

Disclosing a diagnosis of dementia

Helping learners to break bad news

Linda Lee MD MCISc CCFP FCFP W. Wayne Weston MD CCFP FCFP

As a second-year family practice resident, Jerry exuded confidence. We were about to disclose a diagnosis of dementia to a patient and his wife. Did Jerry know how to break bad news? "Sure," he said. "I've seen it done many times." I suggested he rehearse with me. Jerry seated himself and, after a thoughtful pause, he began: "Well, Mr Smith, you have dementia, and there is nothing much we can do about that."

This was a very teachable moment. First, it demonstrated the importance of ensuring that learners are adequately prepared for the role of delivering bad news. Second, learners need to be taught how to break bad news in a sensitive way that provides realistic hope. And third, there is great value to having learners attempt this role-play exercise first.

Full disclosure

Most learners are eager to take on responsibility for patient care, believing that learning by doing is preferable to learning by observing. Although we all learn by pushing the boundaries of our abilities and from our inevitable mistakes, as teachers we need to ensure that learners are adequately prepared for their patient encounters. It would have been helpful to ask Jerry what he knew about dementia and what he intended to tell the patient. In this case, a short role-play exercise revealed that he was inadequately prepared for his role in delivering bad news.

Even experienced physicians find it difficult to disclose a diagnosis of dementia. Studies during the past decade suggest that diagnostic disclosure in dementia is inconsistent, with up to 50% of clinicians routinely withholding a diagnosis of dementia.¹ Yet most elderly patients would wish to be told of a diagnosis of dementia in order to plan, settle family matters, and pursue travel.² Current guidelines state that the issue is no longer one of whether or not to disclose the diagnosis of dementia, but rather how and when to do so. Disclosure should take a patient-centred approach that maintains personal integrity and instills a sense of hope.³

The need for sensitivity cannot be overstated. Dementia is a progressive, terminal disease, but unlike many other terminal illnesses, there are often social implications. Making a diagnosis of dementia has been described as both a medical process and a social act that moves the patient to a new social group, one that is highly stigmatized. Patients in the early stages of Alzheimer disease describe experiencing shame,

discrimination, rejection, social isolation, loss of the sense of control, and altered self-image.⁴

Patient-centred approach

It is important to teach family medicine residents how to disclose a diagnosis of dementia in a compassionate, sensitive manner using a patient-centred approach. The following tips have been helpful.

Determine what the patient knows about dementia and address misconceptions. Often patients and family members have had negative or frightening experiences with others who suffered from dementia. Do they know someone who had Alzheimer disease? What was that like? What aspects do they worry about most?

Try to reassure where possible. It helps to frame memory loss as a spectrum, with "normal aging" at one end, "dementia" at the other, and "mild cognitive impairment" in between; dementia then represents worsening of the inevitable memory loss that interferes with daily life functioning. Described in this way, patients can understand dementia as being part of a continuum of memory loss. In the early stages of the disease, it is helpful to emphasize that much of their brain still functions well.

Identify patients at early stages of memory loss. This gives the patients and their families time to come to terms with the diagnosis. Mild cognitive impairment affects an estimated 16.5% of Canadians older than the age of 65,⁵ with most eventually succumbing to dementia.⁶ This is an ideal time to discuss lifestyle interventions—for example, a Mediterranean diet, regular exercise, and increased social networking—that have been associated with reduced risk of developing dementia. Additionally, it is helpful to introduce the issue of driving at this stage, as the patient still retains insight. In our experience, statements such as "You are fine to drive right now, but someday, if your memory difficulties worsen, driving will become unsafe" provide the patient with the gift of time to prepare for the day when driving will no longer be possible.

Focus on goals of management. Cassell⁷ lists the 3 goals of medical care that are applicable to any chronic disease: 1) make diagnostic or therapeutic plans in

La traduction en français de cet article se trouve à www.cfp.ca dans la table des matières du numéro de juillet 2011 à la page e270.

terms of the sick person, not the disease; 2) maximize the patient's function; and 3) minimize the suffering of the patient and the family. These goals are very applicable to dementia care. Using a patient-centred approach,⁸ identify goals and priorities in the context of the patient's world and develop a mutually agreeable plan of management. Pharmacologic management of dementia might include the introduction of cognitive-enhancing medications as well as withdrawal of drugs known to adversely affect cognition, such as benzodiazepines and highly anticholinergic drugs. Nonpharmacologic management often includes caregiver education and support, providing links to community resources, and establishing power of attorney while the patient still has capacity for decision making. The objective is to maintain the highest quality of life and independent community living for as long as possible for both the patient and family members.

Provide realistic hope. Cassell writes, "There is nothing more that anyone can do' is so devastating. In addition, it is usually untrue—there is virtually always *something* that can be done to improve the patient's situation, no matter how small or seemingly inconsequential."⁷ We can provide realistic hope by highlighting individual variation in disease manifestation and progression, the availability of treatment options that might delay decline for a while, and ongoing progress being made in dementia research.

