

Live Until You Die

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

Dame Cicely Saunders

Amid the profile of Medical Assistance in Dying (MAID) and a prevailing interest to support living until death, discussions of appropriate care and care settings for dying abound. The when and how of easing the passage from this corporeal being to a state of other being, whatever you believe that to be, has been focal in healthcare discussions in recent years. I remember a time when the notion of “palliative care” was somewhat novel, in later years when a family member was the recipient of excellent end-of-life care, but still many recent instances in which we, “the system” fail to ensure that that final life journey is aligned (as much as possible) with a person’s final wishes. Alas, a 2013 survey by the Canadian Institute for Health Information (CIHI) showed that a majority of Canadians preferred to die at home, but few (15%) died outside of a hospital (CIHI 2018).

About 50 years ago, the work of Elizabeth Kubler-Ross and Dame Cicely Saunders were pivotal in informing discussions and writings about end-of-life care. In the 1970s, my undergraduate education included discussions of Kubler-Ross’ work, particularly her seminal book *On Death and Dying* (Kubler-Ross 1969). Throughout my career and life, her chronological stages of grief: denial, anger, bargaining, depression and acceptance have impacted my care of the dying but also brought understanding during periods of personal grief. My very first nursing conference presentation was focused on death and dying, palliative and hospice care. As a panelist, I had the privilege of sharing the stage with an influential Canadian nurse, Sheila O’Neill who led the way for the establishment of a hospice at Montreal’s Royal Victoria Hospital. This hospice was modelled after St. Christopher’s Hospice in London, established in 1967 by Dame Cicely Saunders. Incidentally, my recollection of this experience underscores the influence of nurse leaders on young practitioners; it has stayed with me over all these years. Since those days, hospices, palliative care units, and palliative care teams have appeared across the country, but it is shocking that today Canada ranks 18th among developed countries in palliative care and 11th in the overall quality of death index; a sad lack of progress over the last five decades (The Economist Intelligence Unit 2015).

In this issue, Kaasalainen and colleagues (2019a; 2019b) garner insights into the provision of palliative care in long-term care (LTC). Their scoping review highlights key components to be included in an LTC palliative program. They suggest that further work is necessary to wholly understand palliative care requirements in LTC settings. To this end, they also report on a stakeholder engagement process which included staff, residents and their families, researchers, and decision-makers. The goal of this process was to validate the strengthening of a palliative approach to long-term care (SPA-LTC) model. The results of this scoping review and stakeholder endorsement of the SPA-LTC underscores that there are still many opportunities to improve upon the delivery of palliative care in LTC but also shines a light on those in other sectors of care.

Clausen et al. (2019) describe a tailored leadership development program for nurse managers in an academic health network in Montreal, Canada, developed in collaboration with a university school of continuing studies. This program is aimed toward strengthening individual leadership competencies and developing a resilient nursing leadership community. Given the leadership competencies addressed through this program, one might presume that it will enhance nursing leadership in support of effective end-of-life care. Coincidentally, next fall Montreal will play host to the International Congress on Palliative Care so let's hope we have some Canadian best practices to share.

In a scoping review addressing the management of chronic diseases in Canada, Gordon et al. (2019) examined possible approaches to reduce the burden of care. They conclude that managing complex care that meets the needs of patients and providers can be effectively delivered through nurse-led models, including advanced practice models. Given that chronic conditions inevitably lead to end-of-life or palliative care, it is obvious that we should begin advanced-care planning for those with long-standing disease sooner than later. Indeed, some of the same elements Kaasailanen et al. (2019a) highlight for LTC palliative care (e.g., training and capacity building, client and family engagement) might be worth considering in the care of all persons with a long-term illness. The distinction between managing complex chronic disease and the need to support active dying may not always be readily apparent or progress may occur more rapidly than anticipated.

Donner provides a review of Thomson and White's (2019) book: *The Unexpected Journey of Caring: From Loved One to Caregiver* (Donner 2019). She recommends this as an important read for nurse leaders and nurse educators as it "provides a personal and authentic picture of not only the caregiver experience but also the complexity of care giving today." As we consider the possibility for more Canadians to die at home as they wish, there is an imperative to understand the impact on caregivers and their needs for support. In this regard, if equipped with the necessary knowledge and skills about palliative and end-of-life care, nurses are best positioned to address the needs of the dying and their caregivers, particularly beyond institutional care. Nurses, in the words of Saunders, "*can not only to help others to die peacefully, but also to live until they die.*"

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