

**ALZHEIMER DISEASE &
OTHER DEMENTIAS**



**Strategic Directions
in
Healthy Aging
and Continuing
Care in Alberta**

JULY 2002

Alberta
HEALTH AND WELLNESS

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SUMMARY

Alzheimer disease is the leading cause of dementia and has a devastating impact on individuals and their families. The disease is a progressive and degenerative brain disorder that affects an individual's mental and physical abilities and behavior by destroying vital brain cells.

In the year 2000, it was estimated that 24,040 Albertans sixty-five years and older had a diagnosis of Alzheimer disease or other dementias. The majority (66 per cent) were women with mild, moderate or severe dementia (Ian McDowell, 2001). As estimated at the national level, the number of Albertans with a diagnosis of Alzheimer disease and other dementias will triple between the years 1991 and 2031, with 1,400 new cases of dementia annually in the population eighty-five years and older.¹ The total number of Albertans with dementia is comprised of 6,940 (40 per cent) individuals with mild dementia, 9,430 (39 per cent) with moderate dementia and 7,670 (21 per cent) with severe dementia.

To date, there is no cure for dementia or Alzheimer disease, but the symptoms of individuals with mild and moderate dementia are being successfully managed by new drug interventions and other treatments, allowing them to remain in the community. This trend suggests the need to shift and increase service and delivery options from facility-based to community-based and supportive housing services.

The Canadian Study of Health and Aging estimated that in 1994, the annual net economic cost of dementia was at least \$3.9 billion, which represented 5.8 per cent of Canada's total health care costs. The most significant component cost was care in long term care institutions and for assistance with activities of daily living by professionals, family and friends in the community. These costs are predicted to escalate to over \$12 billion by the year 2031. The economic burden of dementia is significant not only for individuals with dementia, their families and friends, but also for society.

The prevalence of Alzheimer disease and other dementias is primarily related to older adults. With Alberta's growing and aging population, the Government of Alberta, through the Long Term Care Policy Advisory Committee, final report entitled *Healthy Aging: New Directions for Care*, (Broda report), recognized the significance of the population projections for senior Albertans with Alzheimer disease and other dementias.

¹ Ian McDowell, (2001) Special Projections prepared for the Working Task Group.

Strategic Directions and Future Actions: Healthy Aging and Continuing Care in Alberta was government's response to the recommendations in the Long Term Care Policy Advisory Committee's final report.

In November 2000, an Alzheimer Disease and Other Dementias Working Task Group was formed. The Task Group was composed of members with expertise in a variety of areas associated with dementia, such as geriatricians, registered nurses, education specialists, managers, planners, advocacy groups and caregivers.

The mandate of the group was to develop a reference document with information and advice from international and national experts for regional health authorities (RHAs), to assist them in the preparation of their Ten-Year Continuing Care Strategic Service Plans. The goal is to improve and enhance the quality of life for Albertans with Alzheimer disease and other dementias, their family and friends while living with a devastating disease.

The Working Task Group developed six themes embracing quality dementia care that focus on quality of services and program delivery across the continuum of care. The themes were developed following an information gathering process that included a review of the literature and extensive consultation with national and international experts in the field. The working group also received feedback from public consultations held in the regions with client groups and their families. The six themes are as follows:

- Public awareness;
- Education and training;
- Support for informal caregivers;
- Service delivery across the continuum of care;
- Supportive environments; and
- Ethical issues.

Each of the themes contains proposed strategies for achieving the desired outcomes. These strategies are outlined in the body of the report. From the proposed strategies, the working task group identified the following six key priority areas:

- **Public awareness:**
Albertans should have an increased awareness and understanding of Alzheimer disease and other dementias.
- **Guidelines:**
Guidelines should be in place for the care of clients with Alzheimer disease and dementia for all service areas. It should also cover any gaps that currently exist across the continuum of care, such as special care units and unregulated service providers.
- **Support for informal caregivers:**
Informal caregivers providing care for an Albertan with Alzheimer disease or other dementias should have access to education and support.
- **Service delivery across the continuum of care:**
Community care service packages should be developed or expanded upon, in order that service areas are linked and accessible in the community. This includes a broader client assessment based on unmet needs (physical, mental and behavioral) of clients and their families, for example, respite (day and night), day programs and assisted living.
- **Supportive environments:**
The provision of small residential care-like settings, including the client's own home, should be considered as a possible service options utilizing best practice design and layouts.
- **Education and Training:**
Health professionals, including physicians, non-health professionals and dementia care service providers, should have the appropriate skills and knowledge in the delivery of services.

The intent of this document is to provide information and advice to key stakeholders for the planning of continuing care services for this special population. This document will be made available to the following individuals and organizations:

- All government departments, in particular Alberta Health and Wellness, Alberta Seniors, Alberta Community Development, Alberta Learning and Alberta Infrastructure;
- Health authorities, physicians and other health providers; and
- Other agencies directly involved in the provision of dementia care services, community partners such as the Alzheimer Society of Alberta, housing providers and interested individuals from the public.

CHAPTER ONE

Introduction

Alzheimer disease and other dementias are a societal issue that impacts every aspect of a person's life, including their family and friends. Albertans need to be informed about this disease, and services will need to be targeted and coordinated through partnerships with community agencies, if the needs of the individual and their caregivers are to be met and if quality of life and care are to be provided to Albertans with dementia.

The number of Canadians with Alzheimer disease or other dementias continues to increase each year. Currently, at a national level, one out of every thirteen senior Canadians has a diagnosis of dementia, while a third of Canadians eighty-five years and older have Alzheimer disease or some form of dementia. Population projections by the *Canadian Study of Health and Aging* suggest that by the year 2031, the number of Canadians with dementia and Alzheimer disease will triple to 778,000 and 509,000 individuals respectively (Ian McDowell, 2001).

In the year 2000, it was estimated that 24,040 Albertans sixty-five years and older had a diagnosis of Alzheimer disease or other dementias. This number is comprised of 6,940 (40 per cent) individuals with mild dementia, 9,430 (39 per cent) with moderate dementia and 7,670 (21 per cent) with severe dementia. Of the estimated total number (24,040) of Albertans with dementia, the majority (66 per cent) are women with mild, moderate or severe dementia (Ian McDowell, 2001). As estimated at the national level, the number of Albertans with a diagnosis of Alzheimer disease and dementia will triple between the years 1991 to 2031, with 1,400 new cases of dementia annually in the population eighty-five years and older.²

To date, there is no cure for dementia or Alzheimer disease, but the symptoms of individuals with mild and moderate dementia are being successfully managed by new drug interventions and other treatments that allow individuals diagnosed with this disease to remain in the community. This trend suggests the need to shift service delivery options for this special population from facility-based to community-based and supportive housing services.

² Ian McDowell, (2001) Special Projections prepared for the Working Task Group.

