

# Sad but true: your father has dementia

## *An approach to announcing the diagnosis*

Guy Frenette, MD Jean Pierre Beauchemin, MD, CCFP, FCFP, CSPQ

### ABSTRACT

**OBJECTIVE** To show that family physicians have an important role in caring for patients recently diagnosed with dementia.

**SOURCES OF INFORMATION** This article is based on the authors' clinical experience and on the recommendations of the Canadian Consensus Conference on Dementia.

**MAIN MESSAGE** The authors touch on themes often ignored in the literature, such as issues surrounding the first time patients and their families are confronted with a diagnosis of dementia. We show the advantages of informing patients of the diagnosis and refute arguments for keeping it a secret. We then describe aspects of anticipatory counseling, which should begin as soon as the diagnosis is made: natural evolution of the disease, risk factors, power of attorney, driving, medical follow up, risks of polypharmacy, resources for psychological support of caregivers, and orientation to community resources (for helping patients remain at home).

**CONCLUSION** Physicians must inform patients and their families of a diagnosis of dementia and provide anticipatory counseling so that families can prepare for the long-term responsibility of caring for someone with this disease.

### RÉSUMÉ

**OBJECTIF** Démontrer que le médecin de famille a un rôle majeur dans le suivi des patients atteints de démence.

**SOURCES D'INFORMATION** Le contenu de cet article est fondé sur l'expérience clinique des auteurs et sur la Conférence canadienne de Consensus sur la démence.

**PRINCIPAL MESSAGE** Les auteurs abordent des thèmes souvent négligés dans la littérature, soit les aspects qui touchent les premiers temps où le patient et sa famille sont confrontés au diagnostic de démence. On démontre les avantages d'annoncer au patient le diagnostic et l'on réfute les arguments qui justifieraient le secret. Vient ensuite une description des éléments de counselling par anticipation à aborder rapidement une fois le diagnostic posé: l'évolution naturelle de la maladie, les facteurs de risque, la désignation d'un mandataire par le patient quand il sera inapte, la conduite automobile, le suivi médical, les risques de la polypharmacie, les ressources de soutien psychologique aux aidants et l'orientation vers les ressources communautaires (groupes de soutien et ressources de maintien et d'aide à domicile).

**CONCLUSION** Il faut annoncer le diagnostic de démence au patient et à ses proches afin qu'ils puissent entreprendre plus tôt la longue prise en charge de cette maladie.

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When Mr Smith began to tell you he was having problems with memory 2 years ago, you adopted a reassuring attitude, but you now have to consider the evidence. His condition has deteriorated, and he now meets the criteria for a diagnosis of Alzheimer-type dementia. You see him today with his wife and daughter. You expect to meet with them for 30 minutes at the end of your appointments. Several questions arise. Should you tell him that he is suffering from Alzheimer disease? What advice should you give Mr Smith and his family?

**T**his article describes the problems that family physicians often face when they diagnose dementia. It tells of the importance of announcing the diagnosis and ways of confirming a patient has the disease, which families often find hard to accept at the beginning. Counseling that should be offered to patients and families is described. Pharmacologic therapy of Alzheimer-type dementia is not discussed.

### Sources of information

The information in this article is based on the authors' clinical experience and on the guidelines of the Canadian Consensus Conference on Dementia,<sup>1</sup> which are founded mainly on level I and II evidence.

### Alzheimer disease: to tell or not to tell?

Telling patients that they have dementia can be an unpleasant clinical experience for doctors, patients, and their families for many reasons. Reasons often given for not revealing the diagnosis are:

- fear that patients are not sufficiently aware to comprehend the disease. This fear is justified only during the advanced stage of the disease. In the early and middle stages, patients are often astonishingly lucid;
- that the risks of anxiety, depression, and suicide are not alleviated by knowing the truth. In fact, a policy of silence can in itself increase risk of anxiety, depression, and suicide; and
- fear of emotional outbursts from patients or their families. Having a qualified social worker or psychotherapist on hand is not a bad idea.

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*Dr Frenette is on staff at the Centre hospitalier régional de Portneuf at St-Raymond-de-Portneuf, Que.*

*Dr Beauchemin is a Professor in the Faculty of Medicine at Laval University and a Geriatrician at the Laval Hospital and at the CLSC-CHSLD Haute Ville des Rivières in Quebec city, Que.*

A doctor's conduct is guided by his or her legal and ethical responsibilities. Patients have a right to truth and a precise diagnosis. This rule should be broken only under rare circumstances when doctors fear patients will have anxiety attacks or psychotic episodes. There are more advantages than disadvantages for patients and their families in knowing the truth. Remember always that you still need patients' consent to reveal the diagnosis to their families. If patients refuse this consent, you need to explore the reasons for the refusal and try to convince them that revealing the truth is in the best interest of everyone for future care.

