked, particularly when healthcare providers lack training in interfaith care (Puchalski et al., 2009).

A palliative care unit manager for a hospital in Toronto speaks of the importance of their spiritual care team. The team strives to accommodate diverse spiritual and cultural needs in their palliative care unit, ensuring patients receive support aligned with their beliefs. For example, they arranged for a Buddhist patient's body to remain undisturbed for 24 hours, facilitated a rabbi's visit for Orthodox Jewish families, and provided access to an Indigenous care navigator to support smudging ceremonies and other traditional practices. The goal of their palliative care unit is to create a neutral, inclusive space where all patients feel respected and supported in their final moments (Palliative care unit manager, personal communication, January 2025).

Enabling the practice of Indigenous ceremonies within healthcare settings can promote cultural safety for a population that may experience barriers in the healthcare system. However, the practice of Indigenous ceremonies in Ontario remains challenging despite legislation explicitly protecting and permitting ceremonies in hospitals. (Toronto Central Regional Cancer Program, Indigenous Cancer Program, n.d.). A Métis physician and medical professor based in Toronto speaks of the difficulty of incorporating Indigenous spiritual practices into the hospital environment.

“I see the complexity of bridging Western medicine with traditional spiritual care. Many patients and families want both. How do we support the role of the family in a way that honours Indigenous traditions and ensures they have access to their loved ones without disrupting medical care? We must address these questions to provide holistic and inclusive end-of-life support” (Métis physician and professor, personal communication, August 2024).

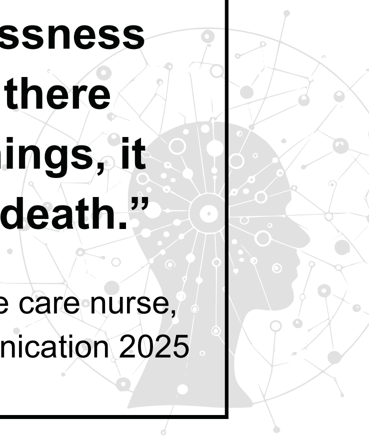
“How do we support the role of the family in a way that honours Indigenous traditions?”

Métis physician and professor, personal communication, 2024

In her book *That Good Night*, palliative care physician Sunita Purin discusses how death often highlights profound spiritual needs, regardless of individual beliefs or whether a patient is secular. She emphasizes that medicine should view this end of life as a transition and a natural part of life. *“Because death stirs people to seek answers to important spiritual questions, it becomes the greatest servant of humanity rather than its most feared enemy”* (Puri, 2019). Ira Byock, a leading palliative care physician and public advocate for improving care through end of life, describes in his writing how the process of dying is rarely enjoyable and is often a wrenching time when people struggle. However, some who approach it with peace and resolution have a very different experience.

“Now and then…I meet a person who, while dying, seems to flow smoothly out of worldly concerns and relationships toward an ethereal, spiritual state. Such people may have worked hard earlier in their lives on relationships and aspects of themselves, acquiring in this way the skills to accomplish the task-work of dying” (Byock, 1997).

A retired palliative care nurse speaks about the stark contrast between those who find peace at the end of life and those who experience deep spiritual suffering. She emphasizes that without proper spiritual support—whether through faith, personal beliefs, or meaningful connection—dying can be an anguished and distressing experience. *“What stands out is that spiritual anguish is real. There is restlessness and delirium; if there are unsettled things, it can be a tough death. But dying can be very peaceful”* (Retired palliative care nurse, personal communication, February 2025).



“There is restlessness and delirium; if there are unsettled things, it can be a tough death.”

Retired palliative care nurse, personal communication 2025

In the absence of adequate spiritual support within the healthcare system, patients and their caregivers often seek external guidance to navigate end-of-life needs. These external supports fill a critical gap in end-of-life care, ensuring that patients receive individualized support that acknowledges the spiritual dimensions of dying.

Some families and dying turn to death doulas, who provide emotional, psychological, and spiritual care, helping individuals find meaning, closure, and a sense of peace in their final days. Death doulas also provide practical support in navigating the healthcare system while dying and can work as an advocate for their dying clients.

*“My primary focus is always on the dying person, helping them express what matters most in their final moments. Many want to reassure their loved ones that it is safe for them to let go. I've never worked with a client without supporting a family member or collaborating with a therapist—end-of-life care is always a deeply interconnected experience” (*Death doula, personal communication, November 2024).

Others bring shamans or traditional healers to facilitate spiritual transitions, incorporating rituals and ceremonies that align with their cultural or personal beliefs. Shamans serve as intermediaries between the physical and spiritual realms in end-of-life care, guiding individuals through the dying process and facilitating a peaceful transition. They provide spiritual support, perform rituals, and address unresolved issues to help patients find closure and comfort. Shamanic practices in end-of-life care use drumming, storytelling, and vision interpretation to help patients find meaning in suffering, illness, and death, offering a therapeutic narrative approach to providing meaning and ritual near the end of life. A shamanic practitioner interviewed sees the palliative care teams as specialists in this transition, and through their experience, they approach their work with a quiet, unspoken spirituality. When she brings ceremonies to hospitals, the staff are curious but deeply respect what is happening.

“I help by speaking to their consciousness and guiding their loved ones to voice what needs to be said. It is not medical care—it's transitional care, supporting both the body and the soul. Being around death enough, you recognize that it comes from somewhere sacred” (Shaman, personal communication, November 2024).

“It is not medical care—it's transitional care, supporting both the body and the soul.”

Shaman, personal communication, 2024

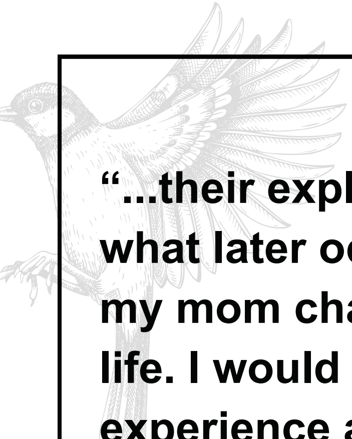
If patients are conscious during their end-of-life, they are likely to experience visions; 50% to 60% of patients in a hospice study report a “visitation” by someone who is not physically there while they dream or are awake: a phenomenon known as end-of-life dreams and visions. Clinicians and researchers view these visions as spiritual moments that stem from the innate human desire for communication and connection. (Puchalski, et. al., 2009) A woman who had no previous spiritual affiliation before her mother's death was told about this as an aspect of the dying process, and she found that experience to be profoundly uplifting not distressing in her mother's final days.

“My mother was an atheist, and we were not spiritual, but that has since changed, largely because of her death. She spoke to loved ones in the room who had died previously. The hospice nurse said she

might have spoken of a train or a trip, but I didn't believe that could happen ... I learned a lot about life (and my initial private resistance to this idea) through this experience. Her death was full of such gifts” (Loved One Survey, February 2025).

A daughter spoke of the profound impact of being guided through their mother's final moments, emphasizing how understanding the spiritual aspects of the dying process brought comfort and clarity, which allowed her to process the death in a significant way.

"They shared things with me about how my mom might transition into death that I honestly didn't believe at that point, and their explanations and what later occurred for my mom changed my life. I would consider this experience a spiritual awakening" (Loved One Survey, February 2025).



“...their explanations and what later occurred for my mom changed my life. I would consider this experience a spiritual awakening."

Loved One Survey, 2025

Ensuring that individuals and their caregivers receive compassionate guidance and the space to address unresolved fears, regrets, or existential questions can distinguish between a turbulent passing and one marked by acceptance and calm.

Hospitals can move beyond viewing spiritual care as an optional service and instead recognize it as a fundamental component of quality palliative and end-of-life care. Integrating spiritual and emotional support into healthcare settings—whether through chaplains, Indigenous healers, rabbis, monks, pandits, death doulas, or shamanic practitioners—ensures that patients receive the holistic care they need to transition with dignity.

As Canada becomes increasingly religiously pluralistic, the absence of inclusive spiritual care policies may contribute to spiritual suffering and unmet cultural needs. Caregivers, too, benefit from this support, finding comfort and meaning in their loved one's final moments. By prioritizing spiritual care as part of a person-centred approach in end-of-life care, healthcare systems can create a physical environment where death is met with understanding, connection, and acceptance rather than fear and isolation. Beyond spiritual support, how might the design of physical spaces themselves shape our experience of dying—and what happens when these environments fail to reflect the emotional and cultural needs of patients and families?

