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THE COST OF CARING: COMMUNITY AND STEWARDSHIP IN SUSTAINING WHOLE PERSON CARE

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> "The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to walk through water without getting wet."
> —Dr Naomi Rachel Remen, Kitchen Table Wisdom, 1996

Whole person care is often described as an ethic of focused attentiveness: an orientation that honours the physical, emotional, relational, and existential dimensions of human experience. It invites practitioners to attend not only to symptoms and treatments, but also to meaning, relationships, identity, and dignity. Yet, embedded within this orientation is a reality that is less frequently named: the cost of sustaining such focused attentiveness over time.

For me and many practitioners, whole person care is a sustained professional commitment. Our work calls for practitioners to honour the multi-dimensional aspects of the human experience. It demands emotional presence, moral discernment, relational responsibility, and ongoing reflexivity. This does not exist at the margins of clinical work; it sits at its core.

While deeply meaningful, it cannot be sustained by individual endurance alone. Caring deeply and responsibly is—by nature—depleting, not because practitioners are insufficiently resilient, but because the work accumulates unique stressors that impact well-being. In my work within home palliative care, I see this depletion as the *cost of caring*, accrued through repeated exposure to suffering, ethical tension, and emotional labour, particularly when practitioners are asked to embody values that systems do not always structurally support.

When left unnamed or individualised, the cost of caring manifests as exhaustion, moral distress, burnout, fatigue, or quiet withdrawal. However, when recognised, named, and shared, I believe it can become the foundation for a more sustainable practice. But achieving this requires both the support of the communities in which we practice, and deliberate stewardship to hold the emotional and moral weight of caring.

The Cost of Caring: Emotional Labour and Moral Distress

The concept of emotional labour provides a helpful lens for understanding the often invisible work embedded in whole person care. Beyond technical competence, practitioners are expected to regulate emotions, remain empathically attuned, and offer presence in the face of uncertainty. Hochschild's [2] description of emotional labour as the management of feeling to align with occupational expectations resonates strongly with caring professions, where emotional regulation is expected yet rarely acknowledged.

In end-of-life care, I observed how this labour is intensified when holding space for difficult conversations, anticipatory grief, and ethical complexity. Practitioners are not merely witnesses to suffering; they are stakeholders in relational processes involving loss, hope, and meaning-making. This work requires repeated emotional and moral engagement that standards of practice alone cannot support.

Moral distress further compounds this cost. Jameton [3] described this as a common experience faced by practitioners—of knowing what ethically appropriate care requires, yet being unable to act accordingly. Constraints such as time pressures, resource limitations, or organisational priorities often marginalise relational work. The resulting dissonance is morally injurious.

What struck me was that these experiences are often internalised and privatised. Practitioners may interpret fatigue or disengagement as personal inadequacy, rather than as signals of cumulative strain (both emotional and moral). Sustainability is then framed incorrectly as an individual responsibility rather than a systemic concern. Consequently, it obscures the structural dimensions where this cost could be shared.

Community as Collective Stewardship

My early understanding of stewardship was shaped by my training in social work and by organisational discourse. In that conventional paradigm, stewardship was largely associated with resource management, governance, and professional standards. While these elements remain important, I have come to see that such an understanding is incomplete if it does not attend to the emotional and relational realities within which care is delivered. Through my work in palliative care, stewardship has gradually taken on a different meaning for me. I have come to understand it less as the management of systems and more as the shared responsibility of holding the moral and emotional weight of caring. In practice, this means recognising that the cost of caring cannot be carried by individuals alone. When practitioners attempt to sustain whole person care through personal endurance, the work quietly becomes isolating and unsustainable.

Community, in this sense, functions as a form of collective stewardship. In teams where reflective dialogue is normalised, practitioners are less likely to equate responsibility with overextension or self-sacrifice. Instead, difficult experiences—ethical tensions, emotional labour, uncertainty—can be acknowledged and shared. Community becomes a relational space in which complexity can be held without isolation, allowing practitioners to remain accountable to their values without carrying the full burden alone.

My experience has also taught me that such communities do not arise spontaneously. They require intentional cultivation and leadership that value reflection alongside action. In fast-paced clinical environments dominated by urgency, productivity, efficiency and excellence, spaces for dialogue are often the first to disappear. Yet it is precisely these spaces that sustain whole person care over time.

Leadership plays a central role in stewarding these conditions. When leaders listen carefully, remain open to difference, and allow uncertainty to be explored rather than quickly resolved, they model a culture in which reflection and relational responsibility are legitimate parts of professional work. Equally important is the flexibility to adapt structures of care as contexts change, while remaining anchored in shared values of compassion, collaboration, and shared responsibility.

