

A new way of loving and living

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*Do not go gentle into that good night
Old age should rave and burn at close of day;
Rage, rage against the dying of the light*
Dylan Thomas¹

These lines of poetry, quoted by a caregiver attending the Centre for Family Medicine's Memory Clinic in Kitchener, Ont, express some of the powerful emotions we feel as death approaches. While research has taught us much about the clinical and pathological aspects of dementia, it is our patients and their caregivers who teach us about its human dimensions. Dementia is devastating not only because it is a terminal illness, but also because while living with it people enter a new social group that is highly stigmatized. People with dementia describe experiencing shame, discrimination, fear of rejection, social withdrawal, and isolation because of their illness.² The fear of losing one's ability to think and live independently causes suffering, which Cassel has defined as "the state of severe distress associated with events that threaten the intactness of a person."³ As Auguste D., Alois Alzheimer's first reported patient with dementia, expressed it, "I have lost myself."⁴

The patient's family members share in this profound loss, and their suffering, too, can be intense. Jack Dueck, a former professor of humanities at Yale, attends our Centre for Family Medicine Memory Clinic with his wife, Eleanor. He eloquently describes his feelings of helplessness and rage as he watches her condition deteriorate:

With Eleanor's Alzheimer's I'm brought up short: there's no traditional solution here; it's an entirely new and disorienting encounter. Suddenly I seem to be moving into an opaque bubble, removed from someone gradually vanishing from me and even becoming a different person. Painful memories surge in face of the coming dissolution of a loved one's personhood

The experience is attended by temptations: self-pity, [a] patronizing, pathological frenzy for solutions (Internet, opinions, and experiments), and rage ... stimulants, but these, like alcohol, only irrigate, not ameliorate, the issue. How [to] deal with the incipient loneliness descending on two people gradually isolated from each other's love and living?

How is a family physician to respond to such anguish? The latest Canadian guidelines on dementia include 149 recommendations,⁵ but only a few relate to support for caregivers. Listening to family members such as Jack Dueck reminds us that every patient with dementia might be living with another "hidden" patient.⁶ We need to care for

both.^{7,8} From 40% to 70% of caregivers have clinically significant symptoms of depression and might neglect their own health as a result of caring for family members. Education, support, and counseling can benefit not only the patients but their family members as well.^{9,10} In a randomized controlled trial, Alzheimer patients whose caregivers received 6 sessions of individual and family counseling were able to delay their entry into nursing homes by 1.5 years, largely because of improvements in their caregivers' well-being.¹¹

An interprofessional primary care team is ideally situated to provide such help. Dueck writes of his experience at the Centre for Family Medicine Memory Clinic¹²:

There's a poignant line emerging in literature throughout the ages: *Where do we go from here?*

The Memory Clinic ... is uniquely in the business of transitions. I found the professional objectivity never divorced from friendliness and compassion; the emphasis on relational aspects of it all reassuring ... the medical professionals of all branches interconnected in this ordeal—all ... [offering direction] toward a new way of loving and living ... provid[ing] a marvelous anchoring in the turmoil.

Optimal care of a patient with dementia involves interprofessional care providers, the patient, and the patient's caregiver. We have an opportunity to reduce suffering for patients with dementia and their family members—to be an anchor during this transition. Indeed, this role is a privilege deeply rooted in the healing tradition of family medicine.

Sharing their experiences of loss and turmoil, courage, and grace, families and caregivers give us a greater understanding of dementia's effects. Listening to their stories helps us to help other patients and families deal with this devastating illness. 🌿

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Competing interests
None declared

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