Emphasize nonabandonment. Nonabandonment has been described as a physician's central obligation, reflecting a joint, longitudinal commitment to care for patients and seek solutions to problems with patients throughout the course of their illness.⁹ A diagnosis of dementia can be devastating for patients and family who grieve progressive losses of functioning and independence and face an uncertain future. A caring, committed relationship with the family physician can help to reduce suffering and facilitate healing as patients and family members come to terms with this demoralizing terminal illness.

Conclusion

Breaking bad news is particularly challenging. We can help our learners by providing tips, demonstrating skills, and coaching through role play and during patient interaction. These combined teaching methods will help students learn that a diagnosis of dementia can be disclosed in a sensitive, compassionate way that instills realistic hope. As Buckman notes, "The task of breaking bad news is a testing ground for the entire range of our professional skills and abilities. If we do it badly the patients or family members may never forgive us; if we do it well, they will never forget us."¹⁰

Dr Lee is a family physician practising in Kitchener-Waterloo, Ont; Director of the Centre for Family Medicine Memory Clinic; and Assistant Professor in the departments of family medicine at McMaster University in Hamilton, Ont, The University of Western Ontario in London, Ont, and Queen's University

in Kingston, Ont. Dr Weston is Professor Emeritus of Family Medicine at the Schulich School of Medicine and Dentistry at the University of Western Ontario and Chair of the Canadian Operating Committee at the Institute for Healthcare Communication.

Competing interests

None declared

References

1. Carpenter B, Dave J. Disclosing a dementia diagnosis: a review of opinion and practice, and a proposed research agenda. *Gerontologist* 2004;44(2):149-58.
2. Erde EL, Nadal EC, Scholl TO. On truth telling and the diagnosis of Alzheimer's disease. *J Fam Pract* 1988;26(4):401-6.
3. Fisk JD, Beattie BL, Donnelly M, Byszewski A, Molnar FJ. Disclosure of the diagnosis of dementia. *Alzheimers Dement* 2007;3(4):404-410. Epub 2007 Sep 19.
4. Aminzadeh F, Byszewski AM, Molnar FJ, Eisner M. Emotional impact of dementia diagnosis: exploring persons with dementia and caregivers' perspectives. *Aging Ment Health* 2007;11(3):281-290.
5. Canadian Study of Health and Aging [website]. Available from: www.csha.ca. Accessed 2011 May 26.
6. Chertkow H, Nasreddine Z, Joannette Y, Drolet V, Kirk J, Massoud F, et al. Mild cognitive impairment and cognitive impairment, no dementia: part A, concept and diagnosis. *Alzheimers Dement* 2007;3(4):266-82.
7. Cassell EJ. *The nature of suffering and the goals of medicine*. 2nd ed. New York, NY: Oxford University Press; 2004.
8. Stewart M, Brown JB, Weston WW. *Patient-centered medicine: transforming the clinical method*. 2nd ed. Abingdon, UK: Radcliffe Medical Press; 2003.
9. Quill TE, Cassel CK. Nonabandonment: a central obligation for physicians. *Ann Intern Med* 1995;122(5):368-74.
10. Buckman R. *How to break bad news. A guide for health care professionals*. Baltimore, MD: Johns Hopkins University Press; 1992.

TEACHING TIPS

- Sensitivity, full-disclosure, and a patient-centred approach are necessary to effectively inform a patient of a diagnosis of dementia.
- Learners should be taught to emphasize that patients will not be abandoned by their family physicians and to instill realistic hope when discussing disease manifestation, patient management, and ongoing progress in dementia research.
- It is important to focus on goals of management when disclosing a diagnosis of dementia; each plan should accommodate the specific needs of the patient, maximize functioning (eg, through lifestyle and pharmacologic interventions), and minimize suffering to ensure the highest quality of life for the longest amount of time.

CONSEILS POUR L'ENSEIGNEMENT

- Il faut de la sensibilité, une divulgation complète et une approche centrée sur le patient pour informer correctement un patient d'un diagnostic de démence.
- Il faut enseigner aux apprenants à insister sur le fait que leur médecin de famille n'abandonnera pas les patients et à inspirer un espoir réaliste dans la discussion de la manifestation de la maladie, de la prise en charge du patient et de l'évolution continue de la recherche sur la démence.
- Il est important de se concentrer sur les objectifs de la prise en charge quand on annonce un diagnostic de démence; chaque plan doit répondre aux besoins spécifiques du patient, maximiser le fonctionnement (p. ex. par des interventions pharmacologiques et visant le mode de vie) et minimiser la souffrance pour assurer la meilleure qualité de vie pendant le plus longtemps possible.

Teaching Moment is a quarterly series in *Canadian Family Physician*, coordinated by the Section of Teachers of the College of Family Physicians of Canada. The focus is on practical topics for all teachers in family medicine, with an emphasis on evidence and best practice. Please send any ideas, requests, or submissions to Dr Allyn Walsh, Teaching Moment Coordinator, at walsha@mcmaster.ca.