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'Leaning in' – Normalizing trauma-informed palliative and end-of-life care

*Trauma is not what happens to you—it is what happens inside you as a result of what happens to you.*¹

The lasting wounds and scar tissue of psychological trauma are generally invisible to our everyday vision. Unbeknownst to us, our friends, neighbors or colleagues may live with the impacts of a traumatic past that forever changed their sense of safety and trust; changing the ways in which they relate to self, others, and their surroundings. Traumatic events and loss are all too common in the lives of everyday people.

Each day, across the world, news bulletins provide a mere glimpse into the sociocultural or political factors and environmental events that not only result in the loss of life but can also cause lasting harm to the physical and mental health of those surviving them. Although distressing to witness in this way, if fortunate, perhaps hearing or seeing this news from a distal place of safety is as close to those harsh realities as we will ever be. For some, such news may trigger memories or emotions from past experiences of their own. For many, it will not be apparent that patients receiving palliative and endof-life care, may have experienced significant traumas throughout their lifetime, or how these experiences can affect the way they behave and experience care when approaching end of life. The invisible nature of trauma means the potential for patients and clinicians alike to be impacted by trauma and re-traumatization can escape the clinical gaze, however skilled and well-intentioned it may be.

For too long, now, the provision of palliative and end-of-life care has been limited in its recognition, understanding, and alleviation of this increasingly prevalent and potentially avoidable form of suffering. For decades, as clinicians we have witnessed and worked within this reality, whilst companioning and caring for the dying. And as fellow trauma survivors, ourselves, we suggest that now is the time to *lean in* to this space.

Trauma may be acute, chronic, complex, or intergenerational in nature and can arise from 'an event, a series of events or a set of circumstances that is experienced by an individual as physically or emotionally harmful and has lasting adverse effects on a person's mental, physical, social, emotional or spiritual wellbeing'.² Traumatic events are widespread across society and can occur across different social contexts of life such as serious accidents, physical and sexual assault, domestic, family, and intimate partner violence, colonization and ongoing racism, natural disasters, war/displacement from homelands and family, or witnessing the trauma of others.^{3,4} They can be experienced more frequently by populations routinely exposed to situations and dangers outside the everyday experience - for example, police and other emergency service first responders or military veterans.⁵

Regardless of the type of trauma or traumatic event experienced, trauma-informed care involves framing care provision around six key principles of a trauma-informed approach: (i) Safety; (ii) Trustworthiness and Transparency; (iii) Peer Support; (iv) Collaboration and Mutuality; (v) Empowerment, Voice and Choice; and (vi) Cultural, Historical, and Gender Issues.²

Traditionally, trauma care may be perceived to be the sole remit of specialist mental health services, a setting where expert psychiatric assessment and treatment are the mainstay. However, a growing awareness of, and heightened sensitivity to, the biopsychosocial impacts of trauma,^{6–8} coupled with increasing exposure to traumatic events and prevalence of traumatic stress disorders across society^{3–5} mean that this no longer reflects best practice. In the same way that palliative care is no longer viewed as the exclusive province of specialist palliative care teams, we must now see trauma-informed care as everyone's business, regardless of setting or clinical specialty.

The implications for practice, education, and research are numerous. Both our common humanity and the potential for vicarious trauma mean that we as clinicians are not immune to the impacts of trauma.9 Many of us carry invisible wounds or scars from lived experiences both past and present. Apart from shaping the realities of personal and professional lives, trauma can impact the way we relate to ourselves and those around us; it not only impacts our health and wellbeing - but also how we show up to work, how we provide care, and if/how we access and experience healthcare services ourselves. Self-awareness, self-compassion, and self-care are therefore vital.¹⁰ Trauma-informed research to better implement and evaluate trauma-informed approaches to palliative and end-of-life care is also needed to build a stronger evidence base to guide practice.¹¹

More than these, tailored education to equip frontline clinicians is imperative. We know from the literature that the re-living of trauma near death is a recognizable phenomenon with physical and psychological impacts that can be alleviated with sound clinical knowledge and appropriate management.¹² However, there may understandably be fear or apprehension where clinicians' understanding of trauma or knowledge of trauma-informed care is limited; and an unfortunate consequence of limitations in knowledge of psychological distress or mental disorders can be the perpetuation of stigma and subsequent avoidance of patients presenting with trauma symptomology. Targeted education is vital, given that undergraduate curricula and postgraduate training in palliative care has not traditionally been included trauma-informed care.

As Viktor Frankl observed, 'an abnormal reaction to an abnormal situation is normal behavior'.¹³ Thus, traumatic stress reactions to traumatic circumstances can best be understood as a *normal response* to *abnormal circumstances*. From this understanding arises some important questions for our practice:

- Is the care we provide aware of and sensitive to potential trauma in this way?
- To what extent do we offer support as an empathetic witness?
- Do we adopt a strengths-based approach to care for trauma survivors, in the same way that cancer survivors are empowered when faced with a cancer diagnosis?
- Do we consider trauma-informed care to be a normal part of everyday clinical practice?

Trauma-informed care is not the sole responsibility of specialist mental health teams – it falls within the remit of each and every clinician providing palliative and end-of-life care, whether it is considered 'normal' practice or otherwise.

If the notion or clinical reality of leaning in to trauma-informed care make us uncomfortable - individually or collectively - we must take pause to consider and understand how or why that is so, before proceeding to enlist the collegial support and organizational resources necessary to address the holistic needs of both providers and recipients of care. Trauma-informed care does not require us to be experts in trauma or mental health; it requires that we care and are aware. It is simply person-centered care within reflective practice and therapeutic relationships that prioritize physical, cultural, and psychological safety, and are oriented towards companioning rather than fixing. Within this space, there is potential for recovery and healing, even at the end of life.

An inconvenient truth of contemporary palliative and end-of-life care is that they do not yet fully recognize, or meet, the holistic needs of those living and dying with the lasting impacts of trauma. Clearly, the process of recovery from trauma continues across the life course, and perhaps becomes even more critical, when approaching death and coming to terms with dying.

It is therefore incumbent on us to prioritize traumainformed care accordingly, and ensure that our practice of person-centered care is not reduced to rhetoric. If not already doing so, we must now take the first steps in beginning that process. If not now, when? The time is now, for *leaning in* to normalize traumainformed palliative and end-of-life care.

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