3.3 Acknowledge the Role of Hospital Design in End-of-Life Care

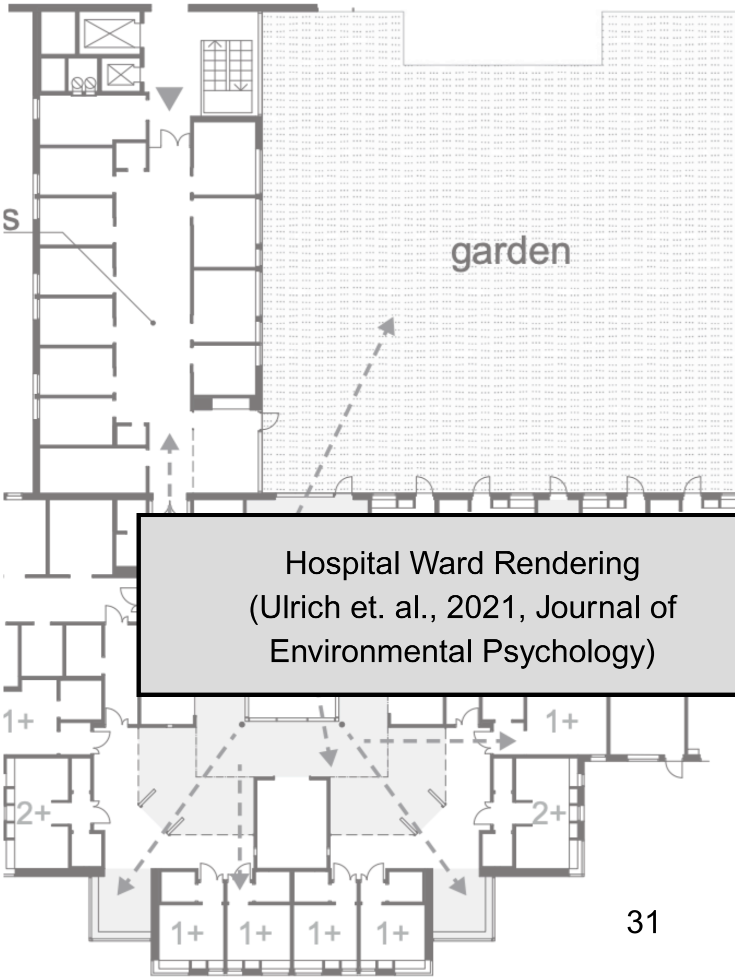
For centuries, hospital design has recognized the healing power of natural light and fresh air. In the 19th century, hospitals were built with large windows and skylights to maximize sunlight, not only for visibility but also because it was believed to have a role in patient recovery. Before the development of antibiotics, infectious diseases, particularly tuberculosis, were thought to be mitigated through exposure to fresh air and sunlight (Sternberg, 2009).

Alvar Aalto’s Paimio Sanatorium, constructed in Finland between 1929 and 1932, became the standard for modern hospital design, featuring south-facing, light-filled patient rooms that overlooked a pine forest (Sternberg, 2009). While medical advancements have transformed healthcare, the physical environment remains a critical factor in patient well-being. Thoughtful hospital design—incorporating natural light, access to nature, and comfortable spaces—is vital in improving patient outcomes, particularly in palliative care settings.

Long-standing research has suggested that hospital design has a significant impact on patient well-being, particularly in end-of-life care. Architects such as Frank Lloyd Wright and Richard Neutra emphasized a connection between architecture, health, and nature, influencing modern hospital design. Roger Ulrich’s 1984 study demonstrated that views of nature could reduce stress and promote healing, leading to a broader exploration of how the physical environment affects patients. Neuroscience and architecture experts have since examined how natural light, artwork, and noise influence recovery, advocating for healthcare spaces prioritizing comfort and psychological well-being. (Sternberg, 2009) These insights should be considered in hospital environments to optimize quality of life and improve the overall experience of patients.

A study conducted by researcher Rebecca McLaughlan regarding the expectations of the hospital’s-built environment as one nears the end of life highlights the impact of hospital design on the experiences of patients and families, emphasizing the need for environments that provide privacy, emotional support, and access to nature. Fresh air, natural light, and home-like settings are repeatedly cited as factors that can ease emotional distress. (Mclaughlan, 2024) However, many hospital environments remain cold and impersonal, with families receiving devastating news in crowded hallways or seeking comfort in uncomfortable waiting areas.

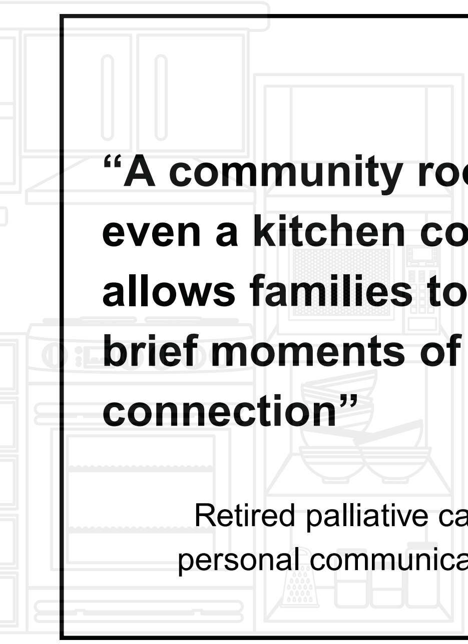
The clinical environment can also impede the ability to accommodate the spiritual rituals that are important to the patient and their family. For instance, Indigenous advocates recommend that healthcare settings designate non-clinical spaces for Indigenous ceremonial practices accessible to patients, families, and staff 24 hours a day. These spaces need to accommodate large extended families when needed, without religious symbols, which may trigger trauma for survivors of the Indian Residential School system and their families (Toronto Central Regional Cancer Program, Indigenous Cancer Program, n.d.).



Hospital Ward Rendering
(Ulrich et. al., 2021, Journal of Environmental Psychology)

A retired palliative care nurse discusses how thoughtfulness in the physical environment can comfort and offer respite to caregivers. She recognizes that small simple moments can help families cope with the immense emotional weight of end-of-life care.

“In palliative care units, having a dedicated family space with a volunteer making tea offers a quiet moment of normalcy amid grief…A community room or even a kitchen counter allows families to find brief moments of connection, reminding them of the bigger picture of what is happening” (Retired palliative care nurse, personal communication, February 2025).



> **“A community room or even a kitchen counter allows families to find brief moments of connection”**
>
> Retired palliative care nurse, personal communication, 2025

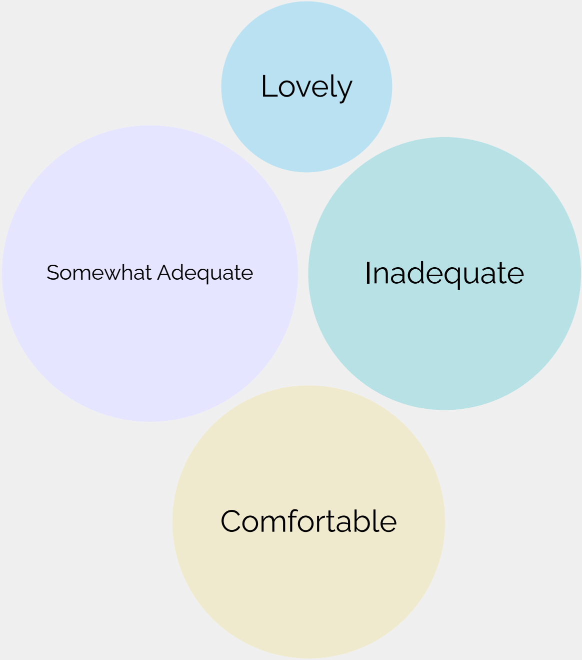
She also speaks of the “camping out” in the hospital. Many people will stay by their loved one for days without considering their own comfort—whether that means staying overnight in an uncomfortable chair in their hospital room or an uncomfortable couch in the family waiting room. The ability to access a pleasant and comfortable space when they are unable to leave the hospital due to the fragile medical condition of their loved one that can shift from moment to moment can be significant.

“The camped-out experience becomes part of the memory. It matters that families feel comfortable and supported in those final days. We need an intentional design that prioritizes both patients and their families” (Retired palliative care nurse, personal communication, February 2025).

A Toronto hospital’s palliative care unit exemplifies best practices in end-of-life care through thoughtful physical design that prioritizes privacy, comfort, and accessibility for patients and their families. Unlike many hospital settings, this unit consists exclusively of private rooms, large windows with beautiful lake scenery, each designed to accommodate multiple visitors and furnished with reclining chairs that convert into beds for overnight stays. The unit also includes dedicated hoteling spaces for family members, ensuring they have a place to rest. It also has accessible showers and bathrooms to support extended visits.

Figure 7: *Loved One Survey on Quality of Physical Environment of Hospital*

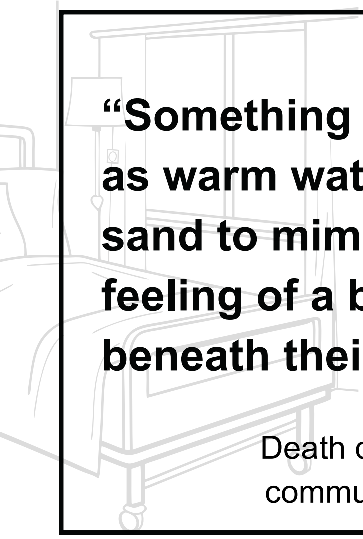
How would you rate the comfort of the physical environment during your loved one’s end-of-life care?



Source: Loved One’s Surveys, 2025

A Death Doula emphasizes that creating a dignified environment at the end of life goes beyond physical surroundings—it also involves small but meaningful acts that honour a person's comfort and sensory experience.

"I always tell people that they don't need the beeping of machines or medical equipment in their final moments. Instead, I focus on bringing small comforts into their space—whether it's a plant for those who can't go outside, printed photos of loved ones, or even something as simple as warm water and sand to mimic the feeling of a beach beneath their feet" (Death doula, personal communication, November 2024).

