

# Alzheimer's Disease and other dementias



Bill Burmeister  
Painting acrylic on canvas, 2009  
11"x14"

## **FOCUS ON**

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*The Alzheimer Society of Canada*

# Alzheimer's Disease and other dementias



Artist Bill Burmeister (1924-2010)  
Photograph provided by  
Dalia Gottlieb-Tanaka, PhD  
Chair of The Society for the Arts  
in Dementia Care

## On the Cover...

Bill Burmeister, a loving family man, owned a flower shop with his wife in Vancouver, B.C. in the 1950s. Together with their children, they created craft work lines, including macramé, wood carvings, stone figures and felt mosaics, to supplement their income. However, he always claimed that his wife was the artist in the family after studying under Jack Shadbolt, an influential Canadian artist, at the Vancouver School of Art.

Bill often looked to create things. It was common for him to bring a piece of driftwood home and say, "What can we do with this?" When he entered the George Derby Centre in Burnaby, B.C., he enthusiastically began weaving and making tapestries. As his cognition waned, he forgot that he once believed he could not paint and drew images rich with nuance and color that represented a curious and creative life. Bill's painting will be exhibited at the Shadbolt Centre for the Arts in Burnaby, B.C., from May 28 to June 20. His work was created with the support of Shelley Klammer, along with a team of 10 therapeutic art instructors at the George Derby Centre.

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## Addressing Ethical Concerns of End-of-life Care

By Paul J. Coolican, MD, CCFP, FCFP

This issue of *The Canadian Review of Alzheimer's Disease and Other Dementias* addresses many of the concerns which make physicians uncomfortable about managing patients with dementia.

The problems we face as physicians are fraught with concerns for which our medical training is incomplete when managing these patients, specifically those with end-stage dementia. We know these patients do very poorly in the face of acute illness and often have multiple comorbidities which worsen their prognosis. It is also understood that their quality of life could be severely compromised and there is often a family member with unrealistic views regarding their loved one's illness.

In their article, Drs. Paige Moorhouse and Laurie Mallery help us address the challenges mentioned above by presenting the PATH model, a structured process for dealing with the issues associated with end-of-life care. In his piece "Caring for patients with Terminal Alzheimer's Disease," Dr. Ladislav Volicer addresses many of

the specifics we face with our patients in a hospital, long-term care facility or at home.

Both of these articles address the complicated issues associated with end-of-life care. These include the lack of studies on this subset of patients; the use of medications which prevent long-term complications in patients with short life expectancy; the management of pain; resistance to care; and how to help the family of patients with dementia make informed choices in the best interest of the patient.

Finally, the article by Dr. Serge Gauthier and his fellow on the pre-dementia diagnosis of Alzheimer's disease (AD) is fascinating and frightening. The authors outline a recently presented protocol suggesting we might diagnose AD before it presents in clinical tests. The validation of a tool or algorithm which might separate amnesic mild cognitive impairment (MCI) from pre-dementia AD would be valuable, time consuming, resource consuming and ethically challenging. Enjoy!

# PATH: A New Approach to End-of-life Care

Due to advances in medical care, aging patients have survived the accumulation of many chronic diseases, including dementia. In an effort to help foster decision making and plan ahead to meet the challenges of end-of-life care in dementia, two physicians created the PATH model, a process which promotes careful consideration of the complex issues relevant to frail older adults nearing the end of their lives.

*By Paige Moorhouse, MD, MPH, FRCPC; and Laurie Mallery, MD, FRCPC*

Programs that foster individualized decision-making and care planning are required due to the increased prevalence of dementia and frailty in Canada's aging population. To address this need, we developed a standardized program, the Palliative and Therapeutic Harmonization (PATH) process, to help promote careful consideration of the complex issues relevant to frail older adults nearing end of life. The program's goal is to empower patients and their families to learn about their health issues in order to improve medical

decision-making. The following article reviews the need for better end-of-life care in dementia, and how the PATH model meets this need.

## **Improving End-of-life Care**

***The frailty tsunami is coming.*** Over the next 30 years, the Canadian healthcare system will treat an unprecedented number of older adults who, due to advances in chronic medical care, have survived the accumulation of many chronic diseases, including dementia. Thus, the hallmark of the aging population is frailty, an accumulation of multiple health deficits.<sup>1</sup> Despite terminal frailty, many older individuals receive highly aggressive care that has little chance of success and results in prolonged suffering before death.<sup>2,3</sup> As such, consideration of how we deliver end-of-life care is essential.

***Evidence-based medicine falls short.*** Most older adults with dementia also suffer from other chronic health conditions and are

therefore underrepresented in scientific studies. Complex medical treatments that work well for healthier populations may have less benefit for frail adults who are vulnerable to the adverse effects of treatment and have fewer years of life to experience treatment benefit if it occurs.

Unfortunately, clinical practice guidelines for end-of-life care designed for chronic conditions are often disease-specific/single-system-based and do not provide guidance about how to understand prognosis when more than one chronic illness is involved. Even clinical practice guidelines for severe Alzheimer's disease (AD) may fail to make specific recommendations about end-of-life care for dementia.<sup>4</sup> Similarly, most risk scores are designed to estimate the risk of mortality associated with an intervention (*i.e.*, cardiovascular surgery), but do not address outcomes, such as institutionalization or permanent loss of function, which many patients consider to be fates worse than death.<sup>5</sup> This lack of

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Table 1

Pre-palliative Era of Cancer Care vs. Current End-of-life Care for Frail Older Adults

Pre-palliative Era of Cancer Care	Current End-of-life Care for Frail Older Adults
<ul style="list-style-type: none"> <li>Information regarding diagnosis withheld</li> </ul>	<ul style="list-style-type: none"> <li>Complexity of comorbidities and lack of applicable evidence-based medicine may lead to avoidance of prognosis discussions</li> </ul>
<ul style="list-style-type: none"> <li>Lack of awareness of palliative care in cancer</li> </ul>	<ul style="list-style-type: none"> <li>Lack of awareness of implications of frailty</li> <li>Lack of attention to how frail patients die</li> </ul>
<ul style="list-style-type: none"> <li>Comfort care may be withheld leading to patients dying in pain</li> </ul>	<ul style="list-style-type: none"> <li>Comfort care may be withheld leading to patients dying in pain</li> </ul>
<ul style="list-style-type: none"> <li>“Cure culture”</li> </ul>	<ul style="list-style-type: none"> <li>Futile treatments may be offered</li> </ul>
<ul style="list-style-type: none"> <li>Spiritual approach at odds with medical care of the dying</li> </ul>	<ul style="list-style-type: none"> <li>Insensitivity to the needs of the dying patient and his or her family</li> </ul>

evidence-based guidelines and frailty-relevant risk scores can lead to uncertainty about how healthcare providers should discuss prognosis and lead to inconsistencies in how information is communicated to patients and caregivers.

