Alzheimer Society
ONTARIO

POSITION PAPER ON
THE CASA VERDE JURY RECOMMENDATIONS

SEPTEMBER 2005

Alzheimer Society of Ontario
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THE ALZHEIMER SOCIETY OF ONTARIO
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INTRODUCTION

In 2001, a 74-year-old male resident with dementia beat two other residents to death with a metal bar in the Casa Verde Long Term Care Home in North York. The incident led to a Coroner's Inquest with five jurors. In April 2005, their work was concluded resulting in 85 recommendations being targeted to various organizations involved with long term care homes including the Ministry of Health and Long Term Care.

The Alzheimer Society of Ontario has been in existence for 25 years and is a widely respected source of expertise on dementia. Collectively each year the Alzheimer Society and its chapters provide $21.5 million worth of services across Ontario

The Alzheimer Society's mandate is to provide support and education to those with dementia, including the 60-80% of residents in long term care homes who have some form of cognitive impairment. We worked hard to support the Casa Verde Inquest by providing resources and by providing recommendations for key witnesses.

The Coroner's jury in the Casa Verde case provided 85 recommendations which are aimed at reforming a long-term care system which is unable to meet the needs of persons with dementia. Specific recommendations were made which involve changes within Ministry of Health & Long-Term Care (MOHLTC), The College of Physicians and Surgeons of Ontario, The Community Care Access Centre, Regulatory Colleges which set standards for practice, and roles of health care professionals and non-regulated staff employed in long-term care homes.

Although there have been some changes noted within recent months in the delivery of care such as increased funding for more professional and front-line staff, there is no standard model of care that has been defined as being appropriate for the dementia population, which would include training, staff – resident ratios, application process and appropriate placement and performance indicators. There have been a number of initiatives from a public policy perspective as well as pilot activities and programs and services that have been developed through various organizations in Ontario that have begun to address some of the issues in the Coroner's report. However, these activities are being delivered in isolation and are sporadic in their effect.

While the Coroner's report addresses complex and behaviorally difficult residents, there is a danger that all persons with dementia will be painted with the same brush. The implication is that all persons with dementia are violent which is simply not the case. Further, each of us has the potential to become aggressive faced with anxiety, fear, frustration or anger. An appropriate framework for care would recognize these emotions as normal and build supportive environments to understand and reduce them in a pro-active manner rather than address the behaviour through problem solving methodologies after a label of aggression has been assigned. Given that 60-80% of residents in long term care homes have cognitive impairment, this suggests the need for a transformation of long term care homes along with the development of specialized units within them, where possible.

Recommendation #2 actually addresses the issue of stigma and how to alleviate it. The Alzheimer Society of Ontario would be pleased to work with the Ontario Seniors' Secretariat on decreasing this stigma since one of its goals is to increase public awareness and education on all aspects of dementia.

Recommendation #22 is aimed at developing specialized facilities to care for those with dementia or for cognitively impaired residents exhibiting aggressive behaviour. We support specialized **units** within long term care homes where those with "the most difficult behaviours" can be cared for in the most appropriate way. Research in some facilities such as at the Adards Home in Australia, has shown that residents with the most difficult behaviours cared for in a specialized environment can often be transferred within 12-14 months to a regular long term care home unit. We recognize that it may not be physically possible for some long term care homes to have a specialized unit and we would therefore suggest a systems approach to ensure that at least a certain number of specialized units exist within a certain geographical area.

PURPOSE OF THIS PAPER:

The Coroner's report is a call for a plan (or "Framework") to ensure appropriate standards, funding, tracking and accountability in Long-Term Care". We support this recommendation because we believe a framework is needed to be in place in order to support resulting changes that will develop. We are requesting that an Inter-Association Task Force be convened at the earliest possible moment with representatives from The Ministry of Health & Long-Term Care and all relevant provincial agencies. The mandate of this group would be to study the issues and propose a framework for dementia care, inclusive of standards and/or policies in the following areas.

