

The Dementia Difference: a Palliative Approach for People with Late-Stage Dementia—an Education Package for Residential Care

NANCY GNAEDINGER, JANICE ROBINSON, KATHERINE MURRAY, and AL VANDERGROOT, The Lodge at Broadmead, Victoria, British Columbia, Canada

The Lodge at Broadmead (TLAB) is a 12-year-old nonprofit, residential care facility (nursing home) owned and operated by the Broadmead Care Society in Victoria, British Columbia. It is home to 225 people. More than half are veterans, who are the primary beneficiaries of special program funding from Veterans Affairs Canada as part of their National Dementia Care Initiative.

One of the specially funded programs at TLAB is an education initiative inspired by recent changes in the characteristics of both the residents and the care environment at the facility: the proportion of residents with dementia has increased; the average length of stay has shortened; and the number of annual deaths has increased. These changes highlighted the need for specialized staff education in end-of-life care for residents with dementia.

No education of this sort was to be found, however, when senior nursing staff at TLAB extensively searched the literature, the Internet, and professional networks for a suitable education package in 2006. Therefore, funding was sought and gratefully received from Veterans Affairs Canada to develop a new education package focused on end-of-life care for persons with dementia.

The first step was to seek professionals to assist in course development. Consultants in hospice palliative care and in adult learning collaborated with TLAB's clinical nurse specialist to develop a two-day workshop that would build upon previous education at TLAB, namely *Supportive Pathways*[®]. (Developed by Carewest of Calgary, Alberta, *Supportive Pathways*[®] had been delivered on site by trained TLAB staff members to 96% of TLAB staff as well as family members, volunteers, and community members between October 2004 and March 2006.)

In addition, the clinical nurse specialist consulted with nursing staff, asking them what they wanted to know more about; and another senior nurse at TLAB interviewed family members to ask them what was most important to them when their relative was dying. The development process took approximately one year, and included several iterations, reviews, and a trial by six senior staff members who had previous experience delivering staff education on site.

The product is a two-day workshop *The Dementia Difference: a Palliative Approach for People With Late-Stage Dementia*, which focuses on best practice with residents who are dying with dementia. It meets Canadian guidelines and standards, and blends evidence-based palliative care with current dementia care best practice and findings from consultations with staff and families. Workshop content covers disease progression, the ambiguous dying syndrome, supporting families, symptom management, making moments meaningful, last days and hours, and staff care. Core information is presented in PowerPoint. Each participant is given a workbook, which contains supporting documentation and other content, such as case studies, used to prompt participatory problem solving. Other learning activities are varied and numerous, including: checking one's personal "baggage" with regard to dying and death; looking through a "death lens"; role playing; learning how to develop "strength-based assessments" for families; and learning how to envision making every moment count during a resident's last days and hours. There is considerable time allocated in each day to allow participants to ask and respond to questions, give feedback, interact with facilitators and with each other, and share stories and feelings.

Five senior staff members who have an in-depth understanding of dementias, two of

whom had previous experience teaching *Supportive Pathways*® at TLAB, were selected as trainers for the workshop. They were given a two-day train-the-trainer course, as well as a chance to comment on the workshop's content and style. Their suggestions for modifications were incorporated in the course.

Between September 2007 and February 2008, *The Dementia Difference* was delivered to approximately 90 TLAB staff members. Teaching was always carried out by a pair of professionals: either the clinical nurse specialist with the hospice palliative care consultant, or one of the trainers with the hospice palliative care consultant. This approach provided consistency in delivery, assurance of an RN presence, a way to constantly evaluate the course's effectiveness, and a way to share the heavy teaching load. The first wave of workshop participants included TLAB's interdisciplinary team (including nurses, occupational and physical therapists, social worker, and dietitian), whose mandate was to "get the word out" and direct care staff from all disciplines who work primarily with people in late-stage dementia.

Five methods were used to evaluate the *The Dementia Difference* education package: a before and after quiz to test participants' short-term increases in knowledge; a comprehensive written evaluation survey for each of the two days, addressing the workshop products, organization, content, learning activities, and more; an open-ended question asked verbally of all participants at the end of the second day, "What are you going to do differently?", which they were to answer in their workbooks; observation by the clinical nurse specialist, when not involved in teaching; and a series of group interviews with a sample of staff who had taken the course, several months after the last workshop was delivered, asking, "What differences have you made or observed in your practice that you would attribute to new perspectives, knowledge, and skills learned in the *The Dementia Difference* workshop?" (The results of preliminary evaluation, highly positive, are fulsome and rich, and will be published separately.)