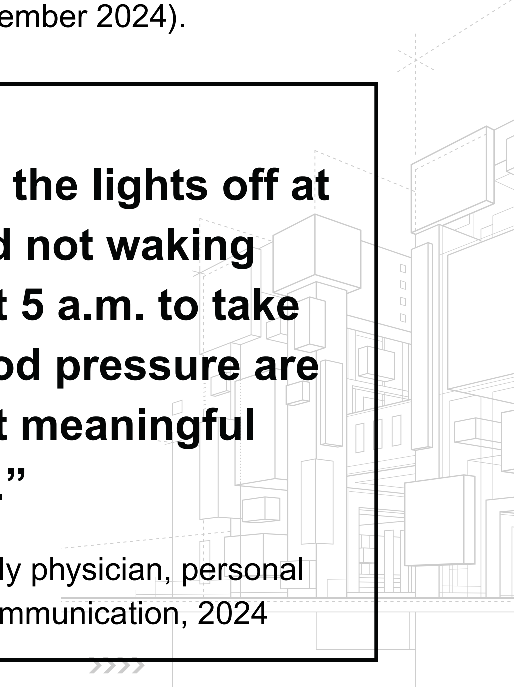


"Something as simple as warm water and sand to mimic the feeling of a beach beneath their feet."

Death doula, personal communication, 2024

The sensory environment plays a critical role in shaping a patient's experience in hospital settings, particularly during end-of-life care. Research shows that noise, lighting, and unnecessary disruptions can contribute to emotional distress and disorientation. The DASH (Delirium Awareness and Safe Healthcare) Campaign highlights how environmental stressors can worsen delirium—an acute condition that not only affects cognitive functioning but also undermines a patient's dignity, comfort, and capacity for meaningful connection. Simple changes such as reducing noise, minimizing night-time disruptions, and turning off bright lights support not just physical comfort but psychological and emotional clarity (Health Quality Ontario, n.d.). In this way, attending to the auditory and sensory aspects of care becomes an extension of attending to a person's inner world—offering a calm space for reflection in their final days and can be considered a key aspect of spiritual support.

A physician of family and community medicine refers to the potential of these simple principles to have greater control over one's end-of-life experience. *"A lot of hospital environments are not designed with patient comfort in mind. Turning the lights off at night and not waking people at 5 a.m. to take their blood pressure are small but meaningful changes"* (Family physician, personal communication, September 2024).



"Turning the lights off at night and not waking people at 5 a.m. to take their blood pressure are small but meaningful changes."

Family physician, personal communication, 2024

Loved ones described in surveys how poor hospital design amplified the emotional strain of end-of-life care. Harsh lighting, noise, and a lack of privacy were common concerns. One daughter reflected on their mother's final weeks in a shared and busy room, saying, *"It was small, uncomfortable, and far from private—it felt like a hallway… it was challenging to have hard conversations, especially* *with the family next door going through their own difficult dealings”* (Loved One Survey, February 2025).

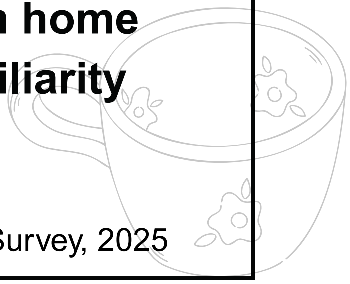
A daughter expressed distress over not having the needed privacy or opportunity to say a proper goodbye to their father.

“When my dad got sick, we all envisioned a scenario where loved ones would surround him as he drifted off into oblivion… if hospitals had more room, we would have had at least a little time to say goodbye. No one should have to die an expected death in the ER” (Loved One Survey, February 2025).

> **“We all envisioned a scenario where loved ones would surround him as he drifted off into oblivion.”**
>
> Loved One Survey, 2025

The shift to a palliative unit made a noticeable difference in the accommodation of the patient and family’s needs and wishes in their dying experience. Loved ones described these spaces as more peaceful and dignified, with private rooms, quiet surroundings, and sleeping cots and chairs that allowed them to stay overnight. As one daughter describes the shift in her mother’s care: *“Her care greatly changed, she had her own room and big, amazing windows… it was quiet and clean”* (Loved One Survey, February 2025).

Small physical comforts also mattered to loved ones and impacted their relationship with the space. *“Little things like flowers in the room, lighting, candles, a warm cup of tea, music, a blanket from home can bring familiarity and comfort,”* one family member shared. (Loved One Survey, February 2025). These seemingly minor details can help to transform sterile hospital environments into more humane spaces.



> **“Little things like flowers in the room, lighting, candles, a warm cup of tea, music, a blanket from home can bring familiarity and comfort.”**
>
> Loved One Survey, 2025

Thoughtful, warm, and beautiful design in the hospital environment and in the delivery of care can significantly impact the experience of patients and their loved ones during end-of-life, easing the emotional and psychological burden of this difficult time. Research and personal accounts illustrate how poorly designed hospital environments contribute to distress and lingering post-traumatic stress for loved ones, while well-considered spaces provide comfort, dignity, and peace (George & Saragih, 2024).

By prioritizing these design principles, hospitals can create settings that not only support medical care but also honour the deeply human experience of dying. In this context, creative practices and interventions such as art and music therapy emerge as powerful extensions of care—addressing the emotional and spiritual dimensions of dying that physical environments alone cannot reach.

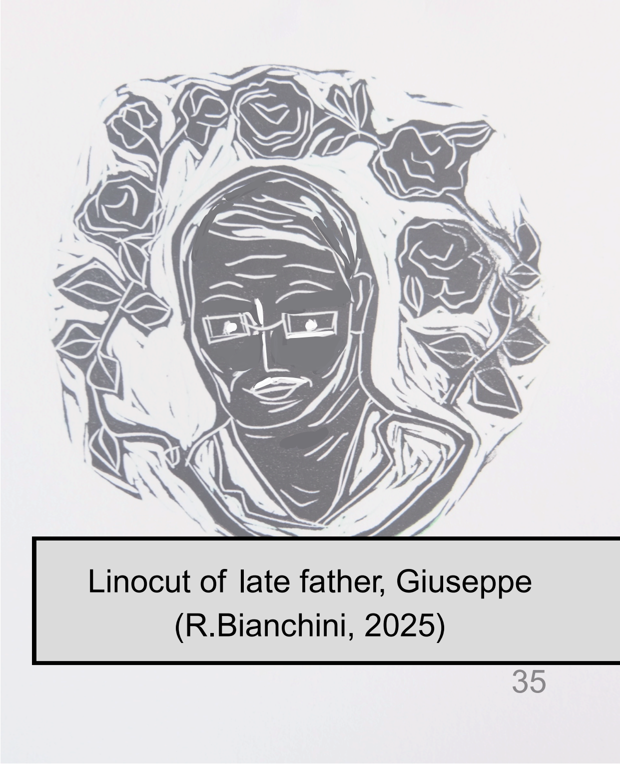
3.4 The Role of Creative Interventions in End-of-Life Care

Creative interventions in end-of-life care, such as art therapy, offer significant emotional and relational benefits for patients and their loved ones. In one study where art therapy was offered to those in palliative care, 60% of relatives found the intervention generally helpful for their loved one—providing relaxation, distraction, and motivation—while others emphasized its deeper impact on self-expression and emotional acceptance (Collette, et. al., 2020). Also, shared creative activities between caregivers, healthcare staff, and the dying fostered meaningful connection, facilitated emotional expression, and offered moments of peace during a profoundly difficult time.

Storytelling within palliative care emphasizes its role in enhancing patient-centered practices. Narrative Medicine is an interdisciplinary approach that prioritizes attentive listening to patients' stories. It aims to bridge the gap between healthcare professionals and patients, helping clinicians provide more humane and individualized care. This narrative approach can enhance the clinician-patient relationship and address broader perceptions of illness to help reduce stigmatization and isolation.

The Bruyère Palliative Care Unit in Ottawa launched a storytelling initiative led by professional storyteller Kim Kilpatrick, which involved collaborating with patients, family caregivers, and healthcare staff to provide a platform to reflect on and share lived experiences by those dying. (Edtstadler, 2023 and Radical Connections, 2021) Integrating storytelling can support families and caregivers as they undergo bereavement and the grieving process to have more positive memories of their loved one's final moments. Findings suggest hearing may be the last sense to go in the dying process; research has shown that unresponsive patients can still show brain activity in response to auditory stimuli. Music therapy has shown promise as an effective intervention in palliative care, offering emotional, psychological, and even physiological benefits for terminally ill patients. Studies suggest music therapy can help reduce pain, anxiety, and depression. (Blundon, et. all, 2020 and Warth, et. all, 2015). Despite these encouraging outcomes, robust research and standardized methodologies remain lacking in fully evaluating music’s clinical impact, nor is it integrated as a standard practice of palliative care.

Shamanic end-of-life practices recognize that hearing is the last sense to be lost and use the vibrational frequencies created by drumming and sound to guide the soul during its transition. These practices offer comfort, grounding, and a spiritual pathway beyond the physical body, as explained by a shamanic practitioner.



Linocut of late father, Giuseppe
(R.Bianchini, 2025)

“The soul is frequency and vibration… sound—whether it’s music, drumming, or spoken words—can reach people even as they begin to transition. It’s not about belief but recognizing that we are energy beyond the body” (Shaman, personal communication, November 2024).

> **“Whether it’s music, drumming, or spoken words—it can reach people even as they begin to transition.”**
>
> Shaman, personal communication, 2024

A music therapist based in Toronto who works in palliative care, also speaks of how music at this final stage is about connecting at a vibrational level. *“If they’re depressed, I match their mood, let the tears fall. I think that is the spiritual component; they may not know what they want to express, but the music expresses it.”* (Music therapist, personal communication, April 2025)

She explains that when she does a music assessment with patients, she asks them to think of the five different ways in which they can interact with music: singing, moving, playing, creating and writing. She also asks questions about the body and finds that focusing on where the pain comes from can distract patients and help dissipate that pain. As a music therapist who works in long-term care and in the community, has witnessed many deaths over the years and sees how music therapy can function as a bridge in this final transition. She also recounted an example where music therapy helped to open a strained and complex relationship between a dying man and his estranged son.