Dr. Alois Alzheimer, a German physician, first described Alzheimer disease in 1906. He found abnormal changes in the structure of the brain in the form of neurotic plaques outside neurons that formed cell breakdown, and neurofibrillary tangles inside the neurons. This damage interferes with the functioning of brain cells and the passage of nerve impulses between brain cells. Consequently, messages get mixed up. These changes occur mainly in areas of the brain that control memory, learning, emotional expression and behavior (Alzheimer Society).

There are two types of Alzheimer disease. Familial Alzheimer disease can be traced over several generations and only accounts for five to ten per cent of all cases. Sporadic Alzheimer disease is the most common form of Alzheimer disease and accounts for 90 to 95 per cent of all cases (Alzheimer Society).

Alzheimer disease and other dementias impact the quality of life of individuals in various ways. Three women with early stage Alzheimer disease spoke at the Alzheimer Society 2001 National Conference. Their topic was “Life from the Inside Out — Living with Alzheimer Disease.” The following summary is from one woman’s presentation about her experience with Alzheimer disease.

Norma currently resides in a senior citizens’ home and she states living with this disease is very difficult. She indicates she lives on a slippery slope and the public needs to understand that individuals with Alzheimer disease are still thoughtful persons with a full life to lead.

She has periods when she gets her words mixed up. One day an elderly man asked her “How are you today?” and she responded “Gorgeous!” She also has difficulty in meal preparation — she went to a kitchen drawer to find the can opener, but found a corkscrew instead, then a potato peeler and finally the can opener. On another occasion the volume on her television was not loud enough and she tried to use the lamp switch to turn the volume up.

Norma believes Alzheimer disease is more bizarre than most diseases, due to the duration and changes in cognitive abilities. As a teacher, Norma was not used to having her letters proofread before sending them out, or having difficulties in memorizing certain passages. Norma knew there was something wrong with her, and she resigned with dignity from her job as a teacher. She then started seeing a number of

specialists who placed her on a long wait list for diagnostic tests. It took her nine months to get an MRI and only 20 minutes for the specialist to tell her the results.

She stated her confusion could be very scary. For example, when she is in the middle of a sentence she often doesn't understand the words being verbalized. Through the use of new medications, her confusion has subsided. For Norma, quality of life means to continue receiving her medications and to remain in the early stage of Alzheimer disease for as long as possible, because she believes she is running out of time for the development of a cure.

She also illustrated her experiences as being on a small sinking boat with other individuals with Alzheimer disease. The trip is not a good one, as the number of people getting on the boat keeps increasing. The only thing Norma knows for sure is the "Big Lottery in the Sky" will continue to pick up more people to join her on the boat. She believes there is a need to stop this lottery and to find people a safe haven.

In 1999, Alberta Health and Wellness developed a document entitled *Strategic Directions and Future Actions: Healthy Aging and Continuing Care in Alberta* in response to recommendations in the Long Term Care Policy Advisory Committee's final report, *Healthy Aging: New Directions for Care*, commonly known as the Broda report. As part of the strategic directions, regional health authorities are responsible for developing and implementing ten-year continuing care strategic service plans that will include dementia care programs and services. The potential strategies outlined in this report will serve as a guide for regional health authorities, who can tailor their plans to meet specific client needs.

With Alberta's growing and aging population, the Government of Alberta, through the Long Term Care Policy Advisory Committee, recognized the significance of the population projections for senior Albertans with Alzheimer disease and other dementias. The government made a commitment to partner with advocacy groups and regional health authorities to develop a comprehensive reference document.

In November 2000, Alberta Health and Wellness established an Alzheimer disease and other dementias working task group. The group's goal was to ensure Albertans with Alzheimer disease and other dementias experience a positive change in accessing information and receiving quality services, while maintaining a high quality of life. The working task

group was composed of members with expertise in a variety of areas associated with dementia, such as geriatricians, registered nurses, education specialists, managers, planners, advocacy groups and caregivers. Their work led to this reference document, *Alzheimer Disease and other Dementias Initiative*.

The reference document will be made available to the following individuals and organizations:

- All government departments, in particular Alberta Health and Wellness, Alberta Seniors, Alberta Community Development, Alberta Learning and Alberta Infrastructure;
- All health authorities, physicians and other health providers; and
- Other agencies directly involved in the provision of dementia care services, community partners such as the Alzheimer Society of Alberta, housing providers and interested individuals from the public.

Vision and Principles

The Alberta Vision for continuing care services was developed by the Long Term Care Policy Advisory Committee (1999). This new vision for aging in the 21st century is a society where all Albertans are treated with respect and dignity, have access to information that allows them to make responsible choices regarding their health and well being, and can achieve quality living, supported as needed by relatives, friends and community/networks, and by responsive services and settings.

Consistent with this vision, the principles address the concepts of wellness, person-centered care, accountability, personal responsibility, appropriateness, choice, collaboration, continuity of care, equitable access, independence, quality, responsiveness and affordability. They also reflect the values and beliefs Albertans place on quality dementia care.