The process of developing and delivering *The Dementia Difference* has taught us several valuable lessons at The Lodge at Broadmead:

- It requires varied perspectives and a depth of experience to produce a balanced and comprehensive education package. By combining nursing expertise in dementia care and in dying and death with expertise in both social work and adult learning, we were able to create a workshop that is current, comprehen-

sive, relevant, and understandable to a wide range of staff members.

- It takes considerable energy to teach a workshop that involves sometimes intense emotion and that may challenge cultural norms. Anyone attempting to do this teaching needs time to recover.
- It is necessary to take the time and spend the money to evaluate both the process (the workshop content and style of delivery, including learning activities) and the outcomes of an education initiative. In this case, we used five methods of evaluation, and improved the quality of the product and the process of teaching in response to each wave of evaluation results.

The next steps for us are to ensure that every staff member at TLAB participates in the two-day workshop; update the workshop content as knowledge in the field changes and increases; and continue with evaluation.

A satisfying consequence of creating a unique education package is that we are repeatedly asked by other residential care facilities and organizations to share information and advice about the development process, content, delivery, and outcomes of *The Dementia Difference: a Palliative Approach for People with Late-Stage Dementia*. In this way, the initial investment by Veterans Affairs Canada is not only helping veterans at TLAB, but is indirectly helping other facility residents.

Even more satisfying is the knowledge that we have been active and apparently successful in our initiative. In summary:

- We took careful stock of the changes in the characteristics and needs of our resident population.
- We asked ourselves and residents' family members if we were doing as good a job as possible with an increasing proportion of our residents who are dying with end-stage dementia.
- We realized we needed more focused and in-depth education on end-of-life care for this special group, and we searched for such education.
- Finding none, we used a collaborative and multidisciplinary approach, and developed a unique education package that is based on current and valid knowledge, individual expertise, and individual experience.
- We tested it and delivered it to almost 100 staff members as a first-year trial.
- We evaluated the workshop thoroughly and learned that it is relevant, meaningful, com-

prehensible, and stimulating for staff members in all positions at our residential care facility.

- We made modifications to the content and some of the learning activities, based on feedback from adult learners, and we are set to launch the second year of teaching this workshop.

In doing all this, we have taken an early and proactive step in a movement that is gradually taking place across the western world, according to recent publications. This is affirmation that we are in the forefront of residential nursing care, providing the best quality of life to our residents until death.

Date received, July 28, 2008; date accepted, June 30, 2008.

BIBLIOGRAPHY

References used in developing *The Dementia Difference: A Palliative Approach for People with Late-Stage Dementia* are the following:

1. Alzheimer's Australia. Palliative Care and Dementia. Discussion Paper 7. 2006. [Electronic version]. Retrieved November 1, 2006 from <http://www.alzheimers.org.au/upload/PalliativeCare.pdf>.
2. Bern-Klug M. The ambiguous dying syndrome [electronic version]. *Health and Soc Work* 2004; 29(1): 55-65.
3. Boersma F, Van Den Brink W, Deeg DJH, Eepsting JA, VanTilberg W. Survival in a population-based cohort of dementia patients: predictors and causes of mortality. *Int J Geriatr Psychiatry* 1999; 14: 748-753.
4. Bowman T. Promoting resiliency in those who do bereavement work. *Lifeline* 1999; 27: 7-9.
5. Cairns M, Thompson M, Wainwright W. Transitions in dying and bereavement: a psychosocial guide for hospice and palliative care. Baltimore, Maryland: Health Professions Press, 2003.
6. Canadian Hospice Palliative Care Association. A model to guide hospice palliative care. 2002. Retrieved from www.cPCA.net
7. Chang E, Hancock K, Harrison K, Daly J, Johnson A, Easterbrooks S. Palliative care for end-stage dementia: A discussion of the implications for education of health care professionals. *Nurse Educ Today* 2005; 25: 326-332.
8. Coventry PA, Grande GE, Richards DA, Todd C. Prediction of appropriate timing of palliative care for older adults with non-malignant life threatening disease: a systematic review. *Age Ageing* 2005; 34: 218-227.
9. Dempsey M, Baago S. Latent grief—the unique and hidden grief in carers of loved ones with dementia. *Alzheimer Society of Niagara Region*; 1998, pp. 1-10.
10. Donnelly M, Samaroo N. Dementia Coalition Literature Review. Vancouver, British Columbia, 2004.
11. Downing M, Wainwright W. *Medical Care of the Dying*. 3rd edition. Victoria, British Columbia: Victoria Hospice Society, 2008.
12. Evans BD. Improving palliative care in the nursing home: from a dementia perspective. *J Hosp Palliat Nurs* 2008; 4(2): 91-99.
13. Lucero M. Enhancing the visits of loved ones of people in late stage dementia. *Alzheimer's Care Q* 2004; 5(2): 173-177.
14. Luchins DJ, Hanrahan P. What is appropriate health care for end-stage dementia? *J American Geriatr Soc* 1993; 41(1): 25-30.
15. MacCourt P. *End of Life Care: Research evidence to support the provincial dementia service framework*. Simon Fraser University, British Columbia: CARMHA, 2007.
16. Missouri's End of Life Coalition's End of Life in the Nursing Home Task Force. Guidelines for end of life care in long term care facilities: Emphasis on developing palliative care goals. 2003.
17. Murray K. *Essentials in palliative care: a resource for caregivers*. Saanichton, British Columbia: Life & Death Matters, 2006.
18. Saunders C. The evolution of palliative care. *J R Soc Med* 2001; 94: 430-432.
19. Travis SS, Conway J, Daly M, Larsen P. Restless in the nursing facility: assessment, palliation and symptom management. *Geriatr Nurs* 2001; 22(6): 308-312.
20. Volicer BJ, Hurley A, Fabiszewski KJ, Montgomery P, Volicer L. Predicting short term survival for patients with advanced Alzheimer's disease. *J Am Geriatr Soc* 1993; 41(5): 535-540.
21. Volicer L. Hospice care for dementia patients. *J Am Geriatr Soc* 1997; 45(9): 1147-1149.
22. Volicer L, Hurley A. *Hospice care for patients with advanced progressive dementia*. New York: Springer Publishing, 1998.
23. Volicer L. End-of-life care for people with dementia in residential care settings. *Alzheimer's Association*, 2005.
24. Wilson SA, Kovach CR, Stearns SA. Hospice concepts in the care for end-stage dementia. *Geriatric Nursing* 1996; 17(1): 6-10.

Publications highlighting end-of-life dementia care and/or calling for more specialization in this field are the following:

1. Aminoff BZ, Adunsky A. Dying dementia patients: Too much suffering, too little palliation. *Am J Hosp Palliat Med* 2005; 22(5): 344-348.
2. Hancock K, Chang E, Johnson A, Harrison K, Daly J, Easterbrook S, et al. Palliative care for people with advanced dementia: The need for a collaborative, evidence-based approach. *Alzheimer's Care Q* 2006; 7(1): 49-57.
3. Kristjanson LJ, Walton J, Toye C. End-of-life challenges in residential aged care facilities: a case for a palliative approach to care. *Int J Palliat Nurs* 2005; 11(3): 127-129.
4. Lloyd-Williams M, Filbert M. Can palliative care improve the symptoms during the terminal phase of dementia? *Eur J Palliat Care* 2004; 11(3): 99-101.
5. Sampson EL, Ritchie CW, Lai R, Raven PW, Blanchard MR. A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *Int Psychogeriatrics* 2005; 17(1): 31-40.
6. Small N, Froggatt K, Downs M. *Living and Dying with Dementia: Dialogues about palliative care*. Oxford: Oxford University Press, 2007.
7. Tilly J, Reed P, Gould E, Fok A. End-of-life care practice recommendations for assisted living residences and nursing homes serving individuals with dementia. *Alzheimer's Care Q* 2008; 9(2): 113-119.
8. Volicer L. End-of-life care for people with dementia in long-term care setting. *Alzheimer's Care Q* 2008; 9(2): 84-102.