

# INTRODUCTION TO SPECIAL ISSUE NO MAP FOR THE JOURNEY: PROFESSIONALS REFLECT ON THEIR EXPERIENCES WITH END-OF-LIFE CAREGIVING

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*"Death is not extinguishing the light; it is putting out the lamp because the dawn has come."*  
- Rabindranath Tagore, Indian educator and Bengali poet (1861 - 1941)

This special edition of *Reflections* demonstrates that loss is universal, pervasive, profoundly heartbreaking, yet can still be a transformative experience. All the authors writing for this edition have a similar experience in common. We're all professional social workers and have all been the caregiver of a terminally ill family member. Contained within all our stories, in one form or another, is a common set of circumstances. After multiple visits to multiple hospitals, the doctor finally tells you that your loved one is dying. Though you knew the end of life would come eventually, you suddenly feel unprepared for what will follow—not the least of which is a willingness to let your loved one go. Literal life and death decisions follow. The next days, or weeks, or months come with all the confusing and contradictory emotions we've seen in our clients who have experienced similar losses over the years. But this time, it's our loss. We've supported the bereaved for years, but now the professional becomes very personal. Families rely on us for answers and resources, but we're frightened too. Who provides care for the family social worker? Shouldn't we know how to handle this situation? We've helped others countless times before.

Caregiving of a dying family member creates an internal conflict for professional social workers since our intellectual knowledge of death doesn't always assuage our feelings of loss. Rational explanations seldom ease feelings. Further, family members often rely on the social worker in the family as the rock

of stability, which only complicates an already stressful situation. How can we be on the receiving end of sympathy and support from others when we've usually been the providers of care? However, within these narratives, you will see a personal transformation in the authors following the loss - a hope that triumphs after a loss, with our perception of social work changed. Out of the chaos of caregiving comes a clearer understanding of compassionate care at the end of life—perhaps the ultimate gift received from the trauma of our loss. Viktor Frankl said it best and quite simply: "Death gives life meaning."

Within these narratives there is a perspective on the distinction between sympathy and empathy. Sympathy is an expression of compassionate understanding of another's issue coupled with a sincere desire to help. So, although we might not have direct experience with another's tragedy, our compassion is extended through sympathy. Empathy calls on a deeper emotion. It is a literal sense that we can feel what another person has experienced. Thus, empathy is extended to those who have experienced a comparable pain to ours. However, as I reflected on these narratives, these definitions fall short. Empathy seems to be the ability to feel an emotion expressed by another person as if it were your own, *while maintaining your awareness that it is not your own*. Thus, empathy is less of an emotion and more of a capacity. It is the capacity to understand a person's subjective experience by vicariously sharing that experience with him/her, yet

keeping healthy objectivity. Sympathy seems to follow empathy; it is a sincere desire to support and/or comfort someone experiencing pain—most often emotional pain. After reading these narratives, I felt my own capacity for empathy and my willingness to offer heartfelt sympathy was expanded, which I believe will make me a better social worker. This was gift received as a by-product of guest editing.

The narratives contained within this issue are written by professional social work educators and practitioners who intellectually understand the phenomenon of caregiving stress and subsequent loss, yet they may be experiencing it from a new perspective as a client for the first time. These expressions of caregiving bravery and dignity in losing a loved one carry with them some important lessons learned. With these narratives we have the opportunity to answer some unique questions facing professionals who provide end-of-life care to a loved one. Does intellectual and academic preparation help us cope with family caregiving challenges? Does our professional experience buffer a personal loss? The themes that emerged from these narratives are perhaps not surprising: the resilience of the human spirit and the transformative power of experiencing the death of a loved one.

I hope you enjoy these narratives and are moved, as I was, by the lovingly written epitaphs to a significant person in the author's life. Beyond that, they are also a commentary on the resilience of humans and our capacity to go beyond self-imposed limits. We are much braver than we think. As social workers, we are witness to inconsolable grief and loss in one form or another as a daily occurrence. We understand that the loss of a loved one and the residual sorrow that follows can profoundly shape a client's views of the world. These narratives demonstrate that our own deep losses can also be reframed so as to shift our perception of our professional world.

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