*Dementia is often not recognized as a terminal illness.* It should be noted that the progressive and terminal nature of dementia<sup>3</sup> may not be addressed during routine care. In particular, for individuals with dementia, the risk of adverse outcomes associated with hospitalization, surgery or other medical interventions<sup>6,7</sup> may not be identified as a central focus for care planning. As a result, more aggressive care may be chosen for patients with advanced dementia when compared with non-demented patients with a similar life expectancy.<sup>8</sup>

By nature of their medical complexity, frail patients with dementia are often cared for using team-based models. Although team-based care requires multiple specialized skill sets to evaluate health, the task of assembling the timeline of health in a trajectory, as well as realistic prog-

nosis is not normally the responsibility of any single team member. As such, the team may not recognize the terminal decline in function, cognition and mobility.

**Existing Strategies for Care Planning**

Most published communication strategies for care planning are designed for cancer care. In addition, medical literature detailing how to communicate with patients and their families is not evidence-based, and has not been validated for use in frail older adults with dementia. In light of these shortcomings, randomized trials are needed to determine whether interventions to improve communication about end-of-life care, specifically in frail patients with dementia, can improve patient outcomes.<sup>9</sup>

The current models of communication pose many challenges when implemented in patients with dementia and frailty, including end-of-life care planning, the “ask-tell-ask” model, and the creation of advance directives to guide future care (Table 1).

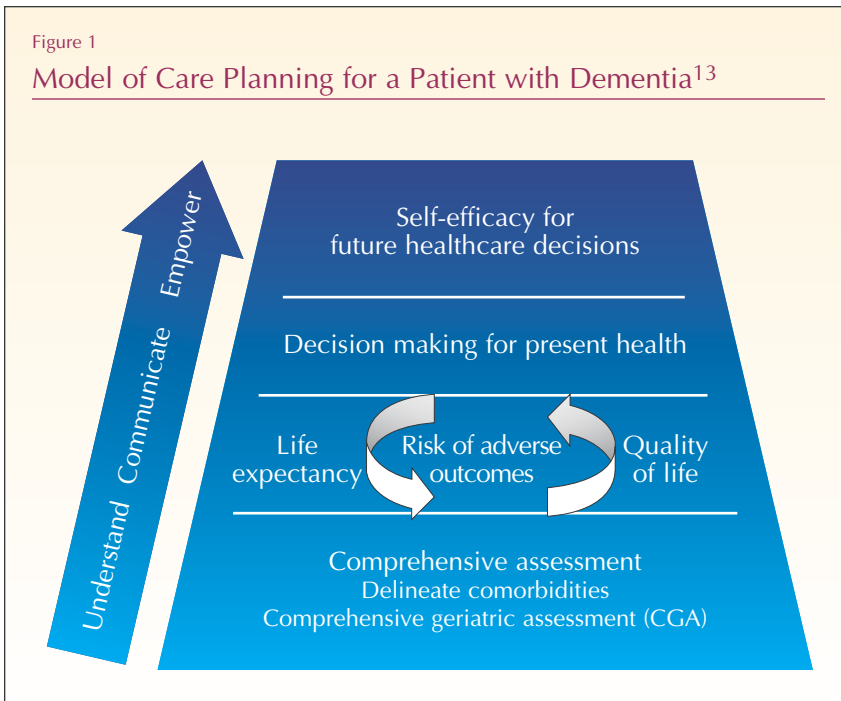
*End-of-life care planning* is frequently discussed when patients have moderate-to-severe stage dementia, and the substitute decision maker is prominently involved in the decision-making process. Traditional models of communication advocate that healthcare professionals begin by gathering information about the patient’s values and goals, and then use this information to contextualize the goals of care,<sup>10</sup> which requires asking questions such as, “What is your biggest fear?” These questions may be difficult for substitute decision makers to answer on behalf of the patient with dementia.

*Ask-tell-ask model.* Many of the recommendations about how to communicate with patients and families advocate that healthcare professionals spend most of the time listening rather than talking, a method also known as the “ask-tell-ask” model.<sup>11</sup> This approach seems patient-centered, but assumes that the substitute decision maker has already been provided with the information needed in order to make a decision, which is often not the case.<sup>12</sup> For frail older adults with dementia, providing infor-



Figure 1

Model of Care Planning for a Patient with Dementia<sup>13</sup>



mation about the prognosis associated with each illness and their sum takes considerable time and is not well remunerated. As such, families may not be aware of the poor prognosis associated with dementia and frailty.

**Guiding future care.** Traditional models advocate the creation of advance directives to help guide future care. Substitute decision makers and care providers alike may be lulled into a false sense of security that the present advance directive will clarify the future goals of care. Although advance directives may be helpful in a single system illness, where the foreseeable decision points and interventions are easier to anticipate, they fall short in those with frailty and dementia whose list of possible scenarios is endless.

Furthermore, commonly used terms, such as “heroic measures,” have different meaning depending on the baseline quality of life (QoL) that they are meant to restore. For exam-

ple, a procedure such as intravenous rehydration that is generally considered routine may be considered a heroic measure in the terminal stages of dementia, where it has a limited chance of improving health, but a significant chance of prolonging death and suffering.