One study showed that 83% of families preferred that patients not be informed of the diagnosis for fear they would become anxious or depressed.<sup>2</sup> Paradoxically, 71% of the same respondents would want to be informed of the diagnosis if it were themselves. It is clear that families feel ambivalent and want to protect themselves and their loved ones from bad news.

Legally and ethically, the advantages of telling a patient the diagnosis are numerous.

- You can proceed to an early multidisciplinary intervention, quickly making therapeutic efforts on the one hand and following the progressive losses inherent in the disease on the other. Long-term planning can reduce the number of crises family caregivers have to handle.
- Patients and their families often find comfort in the announcement of the diagnosis because the uncertainty as to the cause of the symptoms they have observed is as bad as the diagnosis itself. It is not unusual to hear patients and their families say that the diagnosis has confirmed their apprehensions.
- Announcing the diagnosis to patient and family simultaneously will allow you to answer everyone's questions and be sure that they all have the same information. Family members can then organize themselves more quickly and easily. The challenge for a clinician is to decide how much information to give because some people will interpret an abundance of details as indicating that a patient has very advanced disease. Others will think a lack of details indicates a snap judgment and will doubt the diagnosis.

### How to tell the news

No one way works for all patients. Each case is different, and each doctor must adapt his or her manner to suit the particular case. A patient- and family-centred interview is the foundation of this

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intense communication exercise. A doctor must be both judge and participant in the interview. Longitudinal knowledge of patient and family are an undeniable advantage during the interview.

The patient must be at the heart of the discussion. The level of language and explanations must be adjusted to his or her understanding. Some clinicians hesitate to use the term “dementia” because they think it still has the derogatory connotations long attached to psychiatric conditions. They prefer to speak of Alzheimer disease. At this stage it is probably not useful to call a family conference, but it is often helpful to invite the main caregiver or caregivers to accompany the patient.

It is good also to become acquainted with patient and family’s understanding of dementia in order to rectify false perceptions about the diagnosis (lumping it in with other mental diseases or neurologic maladies) as to cause, genetics, or natural evolution. Doctors can often see a need for a second interview (or even more) because certain patients and their families need time to dissipate the denial, anger, and anguish sometimes generated by the diagnosis.

#### Probable or possible dementia: how to deal with uncertainty

Although the concepts “probable” and “possible” dementia are useful in clinical research, uncertainty can create a great deal of confusion for patients and their families. Probable dementia is diagnosed when certain criteria are met (**Table 1**<sup>3</sup>). You can be certain of the diagnosis only after an autopsy of the brain. It is not unusual for clinicians to lack some elements for suggesting a diagnosis of probable dementia.

**Table 1. Criteria for dementia**

Memory loss with at least four of the following:

- Aphasia: trouble with language, comprehension, expression (eg, “losing” a word)
- Apraxia: inability to accomplish a task in the absence of sensory or motor deficit
- Agnosia: inability to recognize objects, people, parts of the body in the absence of sensory or motor deficit
- Disturbances in one or more instrumental functions, such as planning a task, sequential organization, discriminating relevant information, mathematical abstractions, or judgment
- Cognitive deficits sufficient to impair daily functioning
- A noted decline from previous levels of functioning
- Cognitive deficits that survive other than after delirium

*Adapted from American Psychiatric Association.<sup>3</sup>*

You can suggest possible dementia when patients present with the following:

- a dementia syndrome in which the manifestations are atypical of Alzheimer-type dementia (visual hallucinations, urinary incontinence, or early behaviour problems associated with memory impairment);
- a brain disease other than dementia or a systemic disease can be associated with dementia but not be the cause of the dementia syndrome observed (vascular accident in an area not relevant to the clinical picture or mild hypothyroidism);
- an isolated deficit (eg, memory loss) that is progressive and without clear cause.

You must have good communication with patient and family before you suggest a diagnosis of possible dementia. Some will interpret it as a physician’s incompetence to diagnose the condition and will often ask for a second opinion. Others will take advantage of the opportunity to attribute the dementia syndrome to other illnesses, insist it has reversible causes, and begin to deceive themselves about the situation. Then you must insist that the patient is possibly suffering from dementia and that a follow-up visit in 6 months will allow you to be more precise about the diagnosis.