“*They asked me to play live a piece of music that was all about regret, addiction, messing up your life and how it can’t be fixed. The son asked for the song, but the parent liked it as well. It shifted the space to be one of love, and seeing this tough guy tear up was something – it was a bridge to share a gentle moment with his dad and hug and cry together. I felt very lucky to be in that process”* (Music therapist, personal communication, April 2025).

> **“..it was a bridge to share a gentle moment with his dad and hug and cry together.”**
>
> Music therapist, personal communication, 2025

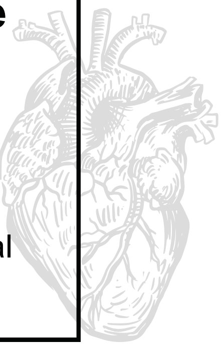
An art professor who bridges both healthcare and creative practice, emphasizes the profound role art can play in humanizing end-of-life care. Drawing on personal experience with her mother's peaceful death surrounded by art and her professional work in decolonizing and community-based practice, she advocates for art as both a therapeutic tool and a method of knowledge translation. She highlights how culturally relevant, participatory, and flexible art interventions can create more comforting environments for both patients and families—particularly in Black and Indigenous communities where systemic inequities persist. She believes art and creative intervention add greater dimensions of care and emotional resonance to end-of-life care. *“Dying isn’t a one-size-fits-all experience. Art can be a way for the dying and their loved ones to connect, to share the legacy, to explore emotion—and most importantly, to feel seen”* (Visual art and design professor, personal communication, October 2024).

A palliative care doctor has witnessed those trained in psychology work with patients to create legacy projects, such as writing letters and making audio recordings or videos, so they have small artifacts and expressions to leave behind. These interventions offer patients meaningful ways to reflect on their lives and connect with loved ones. “*When you are alert enough to have those conversations, that’s what you want—someone trained accompanying you through this existential transformation, which can happen through creative expressions… It’s incredibly important for families to be part of those interventions, too”* (Palliative care doctor, personal communication, December 2024).

The Toronto-based music therapist speaks of how songwriting and recording have become two forms of legacy work in end-of-life care. She speaks of colleagues using it in a neonatal intensive care unit (NICU) in a moving and profound way.

“My friend was working with babies that wouldn’t make it; they would make a recording of the heartbeats and then a song the parents wrote, these are ultimate legacy works. It is beautiful what just an 800-dollar stethoscope and this creative work can do. When you sell music therapy, they need to see how, in these impossibly hard moments how, a dignified death can happen at every age and stage” (Music therapist, personal communication, April 2025).

> **“...babies that wouldn’t make it; they would make a recording of the heartbeats ... these are ultimate legacy works.”**
>
> Music therapist, personal communication, 2025



Together, these creative practices provide comfort, facilitate connection, and help patients and families navigate end-of-life's emotional and spiritual complexity. One loved one spoke of how creative interventions or therapy could have supported her mother’s terminal illness, for her mother was a wonderful artist, and she would have valued an artifact of her final days. *“Her death came suddenly, and everything… felt rushed and disorienting. Looking back, I would encourage families to engage in storytelling or create a memory box to be left with a beautiful object...they can connect with”* (Loved One Survey, February 2025).

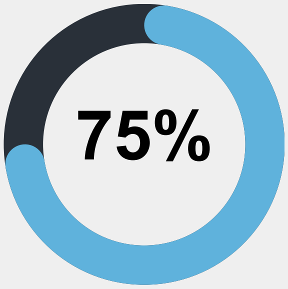
Creative interventions in end-of-life care are more than therapeutic tools—they are acts of meaning-making. Whether through visual art, music, storytelling, or legacy projects, these practices offer patients and the dying a way to express identity, preserve memory, and connect with loved ones during a profoundly emotional time. For families, these interventions can ease the enormity of grief and leave behind tangible memories of presence and love.

End-of-life can be a time of loneliness and isolation, and creative interventions offer shared humanity and connection. As the evidence and stories show, creativity becomes a form of care offering agency and emotional clarity when it is needed most. Truly evolved end-of-life care should include artists, designers, and architects embedded within healthcare teams, not as an afterthought but as central to crafting dignified, inclusive, and emotionally resonant spaces of care.

Yet, as we expand our understanding of what compassionate care can look like, we must also confront a more systemic question: why do so few people have the option to experience this care and die in the comfort of their own homes?

3.5 Barriers to Dying at Home

Surveys show that most Canadians (75%) would prefer to die at home with the right supports in place. Research indicates that early palliative care that takes place in the community or at home improves one’s quality of life, reduces emergency visits, and supports greater dignity in dying. Yet despite evidence of the benefits of dying at home, hospice or a community setting, hospital deaths remain the most common due to gaps in home-based and community care infrastructure (Canadian Hospice Palliative Care Association, 2013 and Health Quality Ontario, 2016).



Of Canadians would prefer to die at home with the proper supports in place (2013)

Source: Canadian Hospice Palliative Care Association, 2013, What Canadians Say: A way Forward Survey Report

Home-based palliative care has been found to enhance quality of life by allowing individuals to remain in familiar surroundings, reducing anxiety and improving emotional well-being. Studies show that home care is associated with higher satisfaction for both patients and caregivers due to its personalized and values-driven approach. This model of care significantly reduces unplanned hospitalizations—55% of Ontarians who died had emergency department visits in their final month—by managing symptoms proactively and lessening the strain on healthcare resources (Selectacare, n.d., McMaster Health Forum, 2013 and Health Quality Ontario, 2016).

Yet despite the benefits compared to an institutional death, the barriers to a home death remain multi-faceted. There are limited hours of home care support, including access to personal support workers via government agencies and inadequate access to needed equipment and medication. There is also a fragmentation of care delivered by nurses who may be underpaid by various agencies, limiting continuity and communication.

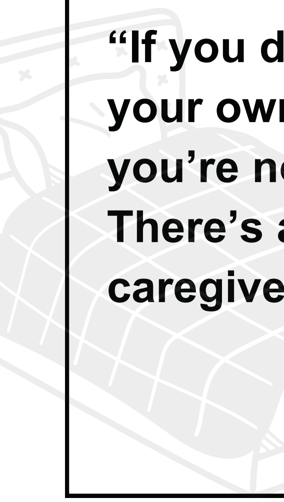
In 2021–2022, almost one in four patients with palliative home care was transferred to the hospital at the very end of life. Almost half (45%) were admitted for the main purpose of receiving palliative care–which likely includes adequate pain and symptom management. (Canadian Hospice Palliative Care Association, 2013) So, although caregivers likely attempted to give their loved one a home death, they were unable to accommodate their loved one’s care choice.

As one family member recounted in caring for her mother at home, due to inadequate support and communication, she felt ill-prepared to provide the care her mother deserved.

"We were asked to perform medical tasks we weren't trained for... it felt like a dark comedy—something my mom would have been humiliated by" (Loved One Survey, February 2025).

A death doula warns that despite a growing interest in dying at home, funding and infrastructure lag, and this becomes less sustainable given our growing aging population.

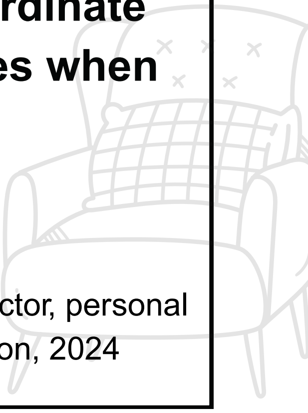
"With the coming boomer crisis, the system simply isn't prepared. Dying at home receives the least funding. If you don't already have your own care team, you're not dying at home. There's almost no caregiver relief" (Death doula, personal communication, November 2024).



"If you don't already have your own care team, you're not dying at home. There's almost no caregiver relief."

Death doula, personal communication, 2025

A palliative care physician states the lack of needed medical support makes it difficult to discharge patients to die at home, *"Even with a good palliative care team in place, it's hard to coordinate timely discharges when home care is so fragmented."* (Palliative care doctor, personal communication, December, 2024) A senior policy advisor on home-based care speaks of the need for a system-side consultation process to address workforce shortages, cultural needs and the lack of integrated care plans to support one's desire to die at home (Senior policy advisor, homecare, personal communication, February 2025).



"It's hard to coordinate timely discharges when home care is so fragmented."

Palliative care doctor, personal communication, 2024

Despite the widespread desire to die at home, systemic gaps in funding, staffing, equipment, and coordination continue to push even well-supported families back into hospitals during the final days of life. These failures are not only logistical—they reflect deeper value misalignments in how we prepare for and support dying. When families are asked to deliver complex care without training, relief, or reliable support, the burden becomes unsustainable. Dying at home, though often idealized, is not simply a matter of preference—it is a test of how well our systems uphold patient autonomy, caregiver capacity, and culturally safe care at the most vulnerable moment of life.

THE FUTURE OF END-OF-LIFE CARE

4.1 System Change: Infrastructure, Research and Collaboration

The persistent barriers to dying at home—fragmented care, caregiver burnout, and lack of infrastructure—highlight the urgent need for systemic reform. Ensuring access to quality end-of-life care across healthcare settings requires investment in coordinated infrastructure, collaborative planning, and research-informed policy. System change can reduce the trauma of over-medicalized deaths by centering the wishes of the dying and supporting caregivers with the resources they need. It also enables greater consistency in care across regions—bridging the gaps between rural and urban hospitals—and ensures that cultural identity, language, and personal values are respected within palliative care delivery. Building a more compassionate and equitable future of end-of-life care begins with recognizing these disparities and designing systems that serve all individuals with dignity.