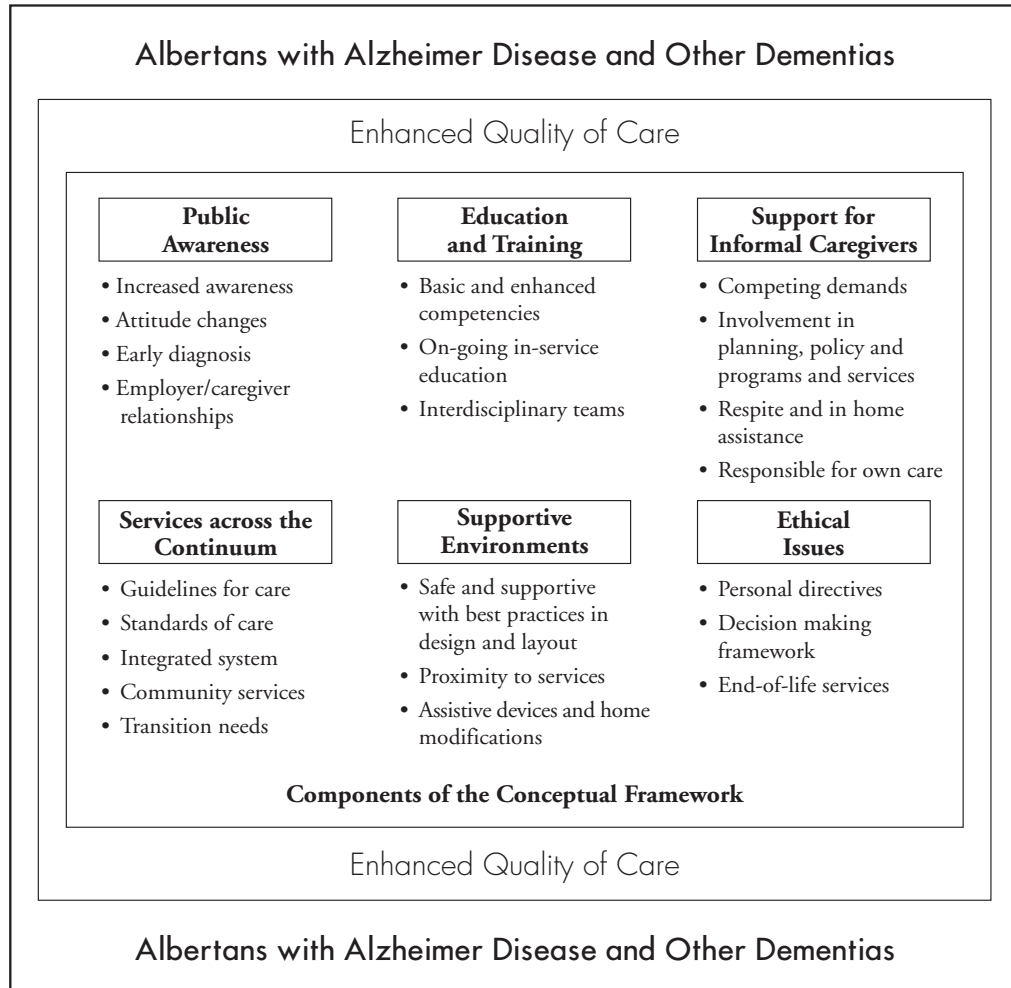
Purpose

The overall desired outcome of this initiative is to enhance the quality of life of Albertans with Alzheimer disease and other dementias. To achieve this, an integrated collaborative approach was incorporated into six broad-based themes developed by the working task group.

Quality dementia care formed the foundation of the six themes described in this report. A major component in the provision of quality dementia care is a person-centered approach. This approach stresses the importance of respecting the individual and meeting the individual’s needs, abilities and life style preferences.

The following illustration provides a conceptual framework of enhanced dementia care, the six strategic themes and the corresponding desired outcomes utilized in the development of the *Alzheimer Disease and Other Dementias Initiative*.

Figure 1



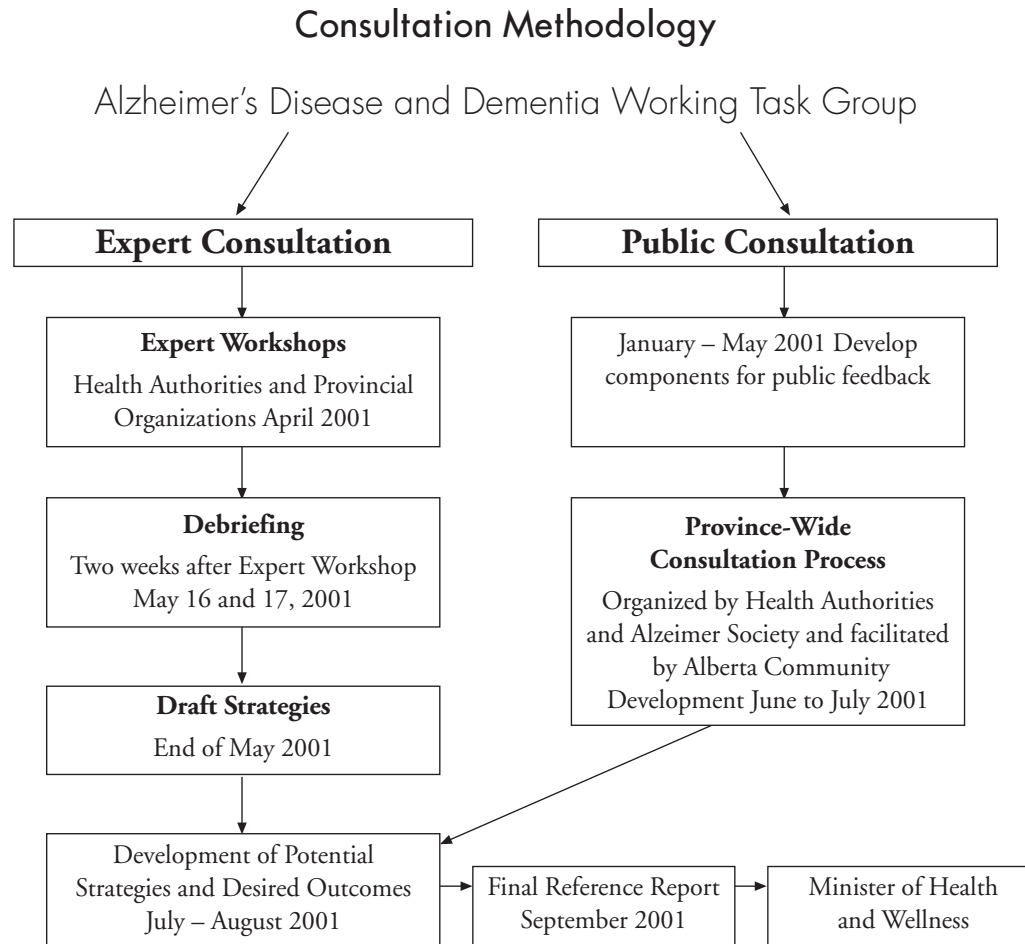
Work Plan

The Alzheimer disease and other dementias working task group developed a work plan that steered their discussions and formed the foundation for the development of this initiative. The highlights of the work plan include a comprehensive literature review and consultation with experts, caregivers and the public.

- 1. Literature Review:** The working task group reviewed the literature on evidence, trends, best practices, different delivery models and research in other jurisdictions, including individual experiences.
- 2. Consulting with Experts:** Expert input from clinicians, academics, formal and informal caregivers and other knowledgeable sources was obtained through:
 - Expertise of the working task group members,
 - Input from experts from within the province, nationally and from outside Canada through the sponsoring of a two-and-a-half day Invitational Planning Symposium in April 2001. Two hundred and fifty participants attended the symposium. A list of participants who attended, a brief summary and individual proceedings are provided in the *Summary of Consultations with the Experts and the Public*.
 - Inviting experts from within the province to present specific topics at the working task group meetings.
- 3. Consulting with the Public:** Province-wide public focus groups, organized by regional health authorities and Alzheimer societies, were held in June and July 2001 to obtain public input from formal and informal caregivers. Staff from Alberta Community Development facilitated these sessions. Major issues identified in these sessions were public awareness, education and training, support for informal caregivers, service delivery, supportive environments and ethical issues. Input was obtained from 518 participants at 30 focus groups.
- 4. Development of Conceptual Framework, Potential Strategies and Desired Outcomes:** The working task group developed the overall conceptual framework of enhanced quality of life through enhanced quality of care and outcomes, based on the wealth of information and advice received through the public focus groups and the Invitational Planning Symposium.

The following graph illustrates the work plan used by the working task group in the development of this strategic direction.

Figure 2



Source: Developed by the Alzheimer Disease and Other Dementias Working Task Group 2001

CHAPTER TWO

Six Themes

The working task group developed six themes for action to improve services for people with Alzheimer's disease and dementia while embracing quality dementia care. The proposed themes are targeted towards the aging population since the prevalence of Alzheimer's disease and other dementias is related to age. The six themes are multi-faceted, targeted at improving the quality of life of individuals with Alzheimer's disease and dementia as well as identifying new service delivery models to provide more effective services. The themes include:

1. Public awareness;
2. Education and training;
3. Support for informal caregivers;
4. Service delivery across the continuum of care;
5. Supportive environments; and
6. Ethical issues.