Where such stewardship is present, the emotional and moral weight of caring becomes distributed across the community of practitioners rather than absorbed silently by individuals. In this way, stewardship is not merely organisational oversight; it is the ongoing cultivation of relational conditions that allow whole person care to remain shared, sustainable, and humane.

Congruence, Boundaries, and Shared Responsibility

Sustainability in whole person care rests on congruence—the alignment between espoused values and lived practice. Incongruence arises when practitioners are asked to embody compassion, presence, and relational depth without adequate relational or structural support. Over time, such dissonance becomes corrosive.

Community plays a critical role in restoring congruence. Through shared reflection and dialogue, practitioners can surface ethical tensions, negotiate boundaries, and redistribute responsibility. Boundaries, in this context, are not barriers to care; they are ethical structures that protect both practitioners and patients. They clarify what is possible, what must be shared, and what must be relinquished. From a values-based leadership perspective, such boundaries are not acts of withdrawal, but expressions of compassion—toward patients, colleagues, and the self—because they preserve the conditions necessary for care to remain attentive, ethical, and sustainable.

Shared responsibility is particularly important in mitigating moral distress. When ethical tensions are held collectively rather than privately, practitioners are less likely to internalise systemic constraints as personal failure. Community thus functions as both an emotional and moral resource, supporting practitioners to remain engaged without becoming overwhelmed.

Leadership has a crucial role here. When leaders model boundary-drawing, reflective practice, and vulnerability, they legitimise sustainability as a collective value rather than an individual weakness. In doing so, they steward not only services, but the conditions that allow whole person care to take place and individuals delivering this care to thrive.

Practice Vignettes: Stewardship, Endurance, and the Limits of the Self

My understanding of stewardship deepened not only through leadership responsibilities but also through lived experience. As my professional responsibilities expanded to include leadership, supervision, programme development, organisational initiatives and teaching alongside clinical work, I came to recognise that stewardship does not apply only outwardly—to systems, teams or services—but also inwardly, to the practitioner.

Whole person care relies fundamentally on the practitioner’s presence, clinical judgment, and emotional availability. The self is not incidental to practice; it is a vessel through which care is delivered. When that instrument becomes depleted through chronic overextension, the integrity of care are compromised—often gradually and almost imperceptibly.

This became clear to me during a period when I was deeply invested across multiple domains of work and life. Alongside carrying complex clinical cases and supervising colleagues, I was involved in developing new bereavement initiatives, contributing to organisational planning, supporting wider community programmes, and taking on teaching engagements. At the same time, I was navigating motherhood and caregiving responsibilities within my personal life.

Outwardly, I appeared competent, compassionate, and committed. Inwardly, I sensed a gradual narrowing. My emotional spaciousness was shrinking; sustaining focus and attentiveness became increasingly difficult, and I carried a persistent sense that I was holding more than I could meaningfully metabolise.

In retrospect, there was no single crisis. Rather, the strain accumulated through small, incremental decisions: agreeing to “just one more” responsibility, holding ethical tensions privately, remaining available to accompany one more family, and postponing reflection in the name of urgency. Without recognising it, I had come to equate stewardship with endurance, and commitment with constant availability.

It was only through reflective supervision and trusted peer conversations that this pattern became visible—not as personal failure, but as a signal that work could not be sustained in isolation. Stewardship of the self required a reorientation: clarifying where responsibility genuinely lay, naming what could be shared, and drawing boundaries without self-reproach. Far from withdrawing from whole person care, this recalibration allowed me to remain present without depletion. This experience reshaped my understanding of leadership: if sustaining practice requires such deliberate attention even within supportive environments, practitioners working without strong professional communities are particularly vulnerable to internalising the cost of caring as a private burden.

One example of collective stewardship emerged during a multidisciplinary team meeting in which a colleague shared the emotional weight of supporting a 27-year-old male patient and his family as they navigated his rapid deterioration, anticipatory grief, and impending death. The case carried a particular moral and relational weight for the team, confronting us with the profound dissonance of accompanying a young adult whose life was ending far earlier than expected.