### Meeting the Challenges of End-of-life Care in Dementia

The issues previously described demonstrate the need for better recognition of frailty through systematic evaluation and better communication of the results of such evaluations. The PATH process is a model of care planning for frail older adults with dementia based on four key principles:

1. Research shows that substitute decision makers want detailed information about overall health and prognosis from healthcare providers, even in the face of uncertainty.<sup>13</sup>

2. It is the responsibility of healthcare providers to anticipate and communicate the impact of each health condition on the patient’s overall health, QoL and the risk/benefit of interventions when discussing care-planning decisions.
3. Healthcare decisions should only be made after full disclosure of this information (above).
4. An organized approach to information gathering and provision can help substitute decision makers make informed choices.

These principles were used to develop a model of care planning characterized by three patient encounters: understand, communicate, and empower (Figure 1).<sup>13</sup>

**Understand.** The PATH process begins with an understanding of the full scope of illness severity, achieved through standardized evaluation of health domains encompassed by a comprehensive geriatric assessment (CGA; Table 2).

The CGA has been widely used in geriatric medicine and is associated with improved QoL and survival.<sup>14,15</sup> The assessment helps overcome poor recognition of the need for end-of-life care by providing a macroscopic view of current health and illness trajectory. Information for the CGA is gathered from a comprehensive review of the medical chart, collateral history from a family member or caregiver, physical examination and cognitive testing, including the Mini-Mental State Examination (MMSE),<sup>16</sup> the Frontal Assessment Battery,<sup>17</sup> the Brief Cognitive Rating Scale (BCRS),<sup>18</sup> and the Functional Assessment Staging Tool (FAST).<sup>19</sup>

At the end of the first patient encounter, the PATH assessor meets with the patient and decision maker to briefly introduce the dementia stage and level of frailty, schedules a second encounter to discuss the findings in more detail, and provides educational materials to take home. The educational materials provide patients and their substitute decision makers with the opportunity to review the concepts of dementia, prognosis, frailty and the PATH model through narrative and descriptive writing. If the patient is not able to participate in the decision-making process, the decision maker may participate in subsequent PATH visits on their behalf.

**Communicate.** The second PATH encounter is a structured interview designed to communicate a detailed description of the stage and prognosis of each comorbidity, and subsequently describe how each comorbidity contributes to frailty. Particular focus is given to dementia, as it is a progressive condition and affects the risk/benefit balance of treatment for other comorbidities. The provision of information about dementia staging helps care providers and decision makers achieve a common understanding of where they are in the trajectory of dementia and what to expect in the future. All discussions and decisions arising from these discussions are documented, and copies of care plans arising from decisions are available to take home. This approach differs from traditional models of care planning because the focus is on providing information and allowing the decision maker to express their treat-

Table 2

### The Domains of the CGA<sup>14,15</sup>

- Cognition: memory, executive function, emotion and behavioral symptoms
- Mobility: transfers and ambulation, falls, balance
- Function: instrumental and basic activities of daily living
- Nutrition: appetite, weight loss, bowel and bladder function
- Social situation: living arrangements, formal and informal assistance, and caregiver stress
- Comorbidities
- Medications

ment preferences within the context of overall health and prognosis.

Of note, the encounter may involve intense emotions and catharsis. PATH participants often describe that they are hearing information about disease progression and prognosis for the first time, and although the content of the discussion can be upsetting, almost all participants indicate that the process is useful for future care planning. A nurse-led debriefing session follows the discussion of frailty and prognosis to ensure that decision makers' questions are answered. Further written materials are provided to support the information relayed about dementia staging. Time between the second and third PATH encounter is not always possible, but allows the decision maker to consider the overall health of the patient with dementia and formulate questions for the next visit.

**Empower.** The final PATH encounter is designed to give decision makers the skills needed to make foreseeable and unforeseeable decisions about future care. The session builds upon the first two visits by encouraging decision makers to apply newly learned concepts, such

as frailty, dementia and prognosis, and begins by discussing foreseeable care planning decisions for dementia, including resuscitation, artificial nutrition and hydration, antibiotics and surgery.

The potential effect of each intervention on cognition, mobility, function, symptom control and QoL are discussed within the context of the current dementia stage, as well as projected decline. Care planning decisions for other comorbidities, such as dialysis for chronic kidney disease, are also discussed when applicable. Due to the fact that unforeseen health crises can arise, decision makers are provided with a framework (Table 3) of questions that will help them gather the information they need to make informed decisions in an organized manner. To plan ahead, the framework is applied to hypothetical health crises pertinent to the patient. The framework questions are then provided in a wallet-sized card that can be carried with the decision maker for future use. Furthermore, written narrative materials describing how other decision makers have worked through health crises using the framework

Table 3

## PATH Decision Framework

### Questions to Ask During a Health Crisis

1. Which health conditions are easily treatable? Which are not?
2. How many patients are diagnosed as frail? How will frailty make treatment risky?
3. How can symptoms be safely and effectively managed?
4. Will the proposed treatment improve or worsen function and memory?
5. Will the proposed treatment require time in hospital? If so, for how long?
6. Will the proposed treatment allow more good quality years, especially at home?
7. What can we do to promote comfort and dignity in the time left?

questions are provided. Decision makers are also encouraged to contact their PATH assessor when faced with difficult decisions so that they can work through the framework questions together.

### Implementation of the PATH Model

The PATH process requires active participation and reflection on the part of the decision maker and therefore may not be appropriate for all

decision makers. Currently, we request consent from the patient or decision maker to participate in the process at the time of referral. To ensure communication of the results of the PATH process, a typed summary of each encounter is mailed to the primary-care physician and other pertinent care providers (including specialists), which is uploaded to the patient's electronic medical record, where available.

The PATH model was originally

implemented in an outpatient clinic setting, but has been modified for inpatient consultations in a tertiary care and community hospital, as well as long-term care facilities. The primary variables have been the time allotted for each encounter, the total number of encounters, the support personnel providing initial assessment or debriefing, patient/family satisfaction, and the types of decisions that are made.

**Limitations of the model.** The PATH process has not yet completed formal validation in a randomized control trial, but neither has the current status quo of advising patients to endure complicated medical therapies based on care-planning strategies developed for single-system illness. However, the model is in accordance with recent studies that demonstrate providing information and education about the risks and benefits of intervention can influence decision makers' preferences in a positive way.<sup>20</sup>

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# Caring for Patients with Terminal Alzheimer's Disease

Patients with terminal Alzheimer's disease (AD) are characterized by their inability to communicate verbally and ambulate even with assistance, and by their complete dependence in activities of daily living. Due to a mean survival of one year, interventions that only have a long-term effect and the use of invasive procedures leading to the patient's discomfort may not be appropriate. The goal of care may be overall comfort instead of survival at all costs and maintenance of function. The risks and benefits of any procedure should be considered with this goal of care in mind.