A preamble, desired outcomes and potential strategies to achieve the desired outcome precede each of the six strategic themes.

Public Awareness

Preamble

New advances in the management of Alzheimer disease and other dementias, as well as improvements in education and support programs, has significantly changed the prognoses for individuals and families experiencing this disease. However, the effectiveness of these interventions can be enhanced upon if they are introduced and implemented early in the disease process. For this to occur, the public needs to be aware of Alzheimer disease and other dementias and understand the disease process. This will promote more acceptance of individuals with this disease and ultimately destigmatize the disease. The public focus groups held in June and July 2001 identified public awareness as a priority area to be addressed.

*"Little understanding
by the public."*

Public Focus Group,
Edmonton, Alberta

*"There are a number of
confidentiality issues
around medical
disclosure."*

Public Focus Group,
Camrose, Alberta

As a result of public awareness, new treatments, education and early diagnoses, Albertans with a diagnoses of Alzheimer disease and other dementias may be able to remain in their homes longer. Being a caregiver in the home can be physically and emotionally stressful. This may impact the quality of life of caregivers, as they will be providing care for individuals with this disease in their homes for a longer period of time.

From a family member or caregiver perspective, a good understanding of Alzheimer disease and other dementias and an awareness that care and support from a team is available will enable them to pre-plan services and prevent crisis situations. Increased public awareness and access to information will assist Albertans and employers in understanding the impact of Alzheimer disease and other dementias on employees who may have this disease or those who may be caregivers. Public awareness will also enable caregivers and individuals affected with dementia to prepare for their own future.

Desired outcome

Albertans will have an increased awareness and understanding of Alzheimer disease and other dementias, and will be aware of the resources/supports available and the processes to access these supports.

Potential strategies

A provincial public awareness campaign should be developed, focusing initially on:

- The early warning signs of Alzheimer disease and other dementias,
- The importance of an early diagnosis,
- The recognition that symptoms of dementia can be managed,
- The personal journey individuals with Alzheimer disease or other dementias are faced with, and
- The linkages to available resources and supports.

Education and Training

Preamble

With an aging population, there will be increased expectations for health professionals, physicians and non-professionals to have the specialized education and training necessary to enable them to meet the needs of individuals with Alzheimer disease and dementia. Both at the expert and public focus groups sessions, education and training was identified as a priority area for enhancing the person-centered approach and quality of life for Albertans with Alzheimer's disease and dementia. Therefore, the enhancement of education and training is targeted towards all Albertans, including family members, volunteers, members of the community as well as physicians, health care providers, and non-professionals.

Intrinsic to the provision of quality dementia care are competent service providers. Combined with the need to expand education and training and the serious shortage of physicians, health professionals and non-professionals, recruitment and retention strategies are critical for the implementation of a service delivery system that provides quality dementia care for this special population. It is also important to enhance the quality of life for health care providers, as this improves recruitment and retention rates in this specialty field. Education of informal caregivers is addressed under Support for Informal Caregivers.

All individuals involved in the provision of health, social and housing services for older Albertans require basic dementia care competencies. Some individuals, due to their specific job functions, will require enhanced job-specific dementia care competencies.

Health providers in Alberta, including physicians, need to enhance and improve their awareness, skills and knowledge of dementia care. Since the majority of continuing care clients have some form of dementia, basic competencies in dementia care that reflect best practices need to be developed and incorporated into education and training curricula. Educational curricula should reflect a person-centered approach to care, as it is an essential component of quality dementia care. This approach stresses the importance of respecting individuality and consideration of an individual's needs, preferences, abilities and preferred lifestyles. Also, to ensure that all Albertans have access to educational programs in dementia

care, educational delivery systems should consider various new technologies for program delivery such as the Internet and tele-health systems.

Personnel delivering health services require a basic understanding of Alzheimer disease and other dementias. The basic competencies³ required for professional practice will vary by health discipline, and will need to be specifically defined for each health discipline. Once defined, basic entry-to-practice competency requirements should be mandated in profession-specific regulations under the *Health Professions Act*. Basic competencies required by non-regulated health occupations will need to be identified and adopted by key stakeholders in the health industry.

To ensure pre-service educational programs match health system requirements, post-secondary institutions and other training providers will need to use competencies endorsed by health professional regulations, or provincial standards to update existing entry-to-practice health profession education programs (credit and non-credit), or develop new courses and programs. This approach will ensure graduates of health education programs attain the basic competencies in dementia care needed by members of their health profession or occupation.

Current employers will need to identify the skill levels of their employees by comparing their existing competencies to the basic entry-to-practice competencies. Appropriate training programs or modules can then be designed or purchased by employers (for in-house use) to ensure these health workers acquire the competencies in dementia care required to fulfil their job responsibilities.

In May 2001, the Continuing Care Workforce Working Group, in collaboration with members of the Alzheimer Disease and Other Dementias Working Task Group, revised the basic competencies for continuing care support workers (other job titles may include nursing attendants, personal care attendants and unregulated front line workers) to include basic competencies in dementia care. Basic competencies will ensure all support workers provide safe and quality care to Albertans and their families. Some continuing care support workers and members of regulated health professions, in particular staff working in dementia care settings, based on job functions and as determined by their employer, may require an enhanced skill set in dementia care in addition to the basic

³ Entry-level skill requirements required by all individuals in a health profession occupation.

competencies. The enhanced competencies may be acquired through in-house or in-service educational programs organized by their employers or through credit programs offered by educational institutions.

While continuing education of physicians and team members will contribute to the early diagnosis and management of Alzheimer disease and other dementias, all individuals caring for individuals with dementia should have basic training and ongoing in-service training available to them.

An interdisciplinary team approach would provide comprehensive, coordinated holistic care to meet the needs of this special population who often have chronic health conditions in addition to cognition challenges. The creation of interdisciplinary teams establishes a culture where team members share common goals with each other and their clients. The team approach also contributes to enhanced service provision, information sharing in a coordinated manner, builds respect amongst the team members and recognizes the distinct contribution of others. For interdisciplinary team models to be effective and efficient, the team needs the support of the institution/setting.

Desired Outcome

Physicians, continuing care support workers and health professionals working as dementia service providers should have the appropriate knowledge, skills and attitudes in the delivery of dementia services.