#### Information for patients and families

The main things family caregivers want from treating physicians are<sup>4</sup>:

- assurance of regular follow up;
- further communication about the diagnosis and information during the whole course of the disease, particularly when they are dealing with behaviour problems; and
- recognition of the important role family caregivers play.

Invariably, patients and families want to know about the progression of the disease, risk factors, and available treatments. The evolution of dementia varies according to its cause. Typically, Alzheimer-type dementia progresses slowly and becomes worse in stages over several years (on average 6 to 8 years after diagnosis). In contrast, vascular dementia progresses in stages (associated with vascular illness, objective or not) with fluctuations in cognitive and functional performance, sometimes from one day to the next.

#### Risk factors

Risk factors can be classified into general factors and factors specific to each type of dementia (**Table 2**<sup>2</sup>). In most cases, dementia is multifactorial. The following general risk factors for dementia are based on level I evidence.

**Age.** After age 65, the risk of getting dementia doubles every 5 years, in men and women alike (Table 3).<sup>5</sup>

## Table 2. Risk factors for dementia

### GENERAL FACTORS

- Age
- Little education
- Heredity

### SPECIFIC FACTORS

- Alzheimer-type dementia
  - Previous serious head injury (brain disturbance or coma)
  - Down syndrome
  - Mild cognitive impairment (rate of conversion is 10% per year to Alzheimer disease<sup>3</sup>)

### Vascular dementia

- Cerebrovascular accident (CVA), lacunar syndrome (pseudobulbar syndrome)
- Computed tomography evidence of CVA, pre-ventricular gaps, and leucoencephalopathy
- Arterial hypertension, diabetes, hypercholesterolemia
- Smoking
- Chronic alcohol abuse
- Exposure to toxins, such as pesticides, fumes from plastic, fertilizer

## Table 3. Prevalence of dementia in Canada

AGE (Y)	PREVALENCE (%)
65-74	2
75-84	12
>85	35

Data from McDowell.<sup>5</sup>

**Education.** People with only an elementary education have four times the risk of getting degenerative or vascular dementia compared with those who have had 10 or more years' education.<sup>6,7</sup>

**Heredity.** No biologic marker has been found for detecting any kind of dementia. Sometimes, the presence of a genotype of a single apolipoprotein E4 (Apo-E4) on chromosome 19 increases risk of Alzheimer-type dementia 2.2 to 4.4 times; the presence of two Apo-E4 genotypes (E4/E4) raises the risk 5.1 to 17.9 times.<sup>8</sup> A systematic search is not, however, recommended. The absence of Apo-E4 does not protect against all dementia, including Alzheimer-type dementia. In fact, the most frequently seen form of Alzheimer-type dementia is the sporadic form (90% to 95% of cases). Vascular dementia is not hereditary, but several risk factors for it are.<sup>1</sup>

## Legal aspects

At this stage of the disease, it is essential to clarify certain legal matters. You must confirm patients' capacity to decide what is good for themselves (consent to care, realistic view of their capabilities, power of attorney in case of incompetence) and their families (finances, will, and power of attorney).

## Driving

You should tell patients and their families that a diagnosis of dementia does not automatically revoke a driver's licence. In many cases, driving is possible and safe at this stage. You should prepare patients for the eventuality of not driving. Certainly a diagnosis of dementia requires physicians to maintain regular and careful surveillance. It is relatively easy, even in the office, to pick out good and bad drivers.

Sometimes you have doubts.<sup>9</sup> You can get help by taking patients to a day hospital or to an outpatient geriatric team. An evaluation will be done by an occupational therapist who can administer a written driving test followed by a road test, if necessary. Only a road test can really assess a driver's ability. Each province has a clear policy on physicians' role in monitoring patients with dementia who drive.

## Polypharmacy

Patients and their families need to be educated about the dangers of polypharmacy. Dementia implies the brain is frail; adverse effects of medications are frequent. Delirium can come on rapidly after a new medication is added (eg,  $\beta$ -blocker, anticholinergic agent, nonsteroidal anti-inflammatory drug, benzodiazepine, codeine) or after an interaction between prescription or over-the-counter medications. Patients must be careful with medications, prescribed or not, and, as treating physician, you should apply to each new medication the old principle "start low, go slow." Medications should be reviewed at each visit.

## Psychologic support for caregivers

More than 50% of family caregivers have serious mental problems (eg, anxiety, depression) during their "careers" as caregivers.<sup>10</sup> Doctors must recognize and validate the essential role of these family caregivers in maintaining patients at home and in offering a prodigious amount of care all through the illness. Doctors must regularly evaluate how the caregivers, as well as the patient, are doing. Informing, reassuring, and supporting family caregivers will have a positive effect on their lives and on their ability to care for the patient at home.<sup>11</sup>

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**Orientation to resources**

Doctors cannot do everything themselves. They need to get patients and their families in touch with the network of resources that can provide them the necessary support.