As noted throughout this research, palliative care is a relatively young discipline, and its relevance remains misunderstood by healthcare providers, caregivers and patients. Yet research and advocacy organizations and multiple levels of government are working to develop frameworks to integrate palliative care into our healthcare systems. A physician and director at an innovation lab states that a full system change is needed in providing end-of-life care, and there remain gaps in strategies.

"*One of the positive things is when the crisis is bad enough, the system can move quickly, and the crisis is bad enough. That is rigour we are up against. You can have all the right things being said at the senior level and at the junior level and have the passion, but the entire system needs to shift.*" (Physician and director of innovation lab, personal communication, August 2024)

> **"...When the crisis is bad enough, the system can move quickly, and the crisis is bad enough."**
>
> Physician and director of innovation lab, personal communication, 2024

The Canadian federal government is working to improve palliative care frameworks and delivery, with a clear recognition of the need for stronger collaboration across governments, provinces, and territories. This cross-jurisdictional approach is essential to sharing data, aligning best practices, and expanding training across the healthcare system. Key priorities include destigmatizing palliative care to allow earlier access during the illness journey, promoting advance care planning, and ensuring equitable access to grief and bereavement support. Additional efforts focus on enhancing provider education through a national competency framework, improving cultural competency, and strengthening care navigation (Health Canada, 2023).

Dr. James Downar, a palliative care physician at the University of Toronto and researcher on end-of-life ethics, is also the chair of the Pan-Canadian Palliative Care Research Collaborative. A national network of researchers, healthcare providers, and patient partners dedicated to advancing palliative care research. Its goals include evaluating palliative care delivery to identify best practices, enhancing research capacity through data standardization, and facilitating collaboration for multi-site studies (Pan-Canadian Palliative Care Research Collaborative, n.d.). He emphasizes the need for improved research and knowledge mobilization to provide consistent and holistic end-of-life care across all healthcare settings and to better address the complexity of issues.

“We need collaboration among multiple centers to share best practices and conduct extensive studies. Bureaucratic challenges, such as stringent privacy laws and ethics board delays, hinder research efforts. More effective collaboration across healthcare settings and a streamlined approach to sharing information could lead to meaningful improvements in patient care. (Dr. James Downer, personal communication, September, 2024)

Dr. Naheed Dosani, a Toronto palliative care physician and advocate, underscores the importance of measurable progress and better data collection in addressing inequities in end-of-life care. Through the Improving Equity Access to Palliative Care Collaborative—encompassing 23 projects—his work highlights how social determinants like housing and food security need to be addressed to make palliative care truly accessible. Despite these promising efforts, gaps remain in data collection and cross-team collaboration, which are crucial for equitable, high-quality care.

Redesigning palliative care to be culturally sensitive and accessible across healthcare settings requires a multi-faceted approach that includes investing in infrastructure and collaborative research (Canadian Cancer Research Alliance, 2017). It also recognizes how end-of-life care is an essential component of healthcare, for it is often not viewed as prestigious as other medical disciplines. Investing in research ensures innovative and creative practices are being developed and breeds future generations of researchers and end-of-life practitioners. The federal government's palliative care strategy also strives to build research capacity, standardize data tools, and integrate best practices across all care settings—including home and long-term care—to help integrate palliative care as part of the continuum of care throughout one’s life (Health Canada, 2023).

However, while these frameworks, policy initiatives, best practices and continued research demonstrate that the need for systemic change across healthcare settings for holistic end-of-life care is understood —there remains a gap in the implementation. This may be partially due to the complexity of systemic change, which involves a cultural shift in how we view death and dying, involving interdependencies between education, training and societal attitudes. Also, shortages of trained healthcare professionals in palliative care principles might affect the quality and availability of palliative care. Investment in training and support for palliative care workers can help to eliminate burnout and ensure retention.

Addressing these systemic and infrastructure issues and gaps in the delivery of end-of-life care requires a multi-faceted approach. This is an evolutionary and iterative process that must build on existing successes while expanding access to care. These strides being made through research organizations, advocacy groups, healthcare providers, and provincial and federal governments in Canada speak to a greater cultural shift in how we perceive death and dying. As these frameworks evolve, how can we ensure they fully account for the diverse identities of the dying—so that compassionate, culturally safe, and inclusive end-of-life care is available to all, regardless of socio-economic status, geography, age, illness, or background?

4.3 Equity in Care: A Paradigm Shift

In delivering patient-centred palliative care, it is essential to recognize that a person's identity affects their feelings and experiences within the healthcare system and that there are social determinants of health. These determinants include economic and environmental factors influencing an individual's overall health, well-being, and ability to access quality end-of-life care. In Canada, access to palliative care is not equal for everyone, with significant disparities based on geography, type of illness, physical ability, age, identity, and socioeconomic status. Access to palliative care varies across provinces and territories; patients in urban and rural areas were identified as palliative at similar rates; rural patients were more likely to be hospitalized for palliative care and more likely to die in a hospital, highlighting the need for improved community-based services in rural areas. Patients with cancer are more likely to receive palliative care than those with other conditions, with 77% of cancer patients identified as palliative compared to only 39% of those with dementia. This may be due to the more predictable progression of cancer, making it more apparent when to transition to palliative care. Age also plays a role, as younger seniors aged 65 to 84 were the most likely to receive palliative care, while Canadians over 85 were the least likely, despite their increased healthcare needs in their final years (Canadian Institute for Health Information, 2023). This situation is most likely because older seniors may reside in long-term care homes where it is more difficult to access palliative care or may have long-term illnesses such as dementia where it is more difficult to determine the trajectory of the illness.

Specific populations face systemic barriers to palliative care access. Research suggests that immigrants and racialized groups are more likely to die in hospitals and less likely to be admitted to palliative care units than those born in Canada. Language barriers, cultural differences, and unfamiliarity with the healthcare system can contribute to these disparities. First Nations communities often lack access to specialized palliative care services, particularly pain and symptom management, forcing many Indigenous patients to leave their communities for care in urban hospitals, where services may not align with their cultural values and traditions (Canadian Institute for Health Information, 2023).

Specific populations face systemic barriers to palliative care access. Research suggests that immigrants and racialized groups are more likely to die in hospitals and less likely to be admitted to palliative care units than those born in Canada. Language barriers, cultural differences, and unfamiliarity with the healthcare system can contribute to these disparities.

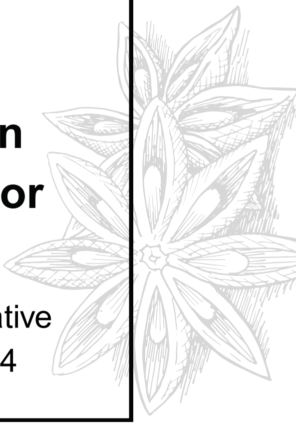
Individuals with physical disabilities often encounter at times heartbreaking barriers when trying to access adequate palliative care. A systematic review titled, *The palliative care needs of adults with intellectual disabilities and their access to palliative care*, examined 52 medical studies which have shown that these individuals are less likely to receive specialized palliative care services and may experience inadequate pain management compared to the general population. Furthermore, barriers to this population's challenges include communication difficulties and a lack of knowledge among healthcare professionals of their needs (Adam et al., 2020). A death doula, speaks of these additional barriers for her clients with disabilities in receiving quality care.

“I had a client who hadn't been outside in six years—just two small steps at the entrance of her building made it impossible for her to leave. People with disabilities face some of the greatest challenges. Their medical care is often compromised, not because of their condition, but due to the lack of fundamental accessibility to healthcare services” (Death doula, personal communication, November 2024).

“I had a client who hadn't been outside in six years—just two small steps made it impossible for her to leave.”

“For those facing structural vulnerabilities, palliative care often feels inaccessible or unsafe”

Naheed Dosani, palliative care physician, 2024



Naheed Dosani, a palliative care physician and health equity advocate, states that homelessness itself can be viewed as a palliative diagnosis, as individuals without stable housing often die decades earlier than their housed counterparts. To address this issue, he founded the PEACH (Palliative Education and Care for the Homeless) program, which delivers palliative care directly to people living on the streets. This approach recognizes that conventional palliative or home-based palliative care models do not accommodate those without stable housing. Dosani emphasizes the need for palliative care systems to integrate harm reduction strategies and eliminate stigmatizing practices that exclude people who use drugs or lack conventional social support.

“Being unhoused significantly increases the likelihood of developing serious or chronic illnesses, contributing to an average life expectancy of just 34 to 47 years—half that of the general population. For those facing structural vulnerabilities, palliative care often feels inaccessible or unsafe” (Dosani, 2024).

LGBTQIA+ individuals may be hesitant to seek care and feel unsafe due to previous negative experiences with the healthcare system. They may feel they need to educate healthcare providers or hide evidence of gender identity or sexual orientation. Dr. Kim Acquaviva is a professor at the University of Virginia School of Nursing and an advocate for LGBTQIA-inclusive hospice and palliative care. Her research focuses on the intersection of end-of-life care and LGBTQIA+ health, exposing the biases and gaps in the healthcare system that leave queer individuals feeling unseen or mistreated. In a study of 290 LGBTQ+ patients and their partners, over one-third reported insensitivity to their identities, and nearly one-third noted a lack of provider knowledge about LGBTQ+ health needs; others cited experiences of judgment, rudeness, misgendering, and having their treatment decisions disregarded (Acquaviva, 2024 and Stein et al., 2023).