We believe that the Inter-Association Task Force will establish a partnership with common goals which will ultimately strengthen the government's commitment to effect change in long-term care and would ensure the safety of one the most vulnerable groups of our society.

BACKGROUND

The prevalence of dementia is expected to rise as the general population ages over the next decade. While Alzheimer Disease generally affects those over the age of 65 years, people in their 40s and 50s can also be affected.

- In Ontario today, about 140,000 people have Alzheimer Disease or related dementias. That number will likely double to 307,000 in the next 25 years.
- 364,000 Canadians over 65 have Alzheimer Disease or a related dementia[i]
    - 247,520 women
    - 116,480 men
- It is estimated that 60 – 80% of residents in long-term care have some form of dementia

Alzheimer Disease, the most common form of dementia, is a progressive, degenerative disease of the brain. It affects the person's ability to understand, think, and remember. The progressive deficits in memory, language, attention, insight, abstraction, judgement, perception, visual-spatial relationships and motor organization all contribute to the decreasing ability to express feelings or use logic in solving problems. Proposed models of care within the new framework must be supportive compensating for these deficits within the day to day framework of care.

Behavioural symptoms occur in up to 90% of patients with dementia with 50 – 85% of patients showing agitation with worsening cognitive function. Agitation, broadly defined to include aberrant motor behaviour and physical or verbal aggression, poses a major clinical challenge. As dementia progresses, agitation worsens.[ii] The reasons for this worsening of agitation may be varied. In the assessment, a medical condition may be responsible for causing or bringing out the behaviour, especially delirium. Research has shown that unmet needs, learning/behavioural issues, and environmental vulnerability/reduced stress-threshold will contribute to agitation.[iii] It is important to be able to assess and reverse aggravating factors. Residents with dementia, especially those with complex behavioural presentations, need a thorough holistic assessment. This requires enough trained staff to be able to assess and communicate findings into a plan of care. Adequate trained staffing, and sufficient time and resources are needed in long-term care homes in order to assess, plan, intervene and evaluate the care provided.

Since 2001, when the tragic incident in Casa Verde occurred and 2005 when the results of the coroner's jury were made known, there has been growing concern about safety and standards within the long term care sector. These concerns are expressed in the following:

- In 2001, PricewatersCoopers study of long term care in ten jurisdictions (including three Canadian provinces, four U.S. states and three countries in Europe) ranked Ontario last in meeting the needs of residents in long term care facilities.
- In the *Commitment to Care: A Plan for Long-Term Care in Ontario* prepared by Monique Smith, Parliamentary Assistant, MOHLTC, Spring 2004, it states that "a revolution is underway within long-term care" and that the government is committed to action. [iv]
- *The National Advisory Council on Aging: Alzheimer Disease and related dementias* paper published in October 2004 called for specific recommendations addressing funding levels, standards, staffing ratios and training in dementia care. [v]

CURRENT PICTURE

Ontario's Strategy for Alzheimer Disease and Related Dementias 1999 – 2004, has resulted in the development of some important initiatives which continue to provide support to the system today. Some of these initiatives are:

- Public Education Coordinators
- Physician training
- Psychogeriatric Resource Consultants
- Staff training (P.I.E.C.E.S., U-First, Dementia Studies etc.)
- Formation of Dementia Networks

Through Dementia Networks, the voice of those with dementia as well as those who provide care is heard and programs and services have been developed to fill some of the gaps.

- An example of this is Family Physician education. Throughout Ontario, family physicians are accessing dementia training on a continuing education basis which is improving their assessment skills as well as management options.

- In Eastern Ontario, a Transitional Care Program is being piloted which is aimed at bridging the transition, for the individual and family, between community and acute-care to long term care.
- A Position Paper on Dementia Education was developed in January 2005 and has received wide-spread support throughout Dementia Networks in Ontario.
- The Dementia Network in Toronto has developed a mapping program of services which assists individuals and care providers in understanding and accessing the services and supports available.

Throughout the province, where there are champions to mobilize issues forward, grassroots organizations have developed projects in order to fill a "gap" in the system.

