

## Essay/Personal Reflections

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It was just the two of us: myself and a gentle-mannered man dying of metastatic cancer. I was his hospice volunteer, and we were walking hand in hand through uncharted waters. His thoughts were wide-ranging, muddled at times by mild delirium: “I’m thirsty. Where’s my family? Am I going back to the hospital?” I tried to answer as best I could; and when I could not, I grasped his hand a little tighter. The moment was a portrait of that messy human condition, potent in end-of-life care.

As in so much of hospice and palliative care, this moment could not be packaged into a neat philosophy. But as in so much of life, the messiness of literature provided tremendous insight. In both arenas, I have found valuable reflection in the Peter Carson translation of Leo Tolstoy’s classic, *The Death of Ivan Ilyich* (Tolstoy, 2014). This novella has much wisdom for hospice and palliative care professionals today—from nurses, to physicians, to home health aides and more. By looking through its lens, we find palpable truths for our complex professions.

First published in 1886, Tolstoy’s work has its protagonist in Ivan Ilyich, an ambitious Russian lawyer. This lawyer’s life is a mixture of vanity and shallow relationships. He is married, but unhappily so; he is successful, but never satisfied. At some point, a seemingly innocuous fall leads to perplexing medical agony and his eventual death.

For most of the story, Ilyich faces a bleak mortality. But in truth, his primary suffering is “the lie, for some reason recognized by everyone, that he was only ill but not dying.” Instead of validation and support, Ilyich’s companions provide this lie, “which could only bring down this terrible solemn act of his death to the level of all their visits and curtains and sturgeon for dinner.” As a result, he is left alone to grapple with pain and mortality. He is denied a meaningful death, instead surrounded by dishonesty and judgment.

There is one source of comfort for Ilyich, however: Gerasim, a young male servant attending to Ilyich’s personal needs. Gerasim moves Ilyich, positions him, and cleans him. But Gerasim also serves a deeper purpose.

The young man, Tolstoy writes, is “a clean, fresh young peasant... always cheerful and sunny.” He carries out the most intimate of tasks, such as cleaning up after Ilyich’s bowel movements. Ilyich is fraught with self-judgment, however, and is “embarrassed by seeing this man... having to do this repulsive job.” One assumes that Gerasim shares such embarrassment—but far from it. He enters the room, “obviously masking the joy in living shining out from his face so as not to hurt the sick man.” The servant does not struggle to find joy in his work, but only to temper that joy. He does not cheapen death, but only refuses to flout life. The result is unprecedented for the dying man: “In all other people Ivan Ilyich was offended by health,” but somehow, “Gerasim’s strength and high spirits didn’t depress but calmed Ivan Ilyich.”

How does Gerasim do this? How does he balance suffering with generous love? How does his strength connect him with someone so weak? Three traits point us toward an answer: honesty, authenticity, and humility. By embodying these traits, Gerasim validates and comforts Ilyich. By following his example, hospice and palliative care professionals—regardless of rank or role—can do the same for their patients.

Honesty is the first and most potent of Gerasim’s characteristics. In the tumultuous experience of illness, Ivan Ilyich wants most of all to be seen. But his physicians and family do not recognize his suffering. The latter group is absorbed in activities and appearances; the former refuses to admit defeat. In both cases, Ilyich is isolated from his caregivers when he needs their intimacy most. But still, he wants “most of all... for someone to have pity on him like a sick child.” Not all patients want such pity, of course. But this lack of transparency hinders Ilyich from what all patients do need: a meaningful life until death.

That is, until Gerasim arrives. For him, death is not shameful, nor a sign of weakness. Death is the most human of experiences. Illness, then, does not separate us, but rather unites us: “We’ll all die,” Gerasim notes, while explaining his dedication to the man, “so why not take a little trouble?” As commentators have noted, this honesty absolves the patient of shame. When Ilyich apologizes for his messy, smelly suffering, Gerasim “replies not with forgiveness, but with the observation that Ivan Ilyich does not need forgiveness for a disease” (Charlton & Verghese, 2010). Caregivers, of course, ought to do the same. If modern patients are anything

like Ilyich, they will benefit from our humble honesty. In acknowledging their vulnerability—but not blaming them for it—we give patients much-needed space to grieve.

But true honesty requires personality. If patients need honest support in their illnesses, caregivers must be authentic in that support. For Gerasim, authenticity has many meanings. Authenticity means the visible joy of life; it means working with “sleeves rolled up over his strong, young, bare arms” and it means that peculiar blend of gentleness and fortitude, which enables him to handle Ilyich “effortlessly and with next to no pressure.”

When entering the room of a hospice patient, I am often tempted to leave myself—my joys, my energy, my youth—at the door. But hospice professionals are trained to bring their *whole* selves to the patient. Each caregiver has unique skills and traits, which contribute to the beautiful spectrum of hospice and palliative care. We should not be ashamed of those traits. If used in a self-giving way, our authenticity will only connect us more deeply with patients.

I have qualified both of the first two traits—honesty and authenticity—by that all-important trait, humility. This is no accident. Indeed, humility is the characteristic that ties all three together. I refer to that sort of humility that is not self-deprecating, but merely self-giving: an other-oriented thought process. Gerasim cleans up after Ilyich; he sits for hours, using his shoulders as a leg-rest for the dying man. He does all these things “easily, willingly, simply, and with a goodness of heart.” Yet his actions are not sourced from a lack of dignity or self-respect. Much the opposite: Gerasim has dignity, but not the vain, self-obsessed type. He finds true dignity in tending to his patient’s humanity.

All caregivers, whether physicians or volunteers, benefit from such humility. Too often our careers, our workloads, and our fatigue can distance us from patients. Too often, self-interest takes hold. But what if cleaning up after a patient was not equated to swallowing one’s pride? What if repositioning a dying man was not a menial task? In that case, humility precedes the truest humanity. As the narrator notes, Gerasim “wasn’t bothered by the work precisely because he was doing it for a dying man and

hoped that in his time someone would do this work for him.” To be human is to suffer; to be a patient is to suffer. Whether one is a health aide, a nurse, or a palliative care physician, this holds true. In each of our respective roles, then, we see a bit of ourselves in the patient—and vice versa. We carry out the messy tasks out of love for that messy human experience.

Yet we are not Gerasim incarnate. He is a character in a novella, and this is real life. When I sat with that dying man in hospice, his experience was not allegorical; it was palpable, viscerally so. I endeavored, therefore, to serve in a useful and authentic way. And that is the point: end-of-life care entails a beautiful range of people and functions. Caregivers need not impersonate Gerasim’s tasks, but simply embrace his spirit of duty. Certainly, they do well to have medical knowledge and communication skills, as well as many other traits. But honesty, authenticity, and humility—these three can heal, even when a cure is impossible.

As I sat with that dying man, he asked one last question, before falling asleep. “What am I doing here?” he wondered, looking around the room. I was silent for a moment, reflecting on that inquiry. I thought of his nurses, his health aides, his palliative care physician. Then I thought of Gerasim, and my role in this man’s life. My response was obvious. I grasped his hand once more, and smiled softly.

“You’re sick, sir, and we’re here to take care of you,” I replied. “You’re here because you are loved.”

**Author disclosures.** All identifying features have been removed from the patient described in this essay. No competing financial interests exist for the author.

## References

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