Advocacy groups are attempting to address gaps in accessing palliative care. Pallium Canada is a national organization dedicated to improving palliative care through education, for they believe an overreliance on specialist palliative care teams is unsustainable based on the needs of the health care system. They offer training, resources and advocacy to all healthcare providers in end-of-life care. Their modalities also address equity issues related to accessing palliative care clinical support and education, especially in rural and remote regions and Indigenous communities, which continue to face health inequity due to embedded colonization within our systems. (Pallium Canada, n.d.) As palliative physician and advocate Naheed Dosani argues, when palliative care is delivered with intentionality and rigour, it becomes a powerful tool for addressing historical inequities in healthcare. Despite limited resources, a justice-driven model can help empower patients and providers to create meaningful, dignified end-of-life experiences. (Meier et al., 2016 and Dosani, 2024).

A loved one, when surveyed, described a moment that felt deeply judgmental and lacking in sensitivity in terms of their loved one's addiction issues: "*We had privately mentioned an unacknowledged alcohol dependence, but the palliative physician brought it up out loud in front of the patient and her sister—who hadn't been part of the earlier conversation. It felt like something essential had been missed regarding continuity and care.*" They also noted a lack of coordination when a medical student arrived to assess the patient's kidneys without context, despite her condition being far more complex. *"There was no physician present to guide him, and it made the experience feel disjointed"* (Loved One Survey, February 2025).

Ensuring equity in palliative care is not just a matter of fairness but a necessity for delivering compassionate, patient-centered care that respects the diverse needs of individuals facing serious illnesses. Without intentional efforts to address systemic barriers, many will continue to experience inadequate symptom management, poor access to services, and exclusion from the supports that define quality palliative care. An effective palliative care system needs to acknowledge and adapt to the social, cultural, and economic realities of patients, ensuring that no one is abandoned in their final days. Understanding the inequalities in accessing timely and quality end-of-life care can also help move us towards care that is more adaptable to the individual's needs and experience of dying.

4.4 No one's Death is the Same: Dying as an Individual Experience

End-of-life care needs to address systemic inequities while also recognizing that dying is an inherently individual experience. Personal, cultural, spiritual, and social contexts shape how each person understands and navigates death—yet current healthcare models often overlook this complexity. The Canadian Cancer Research Alliance has emphasized the need for care frameworks that are culturally responsive and tailored to the unique needs of marginalized and underserved populations (Canadian Partnership Against Cancer, 2016).

This section explores tangible solutions that move toward a more inclusive, equity-oriented care model that respects difference and honours personal meaning-making. These include the integration of care navigators within hospital settings to help individuals and families navigate complex care systems and the development of personalized death plans that go beyond advance directives to include one's emotional, spiritual, and environmental preferences. These practices not only improve patient-centered care but also challenge dominant attitudes of death denial and one-size-fits-all approaches to dying.

Data from the Oregon Death with Dignity Act reveals that those nearing end-of-life are most concerned about losing autonomy (91%), the ability to engage in meaningful activities (86%), and personal dignity (71%) (Oregon Death with Dignity Act: Data Summary, 2024). These findings reflect a deeper call for care models that respond to human values, not just medical conditions.

Palliative care physician Blair Bigham writes about the importance of knowing patients as whole human beings—not just as clinical cases.

"You need to hear their story. It establishes that person's humanity. When the physician acknowledges the depths of this person's life and says, 'I see your family member as a person,' they will be operating from a common understanding of what's at stake, and that's a person's humanity" (Bigham, 2022).

> **"You need to hear their story. It establishes that person's humanity."**
>
> Doctor Blair Bigham,
> *Death Interrupted*, 2022

This more profound understanding of the individual is at the core of several promising solutions. One is the integration of care navigators within hospital and palliative care settings. Assistant deputy minister Gillian Steeve, draws on paediatric care models to suggest that a dedicated care navigator could guide families through end-of-life planning, offering emotional, logistical, and spiritual support. This role could be a central point of contact, ensuring that care aligns with the patient's values and reduces confusion during emotionally charged moments (G. Steeve, personal communication, September 2024).

When surveyed, a loved one speaks of the need for this type of care navigator role to support families during end-of-life care that goes beyond clinical support to more holistic care—allowing for greater personhood and individuality for the dying.

"We needed a more holistic approach to end-of-life—not just about the clinical and medical aspect, but also the spiritual needs of the patient and family. Staff could proactively have a framework with items to discuss with families and with a focus on comfort, dignity, and personal autonomy" (Loved One Survey, February 2025).

Death care plans—personalized documents modelled after birth plans—can empower patients to articulate their full emotional, spiritual, and environmental preferences. Physician Nadine Laraya, advocates for their inclusion as a standard tool in end-of-life planning, noting that even when advance directives exist, they often lack the nuance required for personalized care. A death plan might include requests as simple as avoiding a room near a busy nursing station or as profound as outlining who should be present during final moments. Even when advanced directives may exist for a patient, key information is often scattered, and small nuances are not considered. A death care plan would provide greater detail of the preferences of the dying and could eventually become an accepted aspect of care (Dr. N. Laraya, personal communication, September 2024). A patient-centered document outlining reasonable accommodations could empower individuals and guide families and staff in providing more compassionate, tailored end-of-life care—just as birth plans have reshaped maternity care.

"A death care plan would provide greater detail of the preferences of the dying."

Doctor Nadine Laraya, personal communication, 2024

An innovative palliative care initiative called the 3 Wishes Project, developed at the ICU at St. Joseph's Healthcare in Hamilton, Ontario, honours the dignity and autonomy of dying patients and supports families and clinicians during end-of-life care. The project invites patients and families to express three meaningful wishes—hearing their favourite music, tasting a beloved food, or having a pet visit—to personalize their dying experience. These simple, compassionate acts help humanize a highly clinical environment, creating positive memories for families and offering healthcare providers a more profound sense of purpose (St. Joseph's Healthcare Hamilton 3 Wishes Team, n.d.).

Personal values, cultural backgrounds, spiritual beliefs, and family dynamics shape our death. As care models evolve, they need to be rooted in the understanding that each person's final moments are unique and deserving of respect as a sacred transition, regardless of whether anyone believes in an afterlife. By healthcare providers embracing an understanding and humanity in end-of-life care, can move beyond clinical efficiency to include connection and compassion; involving care navigators, personal and detailed death care plans, and care policies and practices that ensure that end-of-life care is an individual and dignified experience. To truly shift toward person-centered care, we must also confront the cultural discomfort with mortality itself—inviting a broader societal acceptance of death as a natural, meaningful part of life.

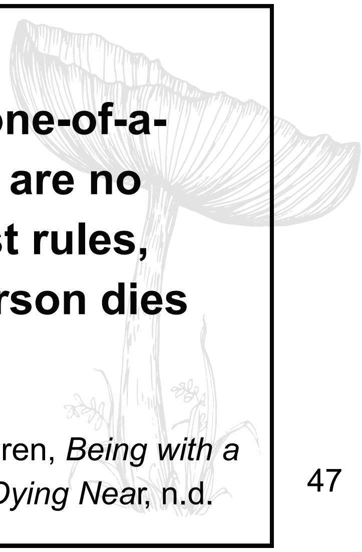
4.5 Death Acceptance: Reclaiming Our Relationship with Dying

Despite the inevitability of death, modern healthcare systems still struggle to support patients and families in preparing for it. As discussed earlier, institutional cultures in North America have long framed dying as a failure to be prevented rather than a natural life transition to be understood. Yet a growing movement—spanning healthcare, public health, design, education, and the arts—is beginning to challenge this cultural resistance through greater death literacy and open dialogue.

End-of-life care experts stress that clinical skills and cultural fluency are the antidote to fear. In societies such as Kerala, India, where palliative networks are embedded in communities, or Wisconsin, where public health campaigns normalized advance care planning, dying is often approached with agency and peace (Bigham, 2022). These models demonstrate that when death is integrated into public life—not hidden—people are better equipped to make informed end-of-life decisions. Also, healthcare providers, when there is greater community support, have a greater capacity for quality and compassionate care.

Healthcare leader and writer Atul Gawande highlights the ethical tensions that arise when clinical culture avoids honest conversations. *“Talking about dying is enormously fraught,”* he writes, “*in part because medicine has absorbed a customer service model that privileges optimism over honesty”* (Gawande, 2014). Similarly, death historian Steve Berry points to consumerism and individualism as shaping a distorted view of mortality: *“The map on our phone puts us in the centre of the world… Given that empowerment, every individual feels particularly deserving of continuation of life”* (Steve Berry, as cited in Bigham, 2022).

To address our gap in understanding the dying experience, a professor and Métis physician created a guide for caregivers entitled: *Being with a Person Who is Dying: A Guide for People When Death is Near* outlining how a person can best support this process by overcoming fear and being more present. He speaks in his guide of how having a sense of what to expect in the dying process can help reduce feelings of anxiety. “*By readying ourselves to notice natural ways that our bodies help us to die can give space for us to be with the person who is dying simply. We are all one-of-a-kind, though, so there are no hard-and-fast rules, and each person dies uniquely”* (McMurren, n.d.).



“We are all one-of-a-kind ... there are no hard-and-fast rules, and each person dies uniquely”

Dr, Chase, McMurren, *Being with a Person Who is Dying Near*, n.d.

