

## End-stage dementia and palliative care

It is widely known that the population of Canada is aging. The first members of the baby boomer generation reached 65 in 2010. By 2026, it is estimated that one in four Canadians will be over the age of 65, with the segment over 80 growing the fastest. With aging comes an increase in neurodegenerative disorders, of which dementia is the most common. The incidence of these chronic conditions rises in prevalence as deaths from cardiovascular disease and cancer decrease, with 30% to 40% of those over the age of 85 diagnosed with some degree of dementia.

Although patients newly diagnosed with an early dementia may have years of quality life to come, it is also true that dementia is eventually a fatal illness. Patients with advanced dementia develop difficulties with mobility, lose the ability to communicate, and do not always recognize family or friends. At that point in the illness, prognosis for prolonged survival is poor, no matter how aggressively the patient is managed. This fact can come as quite a surprise to caregivers, including medical staff. Consequently, patients at the end stages of their illness can be subject to distressing and uncomfortable investigations and treatments that will not change the outcome significantly, but could adversely impact patient quality of life. They are also not offered symptom control modalities that could ease their suffering in the same way that patients with more traditionally recognized terminal illnesses are.

An eye-opening article by Dr Susan Mitchell in the *New England Journal of Medicine* in 2009 describes

the experiences faced in the final years of some 323 residents of Boston nursing homes who were suffering from advanced dementia. Of the patients studied, 54.8% died within 18 months. Time prior to death was characterized by discomfort from dyspnoea or pain (41.1%), concurrent illnesses, and burdensome interventions (40.7%) including parenteral therapy, hospitalization, tube feeding, and emergency room visits.

After adjustment for age, sex, and disease duration, the 6-month mortality for patients who had pneumonia was 46.7%, febrile episode was 44.5%, and eating problems was 38.6%. The authors note that with the 6-month mortality of 25% and median survival of 1.3 years, end-stage dementia is comparable in life expectancy with metastatic breast cancer and stage IV congestive heart failure. An interesting observation in the study is that caregivers with an understanding of their loved ones' prognosis were less likely to pursue aggressive, burdensome interventions.<sup>1</sup>

A common burdensome intervention is tube feeding. Patients with end-stage dementia can often develop dysphagia or anorexia, which may result in malnutrition, dehydration, and aspiration pneumonia. A Cochrane review has shown that tube feeding of these patients is not beneficial in preventing malnutrition, pressure sores, or functional and survival outcomes.<sup>2</sup> It has also been shown that tube feeding does not prevent aspiration pneumonia.<sup>3</sup> However, tube feeding can decrease quality of life by disrupting a patient's food consumption and eating routine (which can be a source of comfort), and limiting human contact. Tube feeding can also require restraints to keep the tube in place, leading to decreased mobility, distress from the restraining

process, and decubiti from immobility. Tube feeding should not be an automatic response to decreased intake of food by mouth or dysphagia in end-stage dementia. Before tube feeding is initiated, it is important that physicians ensure that a full discussion of risks and benefits has taken place with caregivers, as the patient is in no condition to give informed consent.<sup>4</sup>

Families are often worried about their loved one being uncomfortable due to thirst or hunger. Patients with end-stage dementia often lose their hunger and thirst drives, and forcing them to take food or fluid can sometimes cause them to be extremely uncomfortable. Offering familiar foods and fluid in small amounts—as much as they will take—can ensure comfort. Regular mouth care is also important.

Education of caregivers is essential to improving care for patients with advanced dementia. Pain and emotional distress are common in patients with advanced dementia, but these patients are often not offered the same access to palliative care modalities as patients with more traditionally recognized terminal illnesses. Because patients with advanced dementia can't verbally express pain or request medication as needed, caregivers must be educated about reading signs and signals from their loved one—otherwise pain may be undermedicated or not medicated at all.<sup>5</sup> Although there is always fear that narcotics could cause delirium in a frail, elderly patient, untreated pain can also cause delirium. Palliative care provision for end-stage dementia should be as well standardized as it is for many other terminal conditions, given the degree of discomfort that accompanies the final stages of the disease.<sup>6</sup>

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British Columbia Drug and Poison Information Centre for inquiries around unusual toxic exposures (1 800 567-8911). As there are no clinical tests for toxic shellfish poisoning, diagnosis is based on symptoms and identification of toxins in leftover shellfish. Physicians, working with their local health authority, are encouraged to secure shellfish for testing to confirm diagnoses. In the case of suspected shellfish-related reactions, it is important to obtain a detailed history, asking about recent consumption and co-exposed individuals. Patients should then be monitored closely for signs of neurological or respiratory compromise, and provided with symptomatic management.

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#### References

1. McIntyre L, Galanis E, Mattison K, et al. Multiple clusters of norovirus among shellfish consumers linked to symptomatic oyster harvesters. *J Food Prot* 2012 Sep;75:1715-1720.
2. Taylor M, McIntyre L, Ritson M, et al. Outbreak of diarrhetic shellfish poisoning associated with mussels, British Columbia, Canada. *Mar Drugs* 2013;11:1669-1676.
3. Canadian Food Inspection Agency. Report to BC Centre for Disease Control. Paralytic shellfish poisoning. Illnesses in BC, July 2012.
4. Todd EC. Seafood-associated diseases and control in Canada. *Rev Sci Tech* 1997;16:661-672.
5. Quayle DB. Paralytic Shellfish Poisoning: Safe shellfish. Fisheries Research Board of Canada, Biological Station. Nanaimo, BC. 1966.
6. Jeffery B, Barlow T, Moizer K, et al. Amnesic shellfish poison. *Food Chem Toxicol* 2004;42:545-557.
7. Lefebvre KA, Robertson A. Domoic acid and human exposure risks: A review. *Toxicon* 2010;56:218-230.
8. James KJ, Carey B, O'Halloran J, et al. Shellfish toxicity: Human health implications of marine algal toxins. *Epidemiol Infect* 2010;138:927-940.
9. Van Dolah FM. Marine algal toxins: Origins, health effects, and their increased occurrence. *Environ Health Perspect* 2000;108(Suppl 1):133-141.
10. Fleming LE, Broad K, Clement A, et al. Oceans and human health: Emerging public health risks in the marine environment. *Mar Pollut Bull* 2006;53:545-560.

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Finally, patients with a diagnosis of early dementia should be encouraged to set up financial planning initiatives, update their will, consider end-of-life advanced directives,<sup>7</sup> and communicate with their family practitioner, friends, and family. Taking measures like these in advance is one of the best gifts patients can give their families and loved ones. Instead of struggling to make decisions in a crisis, families can be comforted in knowing that they are carrying out their loved ones' final wishes.

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#### References

1. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med* 2009;361:1520-1538.
2. Sampson EL. Enteric tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev* 2009;(2):CD007209.
3. Finucane TE, Bynum JP. Use of tube feeding to prevent aspiration pneumonia. *Lancet* 1996;348:1421-1424.
4. Chung AM. Percutaneous gastrostomy feeding tubes in end stage dementia: Don't just do it. *Can Assoc Radiol J* 2012;63(Suppl3):S5-6.
5. Morrison RS, Siu AL. A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *J Pain Symptom Manage* 2000;19:240-248.
6. Coleman AM. End-of-life issues in caring for patients with dementia: The case for palliative care in management of terminal dementia. *Am J Hosp Palliat Care* 2012;29:9-12.
7. BC Medical Association. Advance Directives. Accessed 28 May 2013. [www.bcma.org/news/advance-directives](http://www.bcma.org/news/advance-directives).

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