Potential Strategies

- Educational opportunities for employees working in dementia care settings are needed in order to acquire basic and enhanced dementia competencies if deemed appropriate. These competencies may be acquired through in-house or in-service educational programs organized by their employer, and/or through credit programs offered by post-secondary institutions.
- Post-secondary educational training programs and/or in-house in-service educational programs should be available to health care providers, undergraduate and post-graduate medical students in order to access the learning of basic and enhanced competencies in dementia care. In addition, the eligibility criteria for the Geriatric In-Service Mentoring Program should be expanded to include other health professionals, besides physicians.
- Regulatory bodies should develop, or enhance the basic competencies in dementia care and incorporate them according to their particular profession into their entry-to-practice competencies.
- Defined and measurable learning needs assessment and evaluation tools should be developed for physicians, professionals, non-professionals and service workers for the identification of learning needs in basic dementia care competencies. These should be included in core curriculum programs as well as enhanced skill sets.
- Establish and remove barriers for interdisciplinary teams to function, and enhance quality of dementia care from a holistic perspective.
- Current research initiatives should continue to be developed, enhanced and integrated into current practice and shared to ensure best practices.

Support for Informal Caregivers

Preamble

The majority of caregivers in the *Canadian Study of Health and Aging* (1994) and the Acton and colleagues (1996) study in the United States were females (spouses and daughters). Both studies indicated that wives were the primary caregiver of clients living in the community, while daughters were the primary caregiver of individuals residing in long term care centres. The following table illustrates the characteristics of informal caregivers in Canada.

“Few public policies support caregivers directly and caregivers have differing needs for support.”

Dr. Norah Keating,
Invitational Planning
Symposium, Edmonton,
Alberta, April 2001.

Table 1 Characteristics of Informal (unpaid) Caregivers (weighted data)

Characteristic	In the Community		In Institutions	
	Dementia (%) N= 327	Comparison (%) N = 481	Dementia (%) N = 547	Comparison (%) N = 117
Female	75.4	66.1	70.8	72.2
Married	70.6	81.0	74.1	67.5
Employed	29.3	36.0	41.4	52.8
Relationship:				
Wife	24.1	29.1	8.9	3.5
Husband	13.3	19.7	4.4	0.4
Daughter	28.9	29.6	44.6	39.3
Son	9.5	12.2	19.3	17.3
Other:	24.1	9.4	22.8	39.5
Mean Age (years)	61.9	58.2	59.1	57.7

Source: Lindsay et. al., Patterns of Caring for People with Dementia in Canada, Canadian Journal on Aging, 1994, Table 6, p. 478.

Supports such as respite, counseling and information are important for informal caregivers to remain healthy and able to look after their own needs. Lindsay and colleagues (1994) found that caregivers were more likely to experience chronic health problems and depression than those caring for a non-demented elderly person in the community. Lindsay and colleagues (1994) also cited feelings of being overwhelmed as the main reason given by caregivers for the placement of a loved one in a long term care centre.

“Have been trying to do it all myself.”

Public Focus Group,
Olds, Alberta

“The need for night care is the primary reason for caregivers burnout.”

Public Focus Group,
Bonnyville, Alberta

At the same time, few informal caregivers access respite services (Gonvea 1988) because of structural barriers, such as the lack of transportation, inconvenient hours of operation and poor location. The majority of community services utilized by informal caregivers in Canada include homemaking and home nurse visits. Very few caregivers use respite services or support groups, as indicated in the following table.

Table 2 Use of Support Services by Community Caregivers

Type of Service	Dementia (%) N = 349	Comparison % N = 484
Homemaking	41.3	21.4
Home Nurse	20.2	6.1
Physiotherapist	15.3	26.2
In-home personal care	18.8	7.4
Meals on Wheels	8.7	1.9
Day Centre	8.0	0.6
Respite Care	3.1	0.3
Support Groups	3.4	0.3

Source: Lindsay et. al., Patterns of Caring for People with Dementia in Canada, Canadian Journal on Aging, 1994, Table 6, p. 480.

“Costs at home are costs to the family — not so in hospitals and nursing homes.”

Public Focus Group,
Calgary, Alberta

Informal caregivers often have high demands on their time and lead “double duty lives.” Employees who are informal caregivers often do not have flexible work schedules that allow them to balance their work and family life. In 1996, Keating and colleagues indicated that approximately 11 per cent (2.1 million) of the Canadian population 15 years and older provided informal care to one or more seniors with a long-term health problem. In their 1999 study of Eldercare in Canada, Keating and colleagues also confirmed that the majority of informal caregivers in Canada were women (61 per cent). In addition, Canadian women sixty-five years and older provided on average 7.5 hours per week in care-giving activities, while women between the age of forty-five to fifty-nine years provided on average 4.8 hours of care-giving activities weekly (Dr. Keating 1999).

Currently, many Albertans with dementia, along with their caregivers, feel overburdened, guilt ridden and isolated. Informal caregivers and families often experience high levels of stress, out-of-pocket expenses and chronic illnesses. Comments provided at the public focus groups included: “family members are falling through the cracks”; “not knowing where to access information”; “too much red tape in accessing services”; and “caregivers and family members are reluctant to seek help due to denial of the disease.”

Informal caregivers and their families need readily available, accessible and clear information in order to make informed decisions. They also need access to education, supports, respite and a broad range of community services. Input and ongoing communication with caregivers is also important to the delivery of quality dementia services. Caregivers need to be aware of self-care caregiver programs that are offered by the Alzheimer Society, or in partnership with other community agencies (for example, the *Taking Care of You* program).

Informal caregivers caring for Albertans with Alzheimer disease or other dementias can provide valuable information to policy makers and program planners from their first hand experience and should have the opportunity to have input in policy and service program planning. Caregivers need to be valued and recognized as intricate members of the multi-disciplinary team, beginning with assessment and care planning and throughout the continuum of care. Once informal caregivers are included in the multi-disciplinary team, a proactive approach to planning services can be utilized rather than a crisis management approach. Formal support provided to informal caregivers, along with an expanded mandate for community-based programs, will actually enhance their ability to provide quality dementia care services.

Desired Outcomes

Informal caregivers of Albertans with Alzheimer disease, or other dementias should have access to ongoing education and support.

Policies should support and recognize formal caregivers and enable them to cope with competing demands and avoid burnout.

Potential Strategies

- The provision of basic education and skill development programs (similar to the curriculum for continuing care support workers).
- Utilization of existing education and support networks to provide education and support to informal caregivers (e.g. Alzheimer Society First Link Program, Calgary Health Authority Caregiver Resource Centre, RISARS).
- Utilization of new networks to enhance community partnerships such as Coordinated Access.
- The exploration of possible mechanisms for family responsibility leaves from employment that include families caring for individuals with Alzheimer disease or other dementias.
- Continue to build on existing home care policies with respect to families providing care.
- Develop, or build upon existing self-care caregiver programs in partnership with the Alzheimer Society or other community agencies (e.g. *Taking Care of You* program).
- Ensure community support programs are in place, such as access to respite services, day programs and/or assistance with care in the home.
- Improvement of public transportation systems, in order to be dementia-friendly.

Service Delivery Across the Continuum

Preamble

Service delivery across the continuum cultivates a culture of regional and inter-regional cooperation and collaboration. Recommendations from both the Broda report and the public focus groups highlighted the need to shift resources from the institutional sector to community/home-based services and programs and the need to develop inter-regional cooperation and collaboration.