Our fear and avoidance of death can begin in childhood. Much of what we understand and come to expect about dying, death and bereavement is gained during our formative years. Television and movie deaths or video game deaths may be the closest exposure to death that many children experience now. The reactions of the adults in their lives to actual deaths, including grandparents, other relatives, friends or even family pets, teach young people about dying and death. Children often are deliberately excluded from discussions about death, visits to dying people, and attendance at funeral or memorial services. This leads to children responding to death with avoidance, revulsion, despair, anger or fear when they grow up. (Macy 2013, as cited in Northcott, Wilson, 2022) Public education and open dialogue are essential tools for breaking this cycle.

Both those with lived experience and clinicians believe a solution to this discomfort with death and dying is a proactive approach to normalize death early in life. A loved one interviewed reflected on the absence of support and understanding during her mother's final days. *"It was clear she was not going to recover, but no one ever said that out loud,"* she recalled. *"It delayed her palliative care… There needs to be more built into hospitals and even school curriculum to provide greater acknowledgement of what's involved in dying"* (Loved One, personal communication, February 2025).

"Provide greater acknowledgement of what's involved in dying."

Loved One Survey, 2025

Shifting toward a future of care rooted in dignity and compassion requires more than individual conversations—it requires system-wide approaches that elevate death education in community settings. Cultural and community initiatives like death cafés are informal gatherings where individuals discuss death over tea and cake. Originating from the ideas of Swiss sociologist Bernard Crettaz and later developed by Jon Underwood in the UK in 2011, these events aim to increase awareness of death to help people make the most of their finite lives. (Angle and Dove, 2024) Death cafés are held worldwide, with over 15,000 death café gatherings held since 2011 in 83 countries. (Polacinski, n.d.) Unlike grief counselling sessions, death cafés have no set agenda, objectives, or themes, providing a respectful and confidential space for open-ended conversations about mortality.

In North America, the death positivity movement offers a hopeful cultural countercurrent to fearing death. Projects like End Well and End with Care unite interdisciplinary voices to challenge taboos, equip caregivers, and aim for compassion and connection in end-of-life planning. These initiatives emphasize storytelling, education, and design as tools for transforming how individuals, institutions, and communities relate to mortality. By reclaiming death as a shared human experience, these efforts make it easier for people to navigate loss and plan for dying on their terms (End Well, n.d., and, End with Care, n.d.).

A future of end-of-life care rooted in dignity and compassion can begin with more openness and less denial of death from an early age, releasing its grip of fear and anxiety when one is forced to confront it. Moving away from a culture of death denial and over-medicalization, requires both healthcare systems and society to normalize conversations about dying—starting in schools, continuing through the healthcare journey and extending into public discourse. By embracing death as part of life—not a failure to fight—we can build care systems that respond with presence rather than panic. Accepting death allows individuals, families, and providers to make informed care decisions rather than reacting in crisis.

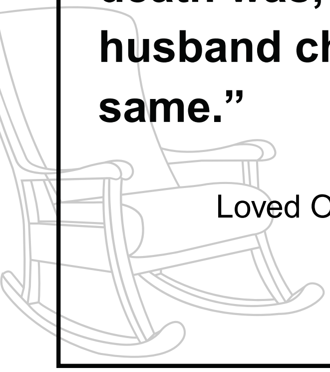
As the death positivity movement and palliative care advocates emphasize, creating space to talk openly about death not only reduces suffering but allows for humane and meaningful experiences during end-of-life. How can a cultural shift in death acceptance help us to consider how end-of-life can expand beyond institutions—into homes, communities, and spaces where people can die with greater comfort and choice?

4.6 Home and Community-Based End-of-Life Care

Greater access to home and community-based supports can significantly reduce the barriers that prevent people from dying outside of hospitals. While many individuals express a preference to die at home or in hospice, systemic limitations—such as fragmented care, workforce shortages, and lack of public awareness—often make this difficult to achieve. Expanding these models and recognizing death as a shared responsibility is central to a future where end-of-life care is not only more accessible but also more humane and individualized. This section explores the distinctions between home, hospice, and community-based models—and what is required to make them more accessible and equitable for all.

Home-based palliative care allows individuals to receive medical and supportive care in the comfort of their own homes. This model provides physical relief and emotional well-being, helping people remain close to family, pets, and the rhythms of ordinary life. A woman recounts both her father and husband dying in 1996, her father in January and her husband in August, and how both had relatively short hospital stays and chose to go home to die. Her husband appreciated being part of daily life, surrounded by family, his children and friends who came and went. He chose a home death when he witnessed his father-in-law's dying experience.

"I decided to bring my father home, and he was grateful. His bed was in the living room with a view of the Humber River, which was in full flood that mild January—I know the sound comforted him. After witnessing how peaceful my father's death was, my husband chose the same" (Loved One Survey, February 2025).



“After witnessing how peaceful my father’s death was, my husband chose the same.”

Loved One Survey, 2025

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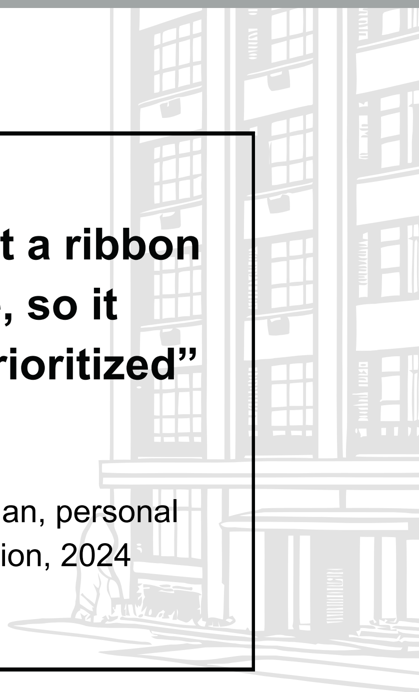


“You can’t cut a ribbon on home care, so it doesn’t get prioritized”

Hospice physician, personal communication, 2024

Hospice care, distinct yet complementary to home-based care, is typically provided in specialized residences. It focuses on comfort, dignity, and holistic support for individuals with a terminal diagnosis. Hospices were established in Canada in the late 1970s mainly by community groups and are still not an integrated part of the healthcare system (Canadian Hospice Palliative Care Association, 2013). Consequently, hospices must fundraise to support their daily requirement, limiting the number of services they can provide and the number of clients they can assist. As an Ottawa-based palliative care physician notes, *“The biggest bang for your buck is in home-based or hospice care—it prevents so many hospital visits. But you can’t cut a ribbon on home care, so it doesn’t get prioritized.”* (Hospice physician, personal communication, August 2024)

Community-based care includes broader support services beyond the medical model, involving volunteers, family members, death doulas, spiritual guides, and social programs. A health futurist, envisions a future where hospitals handle acute medical needs while death, grief, and memorialization are supported through new systems, technologies, and community-based services (Health futurist, personal communication, December 2024).

Other jurisdictions are much more advanced in viewing dying as a collective responsibility, and the community is engaged in end-of-life care. India and Japan have developed impactful volunteer-based programs to support the dying. In India, organizations train volunteers to provide home-based palliative care, offering emotional support, symptom management, and companionship to patients and their families. Similarly, Japan’s Hospice Volunteer Network plays a vital role in end-of-life care, with volunteers supporting patients in hospices and at home by offering presence, practical help, and cultural rituals around dying (Fukui RN, PhD, et al., 2011 & Sallnow, et. al., 2010). Community-based end-of-life care reduces the burden on caregivers and the system.

Research from the U.S. has shown that patients who receive palliative care at home not only experience greater comfort but, in some cases, live longer—with those living with conditions like heart failure or advanced cancer gaining weeks or even months compared to hospital-based care (Gawande, 2014). A retired nurse reflects on how the dying most often desire the ordinary in their final moments and how this always surprised her: "*In their final weeks, people wanted the comfort of the everyday… a kind of gentle distraction*" (Retired palliative care nurse, personal communication, February, 2025).

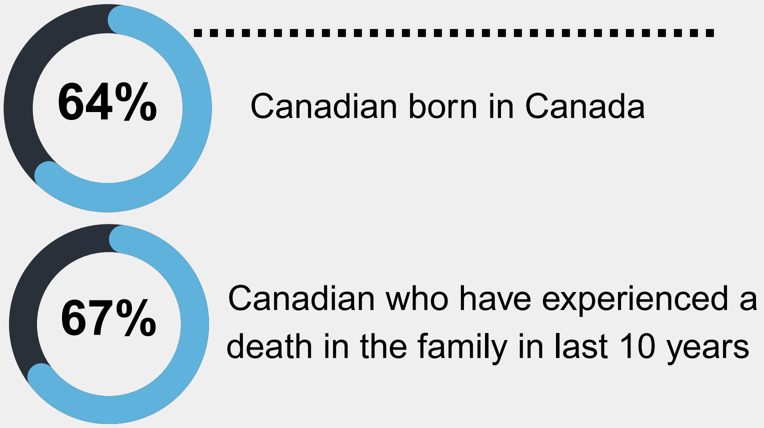
> **"In their final weeks, people wanted the comfort of the everyday."**
>
> Retired palliative care nurse, personal communication, 2025

Yet, these benefits remain out of reach for many. Even when caregivers want to honour a loved one's wish to die at home, a lack of training, equipment, and support often forces last-minute hospital transfers during end-of-life. Also, many caregivers and families remain unaware of their options and how to orchestrate and implement home-based end-of-life care.

