

Palliative care: Learning to fall



Dr Romaine Gallagher

As I walked to his bedside I was struck by the calmness in his eyes despite the gaunt cheeks, the emaciated body, and the struggle of accessory breathing muscles to draw in enough air for the failing lungs. He told me, “I am totally at peace with what is happening and ready to die anytime.” After I acknowledged the wisdom of this he asked, “Are you ready to die, doctor?” My nonverbal response gave me away: I stepped back. Realizing my body had answered for me, I admitted “No, I guess not.”

All humans struggle with the certainty that our lives will end. Society has developed many defences to avoid confronting this fact. In medicine we have changed death from a natural completion of the life cycle to a medical failure and have developed a technical armamentarium to thwart death as long as possible. We live longer—a great advance—but we take longer to die. This has changed the event of dying from a few days of fevered delirium and sepsis to a process that can take many months. Depending on how someone copes, these months can be a time of intense living, of growing both emotionally and spiritually as the body declines. Or they can be months of suffering induced by poor symptom control, lack of support to cope with increasing dependence, and the loss of oneself and one’s dignity. Palliative care is a treatment approach that begins at the diagnosis of serious life-limiting

illness that continues throughout the disease process, that improves symptoms and quality of life, and that provides the right environment for personal growth and meaning-making.

Patients expect physicians to care for the whole person, not just the body. A study of patients with COPD, AIDS, and cancer identified emotional support, communication, accessibility, and continuity as more important than competency.¹ Yet physician-author Abraham Verghese probably speaks for many physicians when he describes his unease in the presence of a dying patient:

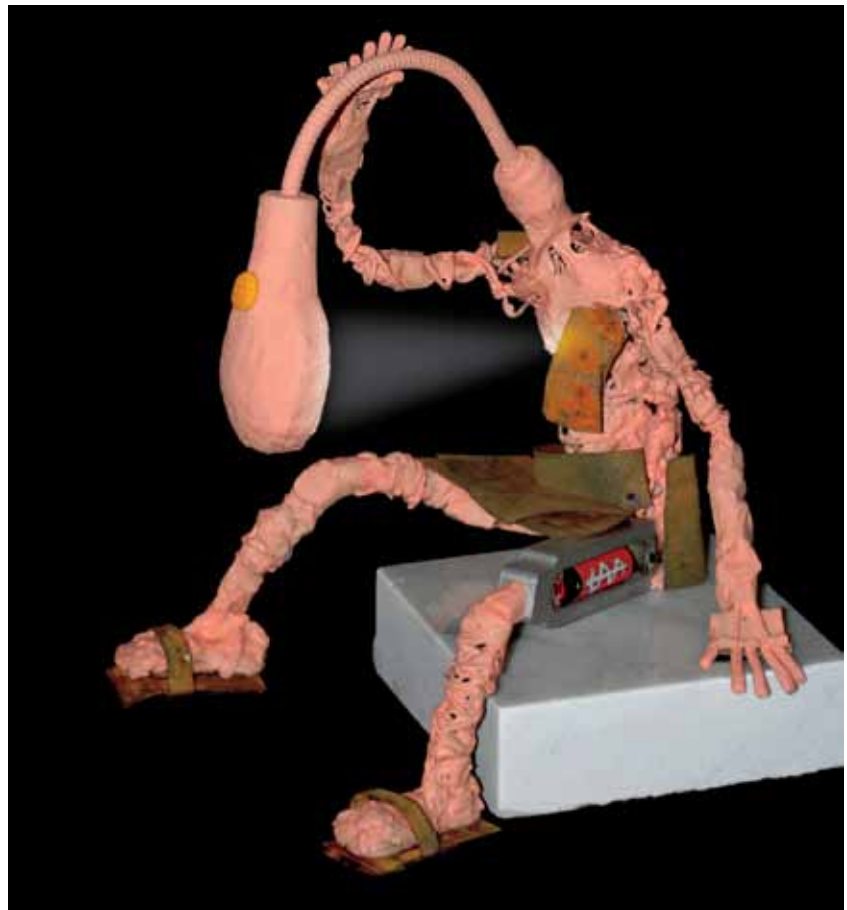
I had always felt inexperienced when a patient was near death . . . Give me a patient with massive gastric bleeding or ventricular fibrillation and I am a model of efficiency and purpose. Put me at a deathbed, a slow dying, and purpose is what I lack. I, who till then have been supportive, involved, can find myself mute, making my visits briefer; putting on an aura of great enterprise—false enterprise. I finger my printed patient list, study the lab results on the chart, which at this point have no meaning. For someone dealing so often with death, my ignorance felt shameful.²

What Dr Verghese expresses here is the helplessness a physician feels in the face of a patient’s inevitable death. As physicians we encounter death more frequently than the average person, and one of our defences against the death anxiety present in all humans is a medical culture that

focuses on a collection of organs rather than on a person who is dying from an illness. We use this organ-focused care as emotional armor against the sharp terror of our own death. The technology of medicine, as wielded by the doctor, bravely fights against disease on the battlefield of the patient's body.³ With the language of fighting there is usually a winner and a loser, and thus death becomes a failure of medicine. For some patients, fighting to the death is the way they wish to end their life, but for most patients, accepting the inevitable brings peace and healing in the face of disease.

Physicians have found that they can use self-awareness to stop themselves from putting on the emotional armor that protects them from admitting their own mortality, which in turn allows the physician to discuss fears and concerns with the dying patient, to experience being completely present with the patient, and to feel greater compassion.⁴ This openness leads to exploring which approach to the illness best matches the patient's preferences and reduces care that is futile or does not feel right to the patient. Many wise traditions from ancient times to the present maintain that facing our own mortality leads to a deepening of appreciation for our lives. Facing death with patients can bring humility, compassion, and connection and give greater meaning to the work we do.

In this theme issue we focus on palliative care, knowing that even in the wake of the Supreme Court decision to no longer prohibit physician-assisted death the vast majority of Canadians will still choose to die naturally and will look to physicians to assist them in living as well as they can and for as long as they can before they die. To help physicians do this, the first article outlines what palliative care has to offer patients and



families and when to implement it. The second article describes how to communicate effectively throughout the illness trajectory. The third and final article provides background on existential suffering and spiritual distress—often the reason a patient wants death hastened—and describes therapeutic communication techniques that physicians can use to help individuals cope with their illness and achieve healing.

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