*“Too many old rules
when it comes to care.”*

Public Focus Group,
Camrose, Alberta

Currently, 50 per cent of Albertans with a diagnosis of Alzheimer disease or other dementias reside in their own homes, and future projections indicate this trend will continue (*Canadian Study of Health and Aging*, 1991). The McMaster University Office of Gerontological Studies (1996) utilized data from the *Canadian Study of Health and Aging* (1991) and determined that individuals in institutions had a higher prevalence of Alzheimer disease than those residing in the community, particularly individuals eighty-five years and older. Findings from the study suggest that the majority of Canadians with mild and moderate levels of dementia reside in the community, while the majority of Canadians with severe dementia reside in long term care centres.

During the next ten years, public policy will need to address the increasing number of Albertans with dementia who will remain in their communities for a longer period of time. This will require the development and implementation of a wide range of community-based services for Albertans with mild and moderate dementia and specific services for Albertans with severe dementia.

Services and programs for Albertans with Alzheimer disease or other dementias should be based on the cognitive and functional abilities of the individual and their stage in the disease process. The concept “one program fits all” is not appropriate for individuals with Alzheimer disease, or other dementias. There is a need for a full range of dementia care programs and services with trained expertise available.

Special care programs with controlled-access doors should be monitored and regularly evaluated with regard to the activities provided to ensure quality of life. Staff in rural areas will need to develop creative solutions, in order to provide a full range of continuing care services for Albertans

with dementia. In addition, there will be a need for inter-regional collaboration and cooperation in the provision and use of current and new dementia care services and programs.

Services and programs integral to the provision of quality dementia care include, but are not limited to, early identification and diagnosis, individual care planning and assessment, the coordinated access initiative that is currently underway, enhanced communication between caregivers' families and providers of service, meaningful activities, individual choice, services according to assessed needs and service integration that allows the individual to move easily through the system. In order to ensure the delivery of quality dementia care, all services must emphasize the individual and their needs.

Quality dementia care can also be achieved through the encouragement and development of dementia care networks. Dementia care networks will assist in the sharing of information across health regions and the sector in general and, in the process, develop partnerships with community agencies and other stakeholders.

The *Guidelines for Care* developed by the Alzheimer Society of Canada encompass eleven principles for providing quality dementia care. Principles outlined in the guidelines include specialized training and education for caregivers, support for caregivers, individualized assessments, individualized care planning, meaningful activities and programs, specialized human resources, supportive physical design, transportation, decision-making, prevention of and response to abuse, and the use of restraints. The *Guidelines for Care* focus on the unique nature of Alzheimer disease and how the disease affects each individual differently, and stress the maintenance of an individual's self-esteem.

On an ongoing basis, regional health authorities should review and evaluate the implementation of the *Guidelines for Care* and recommend best practices, key quality indicators and benchmarks to continually improve quality dementia care. As part of their ten year continuing care service plans, regional health authorities should review their policies in order to eliminate barriers between programs and to ensure Albertans remaining in their own homes have access to a wide range of community care services. Regional health authorities should also develop mechanisms to gather and disseminate information on dementia care best practices and service delivery to others in the region and to other regional health authorities.

Technology also plays an important role in the quality of life of Albertans with Alzheimer disease and other dementias. Technology involves various forms that can range from diagnostic tools such as Computer Assisted Tomography (CAT) scans and Magnetic Resonance Imaging (MRI) used in the early diagnosis of Alzheimer disease and other dementias, to research and development of new drugs and other therapies to the development of universal devices and tools for communicating over great distances.

“Fortunately, the last few years have been highlighted by a dramatic upswing in the development of new technologies in healthcare, education and delivery. One of these noteworthy innovations has been the establishment of an inter-provincial tele-health network in the province of Alberta” (Peter McCracken, 2001).

To ensure the sustainability of Alberta’s health system, there will be a need for the health system to function as an integrated system of programs and services, with common communication systems across the province, as well as partnerships with community-based agencies, housing providers and social service providers. This requires co-ordination and collaboration across all government departments and agencies.

Regional health authorities will need to be able to demonstrate a measurable increase in the continuity of care for Albertans with Alzheimer disease or other dementias. At the same time, Alberta Health and Wellness and other key government departments will need to review public policies relating to services, in order to provide incentives and eliminate disincentives in the provision of community-based services. Alberta Health and Wellness, in partnership with stakeholders such as Alberta Human Resources and Employment, housing providers, mental health providers and transportation programs, will also need to recognize the needs of Albertans with a diagnoses of Alzheimer disease and other dementias, as this is not just a health issue, but a social issue.

Desired Outcomes

All services and programs along an integrated continuum of care should demonstrate timely quality dementia care across the private, public and volunteer sector according to the assessed needs of individuals.

Potential Strategies

- Develop mechanisms to collect and disseminate information on dementia care best practices and service delivery across the continuum of care, such as the utilization of the *Guidelines for Care* developed by the Alzheimer Society of Canada.
- Develop guidelines for care where gaps currently exist across the continuum, that promote integration of services and continuity of care, such as special care units, lodges, unregulated service providers.
- Develop continuing care service packages in order that services are linked and accessible in the community.
- Develop or expand upon enhanced coordinated access processes and existing community care service packages in order that service areas are linked and accessible in the community, including a broader assessment for clients for home care that expands beyond physical unmet needs of clients. Hours of care allocated in home care should be based on both the physical, mental, and behavioral needs of clients and their families, such as respite (day and night), day programs, assisted living.
- Initiate an annual best practice conference on dementia care, in order to disseminate best practice information.
- Develop dementia care networks across the province.
- Encourage the development of an approach to the treatment of chronic health conditions experienced by individuals with Alzheimer's disease and dementia to prevent emergency admission to hospitals.

Desired Outcomes

When transitions between settings for Albertans with a diagnosis of Alzheimer disease or other dementias are necessary, they will be minimized and well managed.

Classification systems will reflect the special needs of Albertans with Alzheimer disease or other dementias. A funding system for long-term care centres should provide incentives for the operators to optimize the unique abilities of this special population.

Potential Strategies

- Develop mechanisms that will assist the health system to minimize the number of times individuals with Alzheimer disease and other dementias are moved from setting to setting, and support them and their caregivers/families in this process.
- Develop a methodology to unbundle resources, so funding follows individuals and they may remain in the community for a longer period of time, if appropriate services are available and accessible.
- Review current classification systems to ensure they meet the care needs of Albertans with dementia.
- Explore incentives that support the development of supportive living and residential housing options, e.g. capital and operating funds.

Supportive Environments

“More options are needed for housing.”

Public Focus Group,
Camrose, Alberta

Preamble

Throughout the disease process, and across all types of living spaces, the physical environment and its design play an active role in supporting individuals with Alzheimer disease and other dementias in their day-to-day lives. An individual’s ability to function effectively within a given environment impacts his or her participation in self-care and leisure activities and their overall quality of life. Increasingly, the environment is being recognized as playing an important role in compensating for memory losses and disorientation, and in discouraging challenging behaviours. The environment includes both physical and social dimensions such as the physical environment, the caring environment and the surrounding community.