**Support groups.** Groups, such as the Alzheimer Society of Canada, offer (among other things) information sessions, mutual support groups for patients and their families, and special activities.

**Regional social services centres.** These centres can do psychosocial evaluations; have resources for helping maintain patients at home, respite beds, and day-care centres; and can refer families to charitable organizations. Some regions have programs for systematically encouraging caregivers to renew their efforts.

**Sources of information.** Many sources of information already exist and can greatly aid patients and their families (Table 4).

Whew! The afternoon is over. Mr Smith and his wife are comforted because someone has finally given a name

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**Table 4. Resources**

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**GERONTOLOGIST AND GERIATRICS WEBSITES**

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- Canadian Association of Gerontology: [www.cacag.ca](http://www.cacag.ca)
- Canadian Society of Geriatricians: [www.canger.org](http://www.canger.org)
- Quebec Society of Geriatricians: [www.interlinx.qc.ca/glacombe](http://www.interlinx.qc.ca/glacombe)
- Geriatrics and aging: [www.geriatricsandaging.com](http://www.geriatricsandaging.com)
- Centre de recherche de l'Institut universitaire de gériatrie de Montréal: [www.iugm.qc.ca](http://www.iugm.qc.ca)
- La gérontologie française: [www.geronto.com](http://www.geronto.com)
- Health Canada, Division of Age and Aging: [www.lc-se-gc.ca/seniors-aines](http://www.lc-se-gc.ca/seniors-aines)
- Alzheimer Society of Canada: [www.alzheimer.ca](http://www.alzheimer.ca)

Aging and Seniors: [www.hc-sc.gc.ca/seniors](http://www.hc-sc.gc.ca/seniors)

**INTERESTING JOURNALS ON AGING**

- Canadian Journal of Aging* (Canadian Association of Gerontology)
- Drugs and Aging*
- Geriatric Nursing*
- Geriatrics*
- Gerontologist*
- Journal of the American Geriatrics Society*

**BOOKS**

Gauthier S. *Clinical diagnosis and management of Alzheimer's disease*. 2<sup>nd</sup> ed. London, Engl: Martin Dunitz; 2001.

**Editor's key points**

- Announcing a diagnosis of dementia to patients and their families is difficult and is best done during a patient-centred interview. Explanations should be given in language geared to patients' level of understanding, and physicians should be mindful of erroneous perceptions surrounding dementia.
- The main elements of anticipatory counseling are general and specific risk factors, legal aspects of managing property, driving, risks of polypharmacy, and available resources.
- The main expectations family caregivers have of doctors are that they will provide regular follow up, that they will communicate information on various subjects (particularly on behaviour problems), and that they will recognize families' important role.

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**Points de repère du rédacteur**

- L'annonce du diagnostic de démence à un patient et à sa famille est un exercice de communication intense qui repose sur l'entrevue centrée sur le patient. Les explications doivent être données avec des termes adaptés au niveau de connaissances et le clinicien doit être attentif aux perceptions erronées entourant la démence.
- Les principaux éléments de counselling abordés par le médecin portent sur les facteurs de risque généraux et spécifiques, les aspects légaux entourant la gestion des biens, la conduite automobile, les risques associés à la polypharmacie et les ressources du milieu.
- Les principales attentes des aidants naturels face au médecin sont d'assurer un suivi régulier, de communiquer de l'information sur différents sujets (plus particulièrement sur les troubles du comportement) et de reconnaître l'importance de leur rôle.

to what is happening. Their daughter finds that it took you a long time to confirm what they have suspected for several months already. She asked many questions about the future and the prognosis. You have offered to meet with her and her brothers and sisters again to answer their questions. She was grateful for that.

**Conclusion**

It is important to announce a diagnosis of dementia to patients with all the veracity you can muster before undertaking, with patient and family, the long-term responsibility of caring for someone with this still devastating disease. Announcing the

diagnosis is not easy, but it can be a rewarding experience for a physician. Anticipatory counseling is important because it allows the family to better prepare themselves not only to organize care, but also to cope psychologically. ❁

Adapted with permission from Frenette G, Beauchemin JP. *Le Médecin du Québec*. 2002;37:41-7.

Correspondence to: Dr G. Frenette at [guyfrene@hotmail.com](mailto:guyfrene@hotmail.com)

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