*By Ladislav Volicer, MD, PhD, FAAN, FGSA*

The progression of Alzheimer's disease (AD) can be divided into several stages, most commonly described as mild, moderate and severe. Two more stages (profound and terminal)<sup>2</sup> were added as the severe stage did not have a generally accepted definition, and according to the Clinical Dementia Rating (CDR) scale,<sup>1</sup> patients retained certain functions at this stage.

Patients are defined as having terminal AD when they have no comprehension or recognition, must be fed or require tube feeding, are totally incontinent and bedridden (*i.e.*, not able to ambulate, even with assistance), and are not able to communicate verbally. The median survival of patients in this stage is one

year.<sup>3</sup> Other progressive dementias (*e.g.*, vascular dementia, dementia with Lewy bodies and frontotemporal dementia) may have different symptoms and course than AD. However, once the patient's dementia progresses to the severe stage, the symptoms and clinical problems presented are the same regardless of the initial diagnosis.

It should also be noted that autopsy examinations have revealed more than one pathological process that may cause dementia, including AD and vascular changes, and AD with multiple cortical Lewy bodies. Thus, management of terminal dementia is similar in all progressive dementias. Also, the medical issues of patients with dementia may be divided into three broad categories: chronic conditions, comfort and end-of-life issues, listed in Table 1.

## **Chronic Conditions**

Many patients with terminal demen-

tia suffer from comorbid conditions, such as congestive heart failure, chronic obstructive pulmonary disease (COPD) and diabetes. The prevalence of these conditions is higher in patients with dementia than in cognitively intact elderly patients.<sup>4</sup> Thus, management of these conditions should be modified in terminal dementia. Most important, since these patients are unable to report symptoms of their disease or side effects of treatment, comorbid conditions should be treated conservatively to avoid consequences of overtreatment, such as hypoglycemia.

Due to the fact that individuals with terminal dementia have short life expectancy, interventions that have only a long-term effect, including treatment with cholesterol-lowering agents or restrictive diets, are not appropriate. Any medical intervention causing discomfort, even a routine examination,

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Table 1

## Medical Issues in Terminal Dementia

Chronic Conditions	Comfort Issues	End-of-life Issues
<ul style="list-style-type: none"> <li>• Diabetes</li> <li>• Arthritis</li> <li>• Hypertension</li> <li>• Congestive heart failure</li> <li>• COPD</li> <li>• Malignancy</li> </ul>	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Behavioral symptoms</li> <li>• Environmental factors</li> <li>• Constipation</li> <li>• Pressure ulcers</li> <li>• Shortness of breath</li> </ul>	<ul style="list-style-type: none"> <li>• Cardiopulmonary resuscitation</li> <li>• Transfer to an acute care setting</li> <li>• Treatment of generalized infections</li> <li>• Eating difficulties (tube feeding)</li> </ul>

such as measuring blood pressure, may cause behavioral problems in persons who do not understand the need for this intervention. Before any treatment is initiated or continued, the risks and benefits should be considered and physicians should ask, “Are the intended results of this treatment promoting the goal of care for this patient?”

### Comfort Issues

Since patients diagnosed with terminal dementia are patients with a terminal disease, comfort may be the most appropriate goal of care. Two alternative goals, survival at all costs and maintenance of function,<sup>5</sup> may no longer apply.

In an effort to ensure the patient’s comfort, it should be taken into consideration that even individuals with terminal dementia most often do not progress to a vegetative state where they would not feel discomfort or pain.<sup>6</sup> Physical and psychological comfort should therefore be monitored and maintained until death. These comfort issues include pain, behavioral symptoms, environmental factors, constipation, pressure ulcers and symptoms which mani-

fest during the dying process, such as shortness of breath.

**Pain.** The most common physical symptom that causes discomfort is unrecognized or undertreated pain.<sup>8</sup> It is difficult to identify and measure pain, as well as distinguish somatic pain and general discomfort in an aphasic individual. When any behavioral changes are observed in a patient with terminal dementia, an evaluation for possible pain should be initiated. These behavior changes may include oral vocalization, increased resistiveness to care, restless body movements, crying, changes in appetite, withdrawal, rubbing/holding a body area, facial grimacing, increased confusion or a change in sleep patterns. The listed changes could be due to unmet physical needs (*i.e.*, being hungry, thirsty or cold), unmet affective needs (*i.e.*, environmental stress and/or lack of meaningful human interaction) or somatic pain.

Several observational scales for measuring pain in individuals with advanced dementia have been developed and evaluated,<sup>7</sup> and may help in pain assessment and communication between different care

providers, including nursing assistants, nurses and physicians.

Treating pain in persons with terminal dementia should include non-pharmacologic strategies, such as application of heat or cold compresses, massage, positioning, sensory stimulation and mild exercise.

Pharmacologic management should start with the administration of acetaminophen. If the treatment is not effective, it is best to proceed to oral morphine and to avoid use of non-steroidal anti-inflammatory agents. These agents often cause gastrointestinal side effects that the individual with advanced dementia cannot report. A concentrated solution of morphine can be used even in individuals who have difficulty swallowing as it is absorbed in the oral mucosa. Another option in an individual with chronic pain is the administration of fentanyl skin patches. However, pain management should strive for pain prevention rather than initiation of treatment after pain has already presented. Thus, chronic pain should be treated with regular doses of analgesics with an option of additional doses if needed.

**Behavioral changes.** The management of psychiatric symptoms in patients with dementia is as important for quality of life (QoL) as management of pain in individuals with terminal cancer. Some behaviors are caused by environmental or physical factors, by interaction between patients with dementia and their caregivers, or by the dementing process itself. It is important to first eliminate the possibility that behaviors are due to environmental or physical causes including cold or hot temperatures, noise, and hunger or thirst.