The aim of supportive living environments is to enable Albertans with Alzheimer disease and other dementias who require care and support to experience quality of life as fully as possible. The design and character of supportive environments contributes greatly to the level of independence that may be safely enjoyed during daily activities. If the physical environment is secure and appropriately staffed, it may be possible for individuals to have considerable choices in what they do and when they do it. Staff will also be assisted if the design of the living space and the provision of equipment and furnishings are appropriate and safe.

Renovations to existing facilities may be an appropriate option to constructing a new setting. There are a number of needs assessment models available to assist in assessing whether an existing or proposed building is suitable for use by individuals with Alzheimer disease or other dementias. Information about assistance programs is necessary for caregivers and providers as the availability of these supports may impact on whether an individual with Alzheimer disease or other dementias can continue to be cared for at home.

Evidence suggests that settings for small groups of individuals with dementia are more conducive to their quality of life than larger settings. This concept is important, as the majority of individuals with dementia, seventy-five years and older, reside in continuing care facilities. Consequently, the physical design of residential facilities needs to be “dementia friendly.” During the next ten years, regional health authorities will need to support their planners and foster the concept that all

environments should be “home-like,” that is, residential in nature with familiar and comfortable furnishings, that balance safety and security. The location of these environments should facilitate access to appropriate amenities, such as shopping centres, wellness clinics and transportation and integration with the surrounding community.

Desired Outcomes

Supportive environments, such as small residential settings in different environments in which Albertans with Alzheimer disease and other dementias may live and receive services, or care should be provided and expanded utilizing best practice design and layouts (include private homes) to be safe, supportive, and familiar.

Potential Strategies

- Encourage the development of guidelines that address design features and provide safety and security.
- Consult with individuals who have the insight and experience on best practices and layout designs when design plans or improvements are under review. Individuals consulted may include informal and formal caregivers, design professionals and other key stakeholders.
- Develop mechanisms to promote and disseminate information on environmental design best practices. Examples of minimum design requirements may include: personalized private spaces, safe wandering paths, access to secure outdoor areas and common spaces that encourage socializing.
- Explore the development of social residential models (i.e. group homes and assisted living) for Albertans with early and moderate Alzheimer disease or other dementias.
- Encourage the conversion of under utilized or vacant facilities to supportive living spaces based on best practices.

Desired Outcomes

Environments that accommodate Albertans with Alzheimer disease and other dementias should be located close to accessible services and amenities, facilitate access to appropriate transportation options and be integrated with the surrounding community.

Albertans with Alzheimer disease and other dementias, and their family caregivers, should have access to information and financial assistance for assistive devices or home modifications that will promote independence, safety and enhance their quality of care.

Potential Strategies

- Develop and evaluate program proposals/ descriptions and distribute available information, such as public policy documents, on proximity to services and amenities, availability and appropriateness of transportation options, and integration with the broader community through relationships and partnerships with other community members and organizations.
- Encourage the development/conversion of affordable housing that will be licensed facilities.
- Encourage the review of provincially owned housing and land to take into consideration the potential suitability for future housing projects.
- Encourage the enhancement of public policy to reflect the need for resources to support home modification assistance programs.
- Encourage the development and maintenance of an inventory to identify all home-renovation assistance programs and include information on assistive devices and design features that promote optimal levels of physical and cognitive functioning.

Desired Outcomes

A range of housing with services/care options should exist locally (e.g. in the person's own community where possible) that can accommodate the special needs of persons with Alzheimer disease and other dementias.

Potential Strategies

- Further develop housing options that are affordable to persons with low or moderate incomes. Strategies such as income supplements for low-income Albertans requiring this type of housing should be considered.
- Encourage the involvement of a variety of community-based stakeholders in the planning and development of local options, in order to ensure that unmet needs are targeted.
- Draw upon findings from agreed-upon needs assessment models, to determine the number and types of housing with service/care options that are required to ensure needs are targeted.

Ethical Issues

“There are a number of confidentiality issues around medical disclosure.”

Public Focus Group,
Camrose, Alberta

Preamble

There are many ethical issues for individuals with Alzheimer’s disease and other dementias beginning at the time of diagnosis. The ethical challenge in dementia care is to meet the needs of a frail and vulnerable population and their families in an acceptable, humane and affordable manner.

“The care provided for dementia-afflicted individuals is a symbol of our society’s view of its members. If we ‘abandon’ afflicted patients and ‘offload’ the burden to families, we will undermine our societal and caregiving mandate and give a clear message as to our societal values” (Gordon, 2001). Dr. Gordon (2001) also identified age-related issues as a major challenge in bio-ethics. These challenges include: end-of-life care, feeding issues, cardio pulmonary resuscitation, the degree of care provided, the role of institutions versus the family, the ability of families to absorb the role of caregiver and associated costs and resource allocation.

A diagnosis of dementia does not necessarily mean an individual is unable to make decisions. Throughout the course of the disease, some abilities remain. These should be respected. When an individual is assessed competent they should be allowed to make decisions that affect their quality of life, including planning their future care, recognizing that the individual’s capacity to make decisions may fluctuate over time. The ability of any person to make a decision varies with the particular decision to be made. It is important to ensure that as an individual’s medical condition changes, substitute decision-makers are in place (Faculty of Medicine, University of Toronto, 2000).

During the progress of such disorders, decisions regarding ability to drive, use of a trustee, admission to a secure unit and competence to consent to treatment may be required. Studies in the United States (Forbes, 2000) indicate that less than 20 per cent of the population have completed personal directives that guide care and treatment when the individual is no longer able to make those decisions. personal directives are important for individuals with a cognitive impairment to ensure their personal wishes and decisions are respected. Individuals with dementia are vulnerable, due to their limited cognitive capacities and the low prevalence of completed personal directives.

Alzheimer disease and other dementias are significant illnesses of later life. Seniors with Alzheimer's disease or other dementias will need care over a significant period of time. Respect for the individual's expressed wishes and interests should guide all end-of-life care decisions. In the transition from life to death, the ultimate goal of care should be to provide comfort and dignity to the person, with a goal of achieving what the individual considers a good death. Palliative care programs provide excellent end-of-life care for short periods of time; however, such programs are time limited (less than three months) and are usually targeted to people with cancer. Some palliative care programs have extended their interventions to a multidisciplinary approach, and there is now a trend to work with patients with dementia from the time of diagnosis, throughout the illness and into the palliative phase.

Family members in their role as caregivers and decision-makers may experience a significant emotional burden. They may not understand the disease progression and the changes in the individual that may take place over years. There may be unresolved family issues, and the family may not be prepared to make serious care and treatment decisions on behalf of their family member. Health professionals will need to understand these concerns if they are to assist family members to deal with their emotions and to make informed decisions.