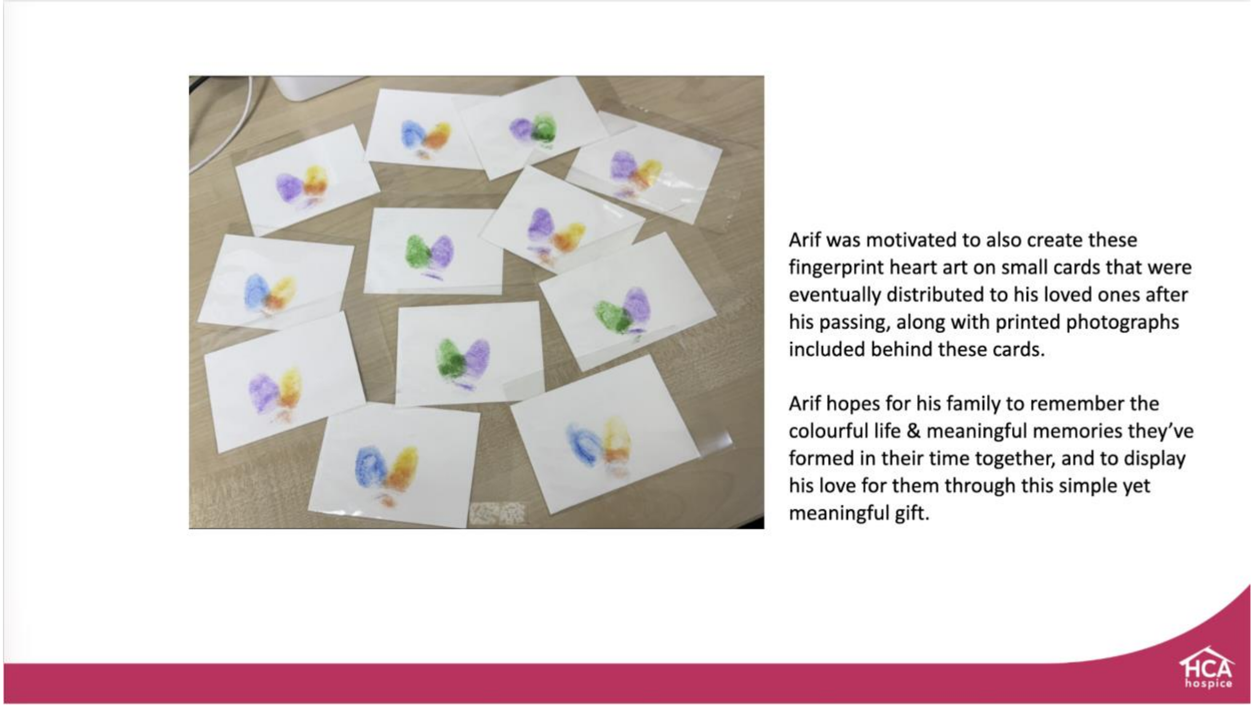
Rather than focusing solely on clinical management, the conversation widened to acknowledge how the emotional labour of this case was affecting the physicians, nurses, and medical social worker directly involved in his care.

As the discussion unfolded, it also became apparent that the case was affecting members of the wider team who had not participated directly in the patient’s care. Listening to the account, colleagues leaned in with quiet attention, carrying the emotional weight of the situation vicariously through the act of witnessing. The team created space not only to discuss care plans but also to hold the emotional and ethical tensions surrounding the impending death of a patient whose life was ending far too soon.

In that space, responsibility began to redistribute itself. Colleagues held space for tears, acknowledged transference, and named the moral distress that accompanies caring for patients whose suffering feels particularly unjust. What shifted was not only the management of a single case, but the recognition that the emotional weight of care did not belong to one practitioner alone.

At the close of the meeting, the medical social worker invited the team to participate in a small act of remembrance and solidarity. Each member of the team placed their thumbprints on a deck of cards, gradually forming a multicoloured collection of hearts. The artwork was later presented to the patient as a simple expression of care, appreciation, and acknowledgement of how his life had touched those who accompanied him in his final months.

The gesture resonated deeply with the patient, Arif. In the weeks that followed, he began creating his own cards using similar thumbprint impressions alongside family photographs. After his death, these cards were given to his family members as parting gifts—small, intimate tokens of connection that carried both memory and love.



Arif was motivated to also create these fingerprint heart art on small cards that were eventually distributed to his loved ones after his passing, along with printed photographs included behind these cards.

Arif hopes for his family to remember the colourful life & meaningful memories they've formed in their time together, and to display his love for them through this simple yet meaningful gift.

Experiences such as this reshaped how I came to understand the role of community in sustaining care. Within clinical teams, collective stewardship redistributes the emotional and moral weight of caring so that practitioners are not left to carry it alone. Yet the same principle extends beyond professional settings. If the sustainability of whole person care depends on shared responsibility within teams, it must also depend on the wider communities in which care, grief, and healing unfold.

This recognition gradually shifted how I approached both leadership and practice. I began to see that sustaining whole person care required not only supportive teams, but also the intentional cultivation of communities where care could be shared, witnessed, and carried collectively.