**Resistiveness to care.** The two most common and important behavioral syndromes are resistiveness to care and agitation/apathy. It must be noted that behavioral problems that occur during interactions between an individual with severe dementia and a caregiver are often erroneously labeled as aggression. These outbursts are actually caused by a lack of effective communication between the patient with dementia and their caregiver. The patient does not understand the need for the caregiver's actions and may resist in certain situations, including undressing, bathing, dressing and being put to bed. The behavior presented is in fact resistiveness to care<sup>9</sup> and can escalate into combative behavior.

Furthermore, the patient with dementia may defend him/herself by striking out because they believe the caregiver to be an aggressor. It is therefore important to prevent escalation of resistiveness to care into combative behavior that may result in injury of the caregiver or patient.

The appropriate non-pharmacologic intervention for such a behavior is improvement in communication, delaying the caregiving activity or modifying the caregiving strategy. Another approach is distraction during care, provided by informal discussion or by a planned reminiscence that utilizes remaining long-term memories. The most effective strategy for management of resistiveness to care is modification of the caregiver approaches. This may include changes in an environment, such as making bathrooms more homelike and comfort-

affect the patients behavior.<sup>10</sup> However, it is difficult to diagnose in the terminal dementia stage as the diagnosis must rely on vegetative symptoms.

**Agitation and apathy.** When a patient with dementia is solitary, they often exhibit agitation and apathy. Agitation is a term that is sometimes used to label all behavioral symptoms in dementia, but is better reserved to define behaviors that communicate to others that the patient is experiencing unpleasant state of excitement which remains after interventions to reduce inter-

*Many patients with terminal dementia suffer from comorbid conditions, such as congestive heart failure, chronic obstructive pulmonary disease (COPD) and diabetes. The prevalence of these conditions is higher in patients with dementia than in cognitively intact elderly patients.<sup>4</sup>*

able, or changes in caregiving strategies. The substitution of a bed (or towel) bath for shower or tub bath greatly decreases resistiveness to bathing without adverse hygienic consequences.

Resistiveness to care should also be considered as one of the important indicators of possible presence of depression in the patient with dementia. If other non-pharmacologic interventions are not effective in preventing the escalation to abusive behavior, antidepressants are the first medication class physicians should prescribe. It should be noted that depression is very common in patient's with dementia and is a factor that may

nal or external stimuli have been carried out.<sup>11</sup> Apathy is a condition different from depression resulting from a different pattern of blood flow in the brain. These symptoms often occur in the same individual and are difficult to treat pharmacologically because sedatives used to decrease agitation often increase apathy, whereas stimulants used to decrease apathy often increase agitation. The best treatment approach for agitation and apathy is a provision of meaningful activities.

**Environmental factors.** Patients with terminal dementia may not be able to participate in regular activities because of their cognitive impairment, but they still require

stimulation and should not be isolated in their rooms or sitting in a hallway. These patients benefit from a comfortable environment and presence of others.

One strategy for maintaining QoL, even in the terminal-dementia stage, is the development of Namaste Care.<sup>12</sup> Namaste Care is an enhanced nursing program based in the United States and Sydney, Australia, which provides a room within the care facility where residents with terminal dementia are gathered with the continuous pres-

these patients, they are offered a beverage (*i.e.*, juice, water, smoothies and other high-caloric beverages). The Namaste caregiver also soaks the residents' feet and washes their legs. Range-of-motion exercises are accompanied by music.

In the afternoon, the patients are often visited by their families. The Namaste caregiver will sometimes offer suggestions and may encourage family members to massage residents' hands and arms, or feed them ice cream if choking is not a concern. Family members may also enjoy

includes a high-fiber diet and osmotic laxatives. Stimulating laxatives should be used only occasionally and stool softeners should be avoided because they often are not effective.<sup>14</sup> Enemas are uncomfortable and require more staff time than administration of an oral medication. As the primary goal of care is comfort and preserving dignity, enemas should be avoided.

Finally, the use of oral laxatives, primarily sorbitol, combined with the close monitoring of bowel movements and subsequent changes in dose or frequency as necessary, minimizes the need for rectally administered laxatives, which is especially difficult in patients with dementia who become resistive during care.

**Pressure ulcers**, which are associated with sepsis, are most commonly located on the sacrum, trochanters and heels. A higher prevalence of pressure ulcers was associated with being chairbound or bedridden, underweight and fecal incontinence. Pressure-ulcer associated death is more common in AD patients than in matched control subjects.<sup>18</sup>

A recent study of New York nursing homes found that pressure ulcers were present in 14.7% of nursing home residents with terminal dementia before they died.<sup>15</sup> The study also noted that, on admission from a hospital to a nursing home, 10% of residents already had one or more pressure ulcers, while only 4.7% of residents admitted from home presented with pressure ulcers.<sup>16</sup> It should be noted that several pressure-ulcer-prevention guidelines have been

***The management of psychiatric symptoms in patients with dementia is as important for quality of life (QoL) as management of pain in individuals with terminal cancer. Some behaviors are caused by environmental or physical causes, by interaction between individuals with dementia and their caregivers, or by the dementing process itself.***

ence of a caregiver. The room provides a home-like, pleasant atmosphere with plants, pictures and curtains, low lights and relaxing music.

The patients are placed in lounge chairs rather than a wheelchair to address the comfort issues often present in patients with terminal dementia. If they are not at risk for choking, residents are offered a small lollipop, which helps to keep their mouths moist.

The Namaste caregiver also washes each person's face and brushes their hair while the residents are spoken to about their lives or about the day, as if it were a normal conversation. To help maintain hydration, often a difficult task in

conversing with the Namaste caregiver as many spouses are very isolated when their loved ones are in a nursing facility. Of note, the Namaste caregiver is a nursing assistant who would otherwise take care of the residents in the unit. By gathering the patients with dementia in the same location, the Namaste caregiver is able to offer better individualized care and constant attention.

**Constipation** is very common in patients with terminal dementia, and fecal impaction may even cause death. Constipation may be due to a combination of decreased enteric neurons,<sup>13</sup> medication side effects, and decreased ambulation. The usual treatment for constipation



developed, and adherence to these guidelines results in decreased incidence of pressure ulcers in hospitalized and/or critically ill patients.<sup>17</sup> However, in nursing homes the adherence to these guidelines is relatively low and is characterized by large variations.