Caregivers, health care providers and support providers need to be aware of their own underlying values and principles that guide the care they are providing. Various tools are available to assist people in resolving ethical dilemmas. One well-known framework for considering ethical issues has the following five components: respect, autonomy, non-maleficence, beneficence and justice (University of Toronto, 2000). Many of the ethical issues include respecting the rights of the individual, maintaining client confidentiality and information disclosure. Promoting informal consent is important in assessing individuals for capacity and capability for involvement in decisions about degree of confinement, desire for cardiac pulmonary resuscitation and do not resuscitate orders, withholding and withdrawing treatments and addressing ethical conflicts in end-of-life care and palliative care situations.

End-of-life care is an important priority area that requires addressing, because of the growing number of seniors and the increased expectations for care and services. Other ethical issues include priority setting for

programs and services and resource allocation as the population ages. There is a need to address systemic ethical issues across the continuum of services.

Desired Outcomes

All Albertans should be able to either make, or be involved in ethical decisions regarding their care.

Potential Strategies

- Encourage the development of an ongoing communication plan targeted at encouraging Albertans to complete a personal directive.
- Encourage care providers to have policies in place that respect individual's choice and enables that choice to be known, honoured and respected.
- Encourage exploration of the development and expansion of the Provincial Health Ethics Network to develop a dementia ethics framework that will address individual and systemic ethical issues.
- Encourage the health system to foster current best practices in the planning and provision of end-of-life care and palliative care.

CHAPTER THREE

Summary of Key Findings

Based on the six themes and potential strategies, the working task group identified the following as priority areas for action by regional health authorities and other stakeholders.

1. Public Awareness:

Albertans should have an increased awareness and understanding of Alzheimer disease and other dementias.

2. Guidelines:

Guidelines should be in place for the care of clients with Alzheimer's disease and dementia. It should also cover any gaps that currently exist across the continuum, such as special care units and unregulated service providers.

3. Support for Informal Caregivers:

Informal caregivers caring for Albertans with Alzheimer disease or other dementias should have access to education and support programs.

4. Service delivery across the Continuum of Care:

Community care service packages should be developed, or expanded upon, in order that service areas are linked and accessible in the community. This includes a broader assessment based on unmet needs (physical, mental and behavioural) of clients and their families, for example, respite (day and night), day programs, assisted living.

5. Supportive Environments:

The expansion or provision of small residential care-like settings, including the client's home, should be considered as a possible service option, utilizing best practice design and physical layouts.

6. Education and Training:

Health professionals, including physicians, non-health professionals and dementia care service providers should have the appropriate skills and knowledge in the delivery of services.

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GLOSSARY OF TERMS

Aging in place at home:

Home is where the majority of services are provided and the other options are substitutes for getting the care people need at home. The vast majority of seniors remain in their own homes, as long as possible, with the care and support they need, when they need.

Alzheimer disease:

Alzheimer disease is the leading cause of dementia in Canada. The disease destroys brain cells that affect an individual's mental and physical abilities and behaviours.

Basic competencies:

Entry-level competencies in Alzheimer disease and other dementias will be required by all personnel delivering health services to Albertans and will be job specific.

Continuing care:

A system of service delivery that provides individuals who have health conditions or disabilities with access to services they need to experience independence and quality living. These services include professional services, personal care services and a range of other services. They may be provided for a short term or a long term.

Dementia care networks:

Dementia care networks are composed of representatives from a wide variety of health and social service organizations who work together to achieve improved coordination and access to programs and services for the residents of their communities.

End-of-life care:

End-of-life care is an active and compassionate approach to care for older people in the last stages of their lives. It offers treatment, comfort and support to those living with progressive or chronic life-threatening conditions. End-of-life care is sensitive to personal, cultural and spiritual beliefs and practices. It also encompasses support for families and friends up to the end, including the period of bereavement (*Excellence in Long Term Care*, May 2001).

Enhanced competencies:

Is defined as competencies beyond the basic competencies required for some health personnel. Some personnel delivering health services will, in addition to their health profession requirement, require enhanced competencies in dementia. This is because they may have specific job functions that require a level of understanding beyond basic competencies. This may be through a credit program for geriatric nurse specialists, or an in-house non-credit program such as the Geriatric Mentoring Program. Enhanced competencies will be defined according to the job function.

First link program:

The First Link Program was designed to provide early access to information and support to the family soon after receiving a diagnosis of Alzheimer disease, or other dementias. The caring relationship with staff begins with a home or office visit, continues throughout the care giving journey to ensure that families receive appropriate and timely access to ongoing education and support services, both from within the Alzheimer Society and throughout the community.

Health authorities:

Health authorities are defined as the seventeen established regional health authorities and Provincial Boards including the Alberta Mental Health Board and the Alberta Cancer Board.

Special care units:

For a unit to be designated as “special” the following five areas must be addressed: the physical environment must meet the needs of the targeted population; specific admission and discharge criteria are in place; the selection and training of a multidisciplinary team of staff; care and therapy programming that meets the residents special needs and programming for families.⁴

⁴ Maas, M.L., Hall, G.R., Specht, J.P., Buckwalter, K.C.: Development of long-term care Alzheimer’s units. In K.C. Buckwalter (Ed.) *Geriatric Mental Health Nursing: Current and Future Challenges*. Thorofare, NJ; Slack Inc, 1992, pp.44-60.

Supportive living:

As one of the three continuing care service streams, supportive living is a housing/care option that:

- Merges housing design with services to support individuals in a setting that promotes principles valued by the client;⁵ and enables them to live in the community (non-institutional) as long as they are able and choose to do so;
- Offers a range of on-site basic services (by housing operator), including meals, housekeeping, linen, laundry, 24 hours, 7 days per week surveillance for safety and security, and life enrichment;
- Publicly funded professional and personal care services are provided on an assessed unmet need basis, and accessed through Coordinated Access; access to persons with Developmental Disabilities, shared living arrangements and Alberta Mental Health Board approved homes occurs through their respective systems;
- Is predominantly a social model of care, with home-like environment, supporting individuals to maintain control over their lives;
- Allows easy access to activities to maintain their lives as contributing members of the community;
- Shares risk and responsibility with individuals, depending on care requirements.

⁵ Adapted from Wilson, Keren, "Assisted Living: The Merger of Housing and Long Term Care Services: duke University Centre for the Study of Aging and Human Development, Vol.1 (4), 1990, pg.4.

Stages of dementia:

- Mild dementia: Individuals are able to live independently in the community, but experience a decreased ability to manage activities of daily living such as ones finances, writing cheques, food shopping and so on.
- Moderate dementia: In this stage of dementia, physical deficits become significant. The majority of individuals have difficulty managing in the community by themselves. Difficulties are experienced in the basic activities of daily living such as choosing appropriate clothes to wear. In addition, individuals experience problems in recalling major events and in their short-term memory.
- Severe dementia: In the final stage of dementia, individuals experience changes in their physical and neurological functioning. The individual loses their ability to ambulate and sit up independently. Speech is reduced or limited and the individual loses the ability to smile.