Growing Sustainable Communities of Care

In recent years, my work has increasingly focused on cultivating communities that embody these principles—among practitioners, teams, and within the broader caregiving ecosystem. Team-based leadership—often enacted through small, interdependent leadership trios within sub-teams—alongside supervision spaces, mortality rounds, reflective forums, bereavement groups, and community-based rituals, has demonstrated how shared spaces can absorb and redistribute the emotional weight of care. These practices reflect a collaborative, values-based approach to leadership, where responsibility is intentionally shared across roles and relationships, reducing isolation and supporting collective resilience.

One illustration of how community redistributes the cost of caring emerged through an open bereavement support group developed for individuals who were socially isolated and experiencing profound loneliness following loss. Many participants entered the group with limited social networks, describing grief as something they carried almost entirely alone. The group was intentionally structured as an open, non-time-limited space, emphasising shared presence over therapeutic progression or outcomes.

Over a period of approximately twelve to sixteen months, a noticeable shift occurred. A core group of bereaved individuals began to form—participants who moved from tentative attendance to sustained engagement. Through repeated encounters, shared stories, and mutual recognition, members began to articulate not only pain and loneliness, but emerging meaning in their grief. Connection replaced isolation; suffering became something that could be witnessed and held collectively rather than endured privately.

Over time, peer leadership began to emerge organically within the group. Members who had initially attended primarily to receive support gradually took on relational roles of their own, initiating parallel social activities beyond the formal group sessions. These included visiting their loved ones' niches together, sharing home cooked recipes that carried memory and meaning, and organising meals and gatherings to mark anniversaries or festive occasions. Such activities were not designed or directed by professionals, but arose from members' growing sense of mutual recognition and care.

Through these shared practices, grief became woven into everyday life rather than confined to designated therapeutic spaces. Acts of remembrance, nourishment, and companionship offered members ways to remain connected—to those they had lost and to one another—without needing to explain or justify their grief. In this way, care was no longer concentrated solely within professional roles, but began to circulate within the community itself, held and expressed through ordinary yet deeply meaningful gestures.

What emerged was not the resolution of grief, but a shared capacity to live with it. This capacity was marked by connection rather than isolation, contribution rather than passivity, and a quiet form of transformation in which members moved from being recipients of care to co-creators of a sustaining community.

What this experience reinforced for me is that sustainable bereavement care is not only delivered; it is grown. When community is intentionally stewarded, the emotional weight of grief—and of caring for grief—can be shared, allowing both practitioners and bereaved individuals to move from isolation and loneliness toward connection, agency, and purpose.

As I reflected on this experience, I recognised strong parallels with Kellehear's concept of Compassionate Communities, which frames care, loss, and dying as shared social responsibility rather than tasks reserved for professionals alone [4, 5]. What I observed within the bereavement group was not simply peer support, but the gradual re-socialisation of grief—where meaning, remembrance, and care were held within everyday relationships and communal practices. In this way, care extended beyond formal service boundaries and became embedded in ordinary acts of presence, reciprocity, and mutual responsibility.

Situating this work within a compassionate communities lens highlights that sustaining whole person care depends not only on professional expertise, but also on nurturing social capacities for care within communities. When grief is held collectively, the emotional and moral weight of caring is no longer borne solely by practitioners. Instead, care circulates across relationships, allowing both professionals and community members to remain engaged without depletion.

This reflects a public health understanding of care, where healing and adaptation occur within networks of relationship rather than through isolated professional encounters. Practitioners themselves are part of this ecology. Without community, the cost of caring becomes unsustainable; with it, care becomes a shared and enduring practice.

Importantly, growing community does not require uniformity. The most resilient communities are those able to hold differences—across disciplines, cultures, roles, and level of experience—while remaining anchored in shared values of dignity, compassion, and presence. When such differences are acknowledged and engaged rather than minimised, community becomes not only a source of support, but a site of shared learning and ethical growth.

Attending to differences in this way is itself an act of stewardship. It requires leaders and communities to cultivate humility, curiosity, and dialogue rather than conformity. Within such relational conditions the emotional and moral cost of caring can be shared collectively rather than internalised by individuals, allowing care to remain both humane and sustainable [1, 3].

Conclusion: Stewarding the Conditions for Care to Continue

The cost of caring is a reality to be stewarded. Whole person care will always require emotional labour and moral courage. The critical question is whether this cost is borne in isolation or held collectively.

Community serves as the quiet architecture sustaining this care. Stewardship must extend beyond systems to include the self. Through congruence, boundary-drawing, and shared responsibility, practitioners can remain engaged without depletion. In attending to these conditions, whole person care endures not as heroic individual effort, but as a shared, ethical, and sustainable practice.■

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