**Shortness of breath** may be the most disturbing symptom during the dying process, not only for the patient, but also for family and caregivers. The best way to manage shortness of breath is by administering morphine that will decrease the respiratory drive. Low doses of morphine administered orally are very useful during the dying process because they will not only decrease dyspnea, but also prevent most pain.

### End-of-life Issues

There are several conditions that may be treated by aggressive or palliative medical interventions. The decision about their management should be made by a proxy before any crisis situation. However, to make an informed decision, the proxy must have information regarding the burdens and benefits of these interventions.

**Cardiopulmonary resuscitation (CPR).** The immediate survival of resuscitated nursing-home residents is 18.5 %; only 3.4% are discharged from the hospital alive.<sup>19</sup> The presence of dementia decreases the probability of successful CPR by three times, as only 1% of demented residents suffering cardiac arrest can be expected to be discharged alive from the hospital.

Even this potential benefit may not be desirable in individuals with severe dementia because CPR is a stressful experience for those who survive. These patients may also experience CPR-related injuries, such as broken ribs, and often have to be on a respirator. Patients who are discharged alive from the hospital after CPR are much more impaired than they were before the cardiac arrest. Finally, the intensive care unit environment is not conducive to appropriate care for demented individuals who may

***It must be noted that behavioral problems that occur during interactions between an individual with severe dementia and a caregiver are often erroneously labeled as aggression. These outbursts are actually caused by a lack of effective communication between the patient with dementia and their caregiver.***

experience worsening confusion and often develop delirium.

**Transfer to acute care setting.** The transfer of demented individuals to an emergency room or hospital exposes them to serious risks. Even cognitively intact hospitalized elderly individuals develop depressed psychophysiological functioning that includes confusion, falling, not eating and incontinence. These symptoms are often managed by medical interventions, such as psychotropic medications, restraints, nasogastric tubes, and urinary catheters, which expose the patient to possible complications, including thrombophlebitis, pulmonary embolus, aspiration pneumonia, urinary

tract infection and septic shock. A hospital admission may not be necessary for treatment of pneumonia and other infections because six-week mortality is lower in residents treated in nursing homes than residents treated in hospitals.<sup>20</sup> Thus, transfer to an acute care setting should be used only when it is consistent with the overall goals of care and not as a default option.

**Treatment of generalized infections.** Effectiveness of antibiotic therapy is limited by the recurrent nature of infections in advanced dementia.

Antibiotic therapy does not prolong survival in cognitively impaired patients who are unable to ambulate even with assistance and who are mute.<sup>21</sup> Antibiotics are also not necessary for maintenance of comfort in demented individuals because their comfort can be maintained equally well with analgesics, antipyretics and oxygen, if necessary.<sup>22</sup>

In addition, antibiotic use is not without adverse effects. Patients may develop gastrointestinal upset, diarrhea, allergic reactions, hyperkalemia, agranulocytosis, and *Clostridium difficile* infection. Diagnostic procedures, including blood drawing and sputum suctioning necessary for rational use of antibi-

otics, can cause discomfort and confusion in demented individuals who do not understand the need for the procedure. Thus, the decision to administer antibiotics to patients with advanced dementia should take into consideration the recurrent nature of infections caused by persistent swallowing difficulties, aspiration and other factors predisposing these patients to the development of infections.<sup>23</sup>

**Eating difficulties.** Patients with terminal dementia are unable to feed themselves and often develop swallowing difficulties that provoke choking on food and liquids. They may also start refusing food by not opening their mouth when they are fed. Of note, choking and food

refusal are often exhibited simultaneously. Swallowing difficulties and choking may be minimized by an adjustment to the texture of the patient's diet, and by replacing thin liquids with thick ones (*e.g.*, yogurt instead of milk). Food refusal often responds to administration of antidepressants or appetite stimulants.<sup>24</sup>

There is no evidence that long-term feeding tubes are beneficial in individuals with advanced dementia. Tube feeding does not prevent aspiration pneumonia and actually might increase its incidence because it does not prevent aspiration of nasopharyngeal secretions and of regurgitated gastric contents. Tube feeding also does not prevent occurrence of other infections.

Nasogastric tubes may cause infections of sinuses and middle ear, and gastrostomy tubes may cause cellulitis, abscesses and even necrotizing fasciitis and myositis. The imbalance between burdens and benefits justifies a recommendation that tube feeding generally should not be used in individuals with advanced dementia.

### Conclusions

In conclusion, the management of terminal dementia should have as its main goal the maintenance of the overall comfort of the patient. Thus, aggressive medical interventions should be limited and emphasis should be placed on palliative care interventions.

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# Pre-dementia Diagnosis of Alzheimer's Disease

Discussed at the 11<sup>th</sup> International Geneva/Springfield Symposium on Advances in Alzheimer Therapy, the Dubois criteria were praised for their potential usefulness in helping improve the ability of physicians to diagnose Alzheimer's disease (AD) before the onset of dementia with clinical and laboratory tests. However, since their introduction, the criteria have been restricted to clinical research settings as there is still a need to determine their validity in diagnosing patients with probable AD.

*By Serge Gauthier, MD, CM, FRCPC; and Antoine Leuzy, BSc*

The diagnosis of Alzheimer's disease (AD) has traditionally required clinical evidence indicating the presence of dementia, defined by a significant decline in two or more cognitive domains with attendant disruption of daily life,<sup>1</sup> followed by a differential diagnosis as to the most likely cause. While the criteria of probable AD<sup>2</sup> have helped to refine the condition's diagnosis and promote encouraging developments on the therapeutic front (*i.e.*, randomized trials and cohort studies), the criteria

require that dementia be clinically apparent before the diagnosis of AD.

It has also been observed that certain patients reporting cognitive symptoms, typically relating to memory and measurable cognitive decline, transition to AD within two to five years despite not showing functional impairment. Patients with this clinical ensemble are said to suffer from mild cognitive impairment (MCI), a syndrome comprised of a heterogeneous group of conditions, which may be reversible, stable or progressive.<sup>3</sup> However, due to its status as a non-specific disorder, regulatory agencies, including the U.S. Food and Drug Administration and Health Canada, are unwilling to approve drugs that would be used to treat MCI, and the diagnosis of this condition does not have specific indications for pharmacologic treatment.