The Alzheimer Society of Canada has developed the Enhancing Care Program which is widely used across Ontario and other provinces. This multidisciplinary team assessment program assists staff to identify within their own long term care home how to enhance the care provided from individualized assessment to a comprehensive plan of care including environmental and programming supports. It is a comprehensive approach which promotes team work and supports staff in identifying the need for enhancing the care they are providing.

Other organizations have developed position papers and are calling for system changes. One such group is The Ontario Association of Non-Profit Homes and Services for Seniors in their paper, "Mental Health Issues and Long Term Care". [vi]They are advocating for better assessment tools, more coordinated services across the system, more resources to support creative models within communities, increased funding to support the needs of those with complex mental health issues.

All of us have learned that the best way to move things forward is through a collaborative approach; one that is proactive, not reactive; one that looks at the whole picture to identify the issues and test solutions. The change process must become a partnership with a common goal that we all move toward.

The Coroner's report and its 85 recommendations are an impetus for change. Mandatory training, increased staffing, comprehensive assessment, better communication, increased funding are all excellent recommendations and are consistent with the messages that have been heard before. However, if these recommendations are enacted upon without the presence of a framework to support them, then we will not be any further ahead. Persons with dementia need to be supported in a caring dignified environment with opportunity for meaningful engagement in activities tailored to their strengths. More Registered Nursing time does not mean less incidents of aggression. A cultural transformation is needed within the long term care sector. It is now time to take all the messages, all the recommendations, all the position papers, all the letters that have been sent to the Ministry advocating for change, and develop a framework for a new long term care system that will support the needs of persons with dementia. And by so doing, staff will be better prepared to care for those with complex care needs and quality of life will be improved.

CALL TO ACTION

Quality care is assured when there is adequate funding and when accountability mechanisms are in place and quality standards are enforced through inspection and compliance activities and where the need s and preferences of the residents are reflected in the standards. [vii]

In order to achieve this, we believe that an Inter-Association Task Force should be convened at the earliest possible moment to identify the issues and develop standards and policies for:

- Appropriate assessment for long term care home placement
- Role of Community Care Access Centres (CCACs)
- Continuum of care
- Models of care that are appropriate for the dementia population
- Appropriate mandatory levels of dementia training for all staff
- Hiring, screening and performance review practices that are suitable for this population
- Basic funding levels that reflect the true care required for residents with dementia
- Evaluation of the framework to ensure its efficacy for the resident, the family, the staff and the funding formula.

The members of the Inter-Association Task Force could include representatives from the Ministry of Health and Long Term Care (MOHLTC), the Ministry of Training, Colleges and Universities, The Ontario Association for Non-Profit Homes and Services for Seniors, the Ontario Long Term Care Association, The Ontario Community Care Access Centre, the Ontario Hospital Association, the College of Family Physicians of Ontario, the Alzheimer Society of Ontario, the Regional Geriatric Assessment Programs, The Registered Nurses Association of Ontario, The Registered Practical Nurses Association of Ontario, The Advocacy Centre for the Elderly and the Ontario Geriatric Psychiatry Association.

In order to accomplish this, the Alzheimer Society of Ontario would be willing to help the Ministry of Health to identify the partners, to draft Terms of Reference for such a Task Group and to do whatever it takes to move this initiative into action.

What took place at Casa Verde was a tragedy. We need to do everything we can to prevent this tragedy from occurring again.

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[iv] The Ministry of Health and Long Term Care; Commitment to Care: A Plan for Long-Term Care in Ontario. Prepared by Monique Smith, Parliamentary Assistant, Ministry of Health and Long-Term Care Spring 2004

[v] The National Advisory Council on Aging Position on Alzheimer Disease and related dementias October 2004

[vi] Mental Health Issues and Long Term Care, Ontario Association of Non-Profit Homes and Services for Seniors January 2005

[vii] The National Advisory Council on Aging Position on Alzheimer Disease and related dementias October 2004