According to the Canadian Hospice Palliative Care Association, Canadians born in Canada are more likely to be familiar with the concept of hospice palliative care (64%) than those born outside Canada (48%). Awareness of the options of community-based hospice care is also greater among Canadians who have contemplated end-of-life issues (67%) or have experienced a death in the family within the past ten years (67%) (Canadian Hospice Palliative Care Association, 2013).

Home and community-based end-of-life care is more cost-effective, reducing unnecessary hospital stays; it also offers a much more humane and private way to die, surrounded by one's belongings and loved ones able to enjoy one's ordinary life pleasures. Systemic gaps emphasize the need to see dying and death as something to be taken out of the medical establishment and to be based more in our communities where support could include volunteers, extended family, neighbours, spiritual practitioners and artists. Dying at home with community support preserves dignity in ways institutional care often cannot. But for this vision to be realized equitably, we need deeper investment in infrastructure, workforce, and comprehensive caregiver respite. Without it, the promise of dying at home remains out of reach for far too many. A future in which dying is grounded in community rather than institution will require policy reform and a reimagining of who is responsible for supporting this final chapter of life.

Figure 7: Canadians that are familiar with the concept of community-based hospice care



Source: Canadian Hospice Palliative Care Association, 2013, What Canadians Say: A way Forward Survey Report

CONCLUSION: REIMAGINING HOW WE DIE

5. Conclusion: Reimagining How we Die

This paper has explored the disconnect between how most people would choose to die and the reality of death and dying that unfolds in North American hospital settings. It has highlighted systemic, cultural, and design-related barriers to dignified end-of-life care while offering promising practices and insights.

5.1 Where We Stand: Key Conclusions on End-of-Life Care

- Hospital-based end-of-life care is often misaligned with patient values—prioritizing aggressive intervention over comfort, communication, and autonomy.
- Death denial remains a central barrier to meaningful conversations about dying. A lack of advance care planning leaves loved ones and healthcare providers navigating complex decisions in moments of crisis.
- An inability to transition from the ICU to palliative care comes at an economic cost and strain on our healthcare system and a psychosocial cost for caregivers, healthcare workers and the dying.
- Palliative care models of care are underutilized and often introduced too late in one’s healthcare journey. Early integration improves quality of life, reduces suffering, and supports informed decision-making.
- Spiritual and emotional needs remain unmet in many healthcare settings. Holistic care should include attention to meaning, identity, and connection—regardless of religious affiliation.
- Creative interventions and art therapy integration into end-of-life care have the potential to provide respite, deeper meaning and legacy for the dying and comfort to their loved ones.
- ICU design and hospital environments shape the dying experience. Lack of privacy, access to nature, sensory overload, and institutional aesthetics can compound trauma for patients and families.
- Better access to research and data, policy coordination, inter-professional collaboration, and agreed-upon care frameworks are needed to ensure equitable, consistent, and culturally safe end-of-life care across all healthcare settings.
- A patient's socioeconomic status, location and cultural background impact their access to quality end-of-life care. Those who are unhoused, under-resourced, or marginalized face systemic barriers to receiving compassionate, sensitive, end-of-life care.
- Death literacy, death positivity, and public dialogue are essential for system change and to combat the cultural and situational discomfort and denial of death.
- Home and community-based models of care offer better outcomes, yet they remain underfunded, fragmented, have an insufficient workforce, and are out of reach for many.

5.2 The Future of Dying Well: A Collective Mandate

To reimagine end-of-life care as less traumatic and more deeply human, we need to reconsider how, where, and with whom we die. The future of care can be design-led and human-centered—where art, environment, technology, and community come together to transform the experience of dying into one of connection and dignity.

Dr. Sunita Puri writes, "*Death was even an unexpected reminder of human equality… we are unified in the brevity and fragility of our lives. Death amplifies life's significance.*" Yet, in many healthcare systems, death is still treated as a failure. This research reveals how systemic inequities, institutional rigidity, and a lack of preparation have resulted in avoidable suffering—leaving patients and families overwhelmed and robbing death of the presence, support, and grace it deserves.

Through interviews, research and case studies, a different vision emerges—one rooted in community, creativity, and care – where it becomes easier to feel greater depth and meaning during end-of-life.

Talk About Death and Dying:
Normalize open conversations about death—within families, communities, and institutions—through initiatives like death cafés and public education. Help people understand what to expect at the end of life, reducing fear and isolation around illness, dying, and grief. Make advance care planning a natural, ongoing part of life, not something reserved only for the final days. By treating death as an inevitable and meaningful transition, we can empower individuals to make informed choices, maintain autonomy, and experience greater dignity at the end of life.

Individual Dying Support: Advocate and encourage every person entering the hospital with a serious illness and injury to prepare a personalized death care plan — modeled after a birth plan. Allowing individuals to document their end-of-life goals, advance directives, and personal preferences—like requesting a quiet room, access to nature, or favourite comforts from home. Assign the patient a care navigator within the hospital to help patients and families translate these wishes into real-time care, ensuring they are heard, respected, and supported. This approach is simple but powerful, and would humanize the institutionalization of dying, restore personal autonomy, and offer a more compassionate, individualized end-of-life experience across healthcare systems.

Ensure everyone has a good death:
Acknowledge that dying is a deeply personal and challenging experience for loved ones and the patient, and make space for people to be seen, heard, and comforted in their final moments. Integrate palliative care earlier and ensure comprehensive end-of-life care training is provided for all healthcare staff including nurses, doctors and personal support workers. Attend to all the needs of the dying, not just physical but also psychological, cultural, spiritual and social well-being. Ensure that all care choices are communicated clearly and consistently with patients and loved ones and supported as they navigate every step of their end of life.

Recognize cultural and spiritual needs: Ensure institutional spaces, including hospitals and hospices, offer access to interfaith and spiritual care providers—not just chaplains from dominant traditions. Design environments with flexibility for ritual and reflection, such as meditation spaces, access to nature, rooms for extended family gatherings, or private areas for last rites and cultural customs. Partner with and integrate local cultural organizations, Indigenous communities, immigrant-serving agencies, elders and families to co-create end-of-life pathways that reflect diverse values, languages, and worldviews. Restore rituals, guidance and grace to end-of-life care to help navigate grief and loss.

Build systems of equity: Support caregivers, fund culturally safe services, and ensure every person—regardless of income or background—can die with dignity. Invest in home and palliative care services that reach rural, remote, and underserved communities. Address structural barriers by ensuring language interpretation, accessible transportation, and financial support for patients and unpaid caregivers. Create workforce strategies that recognize and resource care work—especially for personal support workers, many of whom are racialized and precariously employed. When developing and designing policies and frameworks, include marginalized voices to understand their needs, such as those of 2SLGBTQ+, Indigenous, Black, disabled, and immigrant communities, and incorporate equity-based data collection that is lacking in quality end-of-life care. By understanding and confronting biases in our healthcare system, we can aspire to greater equity in end-of-life experiences.

Envision Death and Dying as a Creative and Community Experience: Encourage collaboration and build bridges across disciplines, bringing designers, artists, spiritual leaders, and volunteers into end-of-life care alongside healthcare teams. Diverse voices can reimagine not just services but also the environments in which we die through sensory design, storytelling, music, art therapy, and comfortable physical spaces rather than isolation. These collaborators can help restore presence, meaning, and beauty to the dying process in ways medicine alone cannot.

Invest in home and community-based models: Develop support systems that allow people to die in familiar, connected environments—not just institutions. Home care enables dignity and comfort, but only when supported by well-coordinated teams, adequate staffing, and caregiver relief. Community-based models extend care beyond the medical, involving neighbours, volunteers, and local organizations to surround the dying with presence, ritual, and practical help. In countries like India and Japan, volunteers are trained to offer emotional and spiritual support, symptom monitoring, and companionship—relieving pressure on families and healthcare providers. These models recognize that dying is not solely a medical event but a shared human experience. By treating death as a collective responsibility, we create a culture where no one dies alone or unsupported.

Embrace and Normalize Grief: Our fear of death and the inability to have open conversations about end-of-life care choices are also rooted in our glossing over and hiding of grief in Western society. Grief and mourning should be restored as a visible, communal act through ceremony, storytelling, and cultural practice. This helps people to feel less isolated in their grief and to work through any guilt and post-traumatic stress when losing a loved one. As stated by author Martín Prechtel in Chase McMurren's *Being with a Person Who is Dying: A Guide for People When Death is Near*, *"Grief that's not expressed becomes a kind of toxic waste… We need to begin feeling our grief—that delicious, fantastic, eloquent medicine."* (Martín Prechtel as cited in McMurren, 2024)

> **"We need to begin feeling our grief—that delicious, fantastic, eloquent medicine."**
>
> Author, Martín Prechtel, 2024

Health futurist Zohreh Khayat explains that inclusive end-of-life care must embrace a broader definition of the "patient"—one that includes not only the individual, but also their family, their community, and their spirit (Z. Khayat, personal communication, December 2024). Dying, and the grief it leaves behind, is never an isolated medical event; it is a profound relational and cultural experience. Recognizing this allows us to design care that honours the full web of connections that sustain a person's life—and their death.

Death, although challenging and complex, offers us a rare and profound opportunity: to meet one another with courage, clarity, and care at life's final threshold. When we approach dying with intention rather than fear, we create space for dignity, meaning, and shared humanity. This work—transforming how we die—is not just for the sake of the dying. It is a gift we give to ourselves, to our communities, and to those we leave behind.

Reimagining how we die is not simply about changing healthcare systems—it is about restoring death to its rightful place as a sacred, human experience. This is our collective work.

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