In terms of arresting the progression of AD, the drugs currently under development aim to modify pathophysiological mechanisms, such as A $\beta$

deposition and tau hyperphosphorylation. To date, such drugs have not proved effective in treating mild-to-moderate stages of AD, which has raised the possibility that such interventions may be effective primarily, if not exclusively, in the earlier, pre-dementia stages of the disease before the prominence of cerebral atrophy.

These considerations have led to the creation of a work group led by Drs. Bruno Dubois and Philip Scheltens, whose 2007 position paper outlined the criteria to help diagnose early AD.<sup>4</sup>

## The Dubois Criteria

During the 11<sup>th</sup> International Geneva/Springfield Symposium on Advances in Alzheimer Therapy, held from March 24 to 27, 2010, in Switzerland, the "Dubois criteria," as they were dubbed by the international community, were praised for their potential usefulness in the pre-dementia diagnosis of AD. The criteria are grouped into two categories: clinical and lab-

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Table 1

## Dubois Criteria Summary<sup>4</sup>

### Clinical Diagnostic Criteria

Presence of an early and significant episodic memory impairment that includes:

1. Gradual and progressive change in memory function reported by patients and/or family or friends over a six-month period.
2. Objective evidence of significantly impaired episodic memory on testing, such as a recall deficit, that does not improve significantly with cueing or recognition testing.
3. Episodic memory impairment that can be isolated or associated with other cognitive changes.

### Supportive Laboratory Criteria

The patient presents with abnormalities in one or more of the following:

1. Medial temporal atrophy on MRI.
2. Low CSF A $\beta$ 42, high tau or phospho-tau levels.
3. Functional imaging showing reduced glucose metabolism in bilateral temporal parietal regions (FDG-PET) or increased amyloid uptake using amyloid ligands, such as Pittsburgh compound-B (PIB-PET).
4. Proven AD (presenilin or amyloid precursor protein [APP]) autosomal dominant mutation within the immediate family.

oratory (Table 1).<sup>4</sup> The clinical criteria consists of subjective memory complaints, as well as a measurable decline in working memory that remains unimproved despite the assistance of the clinician in the form of cueing. The supportive laboratory criteria consists of brain scans and tests, including magnetic resonance imaging (MRI), positron emission tomography (PET), cerebrospinal fluid (CSF) or genetic abnormalities.

The introduction of these revised criteria for pre-dementia diagnosis of AD by Drs. Dubois and Scheltens has so far been restricted to clinical research settings. There is still a need to determine their validity and which tests would prove most sensitive as indexed by the patient's progression and type of dementia. The question of

whether more than one test would be required to increase the certainty of this diagnosis remains unanswered.

### Following the Publication of the Dubois Criteria

Investigators and regulators alike have recognized that the Dubois criteria offer the possibility of identifying at least one condition from among the many subsumed under the category of MCI that would prove amenable to therapeutic investigation. In addition, some clinicians are better able to treat patients they suspect as having mild AD as it can now be diagnosed prior to the onset of dementia. However, a note of caution was raised about the risk of false positives<sup>5</sup> and of catastrophic reactions in patients with probable AD who are

fully aware of the meaning of such a diagnosis.<sup>6</sup> These and other ethical issues regarding early diagnosis of AD have been illustrated in published case studies.<sup>7</sup>

New data suggest CSF abnormalities—specifically lower levels of A $\beta$ 42 and higher levels of tau protein—precede changes noted in the Pittsburgh compound-B (PIB)-PET and fluorodeoxyglucose (FDG)-PET, as well as medial-temporal and whole-brain atrophy.<sup>8</sup> Furthermore, medial-temporal atrophy is less specific to AD relative to other laboratory markers. This may require the implementation of a system whereby laboratory findings will possess differential weighting in terms of diagnostic validity. Indeed, some reports suggest that a combination of two abnormal markers carries more weight vis-à-vis the diagnosis of AD.<sup>9</sup> The practicality and consequences of using the Dubois criteria in the absence of established treatment have been examined in the case studies by Frisoni et al.<sup>10</sup>

Some clinicians have already proposed the introduction of modifications to the Dubois criteria to help find subjects with mild memory symptoms and no measurable cognitive decline, yet who present with abnormal laboratory tests specific for AD, including CSF A $\beta$  reduction and/or increased PIB uptake on PET. Once identified, these patients would be invited to participate in preventive clinical trials where reversibility of the biomarkers, as well as the delay of clinical progression, are viewed as equally important. The recent finding that PIB uptake can be reduced by

immunotherapy against A $\beta$ 42 suggest that this may be feasible,<sup>11</sup> although most investigators will favor clinical improvement over reversal of laboratory abnormalities as the main treatment goal.<sup>5</sup>

### The Dubois Criteria and AD Research

The ability to diagnose AD in a pre-dementia stage may increase the response to disease-modifying drugs because neuronal cell loss has not yet reached a critical level. Placebo treatment arms can be used until dementia is clinically evident, since there are no proven therapies at that stage of AD. Delaying time to dementia would offer high face validity as an outcome, facilitating acceptance of regulators, payers and users.

### The Dubois Criteria and Clinical Practice

At the clinical level, the revised criteria will make it possible to diagnose AD in its earliest stages, an important realization, especially for those in certain professional positions. For instance, physicians, pharmacists, lawyers, and those handling investment

portfolios may not be able to make decisions reliably even in the pre-dementia stages of AD. Thus, an early diagnosis of AD would make it possible for an early retirement with full benefits due to a medical disability.

With an increase in self-referrals to our memory clinics from persons at risk of AD—due to a family history of AD, with or without early memory and executive-type symptoms—these criteria offer a framework where a work-up can be made, with attention paid to the risk of catastrophic reaction, which could be preempted using a check-list designed for disclosure of genetic findings, such as ApoE4 carrier status.<sup>12</sup>

The cost of these additional laboratory tests and related procedures remains to be determined, relative to current standard treatment for AD at the dementia stage. Furthermore, spinal taps are not routinely conducted in Canadian memory clinics, and as such their introduction will require comprehensive and sensitive explanations for patients, as well as the acquisition of new skills on the part of the physician. A central laboratory will likewise have to be estab-

lished to oversee the analysis of CSF for A $\beta$  and tau protein.

If the number of persons presenting for consultation due to concerns of early AD is high, this will further dilute the already limited human resources (*i.e.*, nurses, neuropsychologists and physicians) currently available to attend to the needs of persons with dementia and their families.

### Conclusions

The introduction of the Dubois criteria to help facilitate the diagnosis of AD in the pre-dementia stage marks a turning point in the history of AD therapy, as they will help with a more specific diagnosis of AD than is currently possible with the current clinical criteria and accompanying non-specific laboratory tests. However, the revised criteria require further validation in order to properly determine their positive predictive value. Finally, their widespread adoption will impact the resources currently available for treatment, and as such it is of chief importance that their implementation remain confined to clinical-research settings until existing questions have been answered.

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## News from the Alzheimer Society of Canada

### Turning the Rising Tide of Dementia

In January 2010, the Alzheimer Society of Canada released *Rising Tide: The Impact of Dementia on Canadian Society*. This new report reveals that Alzheimer's disease (AD) and related dementias are already the leading cause of disability among seniors. As the first wave of Canada's 10 million baby boomers turn 65, an enormous number of people will be at an increased risk of this disease in the coming decades. In fact, if nothing changes, *Rising Tide* estimates there will be more than 1.1 million people in Canada living with dementia by 2038.

Even more troubling, the report estimates approximately 70,000 Canadians under the age of 65, specifically those in their 40s and 50s, will also be affected. If not mitigated, the prevalence of dementia will create an increase in the demand for long-term care beds and cost the Canadian economy a staggering \$153 billion annually.

"Today, someone in Canada develops dementia every five minutes. In 30 years, there will be one new case every two minutes," says Kelly Duffin, CEO of the Alzheimer Society of Canada. "This sharp increase in the number of people living with dementia will amount to a massive cumulative total of \$872 billion over a 30-year period."

#### Strategies To Help Alleviate the Pressure of Dementia

**Promoting brain health.** Recognizing the urgent need to start turning the tide of dementia, the report outlines a series of potential interventions that could help alleviate the pressure of dementia on families, the health-care system and the Canadian economy. One of the four

proposed interventions looks at the benefits of delaying the onset of dementia in people by two years. The scenario in the report outlines if people aged 65 years or older engage in activities and a lifestyle promoting brain health, including eating brain-healthy foods, doing brain-healthy activities, such as puzzles or learning a new language, and staying socially active, the intervention alone could potentially save Canadians \$219 billion over a 30-year period.

**Exercise.** Another intervention strategy outlined in the *Rising Tide* report is increased physical activity. Exercise is one of the most documented risk-reduction strategies for dementia well supported by scientific evidence. If Canadians older than 65 years who are already moderately to highly active increase their level of exercise by 50 percent, they could reduce their risk of developing dementia, as well as reduce the pressures on long-term care and direct health costs.

**Caregiver support.** However, if nothing changes, the report stipulates the amount of time Canadians spend caring for spouses or family members with dementia will triple in the next three decades to 756 million hours per year. To help prevent this projected outcome, the Alzheimer Society proposes establishing a caregiver development and support program. The program would reduce the amount of caregiving time provided by informal caregivers, as well as the health and economic burden placed on them. It could also delay the admission of a person with dementia into a long-term care facility, further reducing pressures on facility resources, and help cut health costs.

**Additional support.** The fourth intervention outlined in the report is a strategy which involves intro-

ducing a system navigator or case manager who would help each newly diagnosed person with dementia and their caregivers get the best support when navigating through the healthcare system. This strategy could help cut health costs by delaying admission to long-term care facilities and reducing the pressure put on those resources.

### **The Alzheimer Society's Efforts**

As the national voice for people affected by dementia, the Alzheimer Society is at the forefront of efforts to help turn the tide of dementia. The Society is taking an active role by:

- Advocating the development of a national strategy to address dementia at all levels of government, and working with the neurological community in its efforts to affect policy change.
- Educating Canadians about the importance of prevention, early diagnosis and looking after their brain health.
- Continuing to invest in dementia research and to support increases in research funding.
- Providing support and education to people living with dementia, their caregivers and their families.

The Alzheimer Society is also asking Canadians to continue to champion the fight against dementia by taking care of their brain health, encouraging their federal and provincial governments to take action, and by making a donation to support critical research. To

download a copy of the *Rising Tide* report or to learn more about the Alzheimer Society, please visit [www.alzheimer.ca](http://www.alzheimer.ca).

### **10 by 20: Ontario's Action Plan for Dementia**

In March 2010, the Alzheimer Society of Ontario released another report based on the figures from *Rising Tide* that further detailed the impact and number of people affected in Ontario. The report *10 by 20: Ontario's Action Plan for Dementia* includes a comprehensive 10-step plan to improve the quality of care for families facing dementia, as well as curb the province's healthcare spending.

The report appeals to our provincial and federal leaders to make dementia a healthcare priority and offers a framework to help people with dementia and their caregivers, as well as healthcare funders and the general public who are looking for ways to reduce their risk of developing the disease. The Ontario report focuses on:

- prevention, earlier diagnosis and intervention;
- accessible and equitable caregiver support;
- a coordinated, seamless, and better-trained dementia workforce;
- greater research investments toward treatment and a cure; and
- leadership from the Ontario government.

To learn more about Ontario's report, please visit [www.alzheimeront.org](http://www.alzheimeront.org).

*The Alzheimer Society is the leading, nationwide health organization for people affected by dementia in Canada. The Society is a principal funder of Alzheimer research and training, provides enhanced care and support to people with the disease, their families and their caregivers, while acting as a prominent voice in the call for policy change within all levels of government. Active in more than 140 communities across Canada, the Alzheimer Society is also at the forefront of worldwide efforts to fight dementia as a founding member and affiliate of Alzheimer's Disease International.*

*For more information on Alzheimer's disease or related dementias, Alzheimer Society programs or to support the Alzheimer's Advocacy campaign, contact 1-800-616-8816 or visit the Society's website at [www.alzheimer.ca](http://www.alzheimer.ca).*