

A Strategy for
*Alzheimer
Disease*
and
*Related
Dementias*
in Manitoba

October 2002

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EXECUTIVE SUMMARY

Alzheimer Disease, the leading cause of dementia, accounts for 75 percent of all dementias in Manitoba (MSHA Research Group, 1995). The features of the disease include a gradual onset and continuing decline of memory, changes in judgement or reasoning, and inability to perform familiar tasks.

Related dementias (other than Alzheimer Disease) may be demonstrated through symptoms of sudden onset of memory loss, early behaviour problems, or difficulties with speech and movement. Causes may be related to diseases such as vascular dementia, Creutzfeldt-Jakob Disease, Lewy Body Dementia or Pick's Disease.

Studies conducted by the Manitoba Study of Health and Aging, have revealed that 1 in 12 Manitobans age 65 and over currently has Alzheimer Disease or a related dementia. This finding is supported by the results of a survey commissioned by the Alzheimer Society of Manitoba that found that 1 in 3 Manitobans currently has a close personal friend or family member with Alzheimer Disease. (Probe Research Inc., 2001). In this report, "dementia" refers to Alzheimer Disease and related dementias.

The proportion of Manitoba seniors is increasing and increasing age is associated with the likelihood of having Alzheimer Disease and related dementias. Manitoba population projections show an increase in the age 65 and over population from 13.6 percent of the total population in 2001 to 18.8 percent by 2021. (Statistics Canada, 2001). The percentages of Manitoba residents age 65 years and over per Regional Health Authority range from 3.3 percent in Burntwood to 19.5 percent in Assiniboine. (Manitoba Health, 2002)

In early 2000, Manitoba's Minister of Health, recognizing Manitoba's growing aging population and the fact that more Manitobans were being diagnosed with Alzheimer Disease or a related dementia, directed Manitoba Health to develop an Alzheimer Strategy for Manitoba in order to start planning for the future.

For the past two years, the Alzheimer Strategy Steering Group and Working Groups researched the topic, sought opinions from experts in the field, individuals, families and caregivers; discussed, deliberated and arrived at a consensus on a number of issues, goals and actions for a Strategy.

In this Report to Manitoba Health, the Alzheimer Strategy Steering Group recommends Actions that are pivotal to developing Implementation Strategies for the care of Manitobans with Alzheimer Disease and related dementias and their families. The key Strategic Issues to be addressed are:

- ▶ Education for professionals, paraprofessionals, family, individuals, communities and the general public.

- ▶ Guidelines for diagnosis.
- ▶ Standards across all programs and services.
- ▶ Family and individual support.
- ▶ Comprehensive programs and services for individuals at the community and facility levels.
- ▶ Case management and interdisciplinary collaboration.
- ▶ Equitable access to programs and services across Manitoba.
- ▶ Human and financial issues including recruitment, retention and remuneration.
- ▶ Ongoing rigorous research and evaluation.

The Steering Group recognizes the challenges that lie ahead in order to change the culture of care for people with dementia and their families. The implementation of the proposed Actions in this Report would be a positive beginning for the provision of the best care possible for Manitobans affected by Alzheimer Disease and related dementias.

By working together we can have help for today and hope for tomorrow

RÉSUMÉ

Principale cause de démence, la maladie d'Alzheimer est responsable de 75 % des cas signalés au Manitoba, selon une étude faite en 1995 par le groupe de recherche du centre d'étude manitobain de la santé et du vieillissement. Des pertes de mémoire et le déclin ininterrompu de cette faculté, des modifications du jugement et du raisonnement, ainsi que l'incapacité d'exécuter des tâches familiales, sont parmi les symptômes qui caractérisent la maladie d'Alzheimer.

Les premiers symptômes des démences connexes (autres que la maladie d'Alzheimer) peuvent être perçus comme des pertes de mémoire ou des troubles du comportement, de la parole ou de la motricité. Ces troubles peuvent être causés par des maladies comme la démence vasculaire, la maladie de Creutzfeldt-Jakob, la démence à corps de Lewy ou la maladie de Pick.

Des études effectuées par le centre d'étude manitobain de la santé et du vieillissement ont révélé qu'au Manitoba, une personne sur douze âgées de 65 ans et plus est atteinte de la maladie d'Alzheimer ou d'une démence connexe. Ces chiffres sont corroborés par une enquête menée pour le compte de la Alzheimer Society of Manitoba, et selon laquelle une personne sur trois, au Manitoba, compte quelqu'un qui est atteint de la maladie d'Alzheimer parmi ses amis intimes ou les membres de sa famille (Probe Research Inc., 2001). Dans le présent rapport, le mot « démence » signifie la maladie d'Alzheimer et les démences connexes.

La population du Manitoba vieillit sans cesse, et il y a donc une forte probabilité pour qu'une proportion toujours plus grande de Manitobains et Manitobaines âgés soient atteints de la maladie d'Alzheimer ou d'une démence connexe. Les projections démographiques font voir une augmentation du nombre des personnes âgées de 65 ans et plus, qui, après avoir représenté 13,6 % de la population de la province en 2001, en représenteront 18,8 % en 2021 (Statistique Canada, 2001). L'âge moyen n'est pas le même dans chaque région de la province et, par conséquent, le pourcentage de Manitobains et Manitobaines âgés de 65 ans et plus varie selon les offices régionaux de la santé, passant de 3,3 dans Burntwood à 19,5 dans Assiniboine (Santé Manitoba, 2002).

Au début de l'an 2000, le ministre de la Santé du Manitoba a pris acte du vieillissement de la population de la province et du nombre croissant de Manitobains et Manitobaines atteints de la maladie d'Alzheimer ou d'une démence connexe. Le ministre a alors donné des instructions pour que Santé Manitoba élabore une stratégie relative à la maladie d'Alzheimer afin de commencer à planifier pour l'avenir.

Au cours des deux dernières années, le groupe directeur du Comité chargé de la stratégie relative à la maladie d'Alzheimer et aux démences connexes et les groupes de

travail ont poussé les recherches dans cette voie; ils ont sollicité l'opinion de spécialistes et de soignants, de malades et de membres de leur famille; et ils ont dégagé un consensus autour de plusieurs questions, et des mesures à prendre et des buts à atteindre dans l'élaboration d'une stratégie.

Dans le présent rapport à Santé Manitoba, le groupe directeur du Comité chargé de la stratégie relative à la maladie d'Alzheimer et aux démences connexes recommande des mesures capitales pour l'élaboration de stratégies de mise en œuvre des soins à donner aux Manitobains et Manitobaines atteints de la maladie d'Alzheimer ou d'une démence connexe, ainsi qu'aux membres de leur famille. Voici quels sont les principaux enjeux stratégiques :

- ▶ éducation des intervenants professionnels et paraprofessionnels, des malades et de leur famille, des collectivités et du grand public;
- ▶ directives concernant l'établissement des diagnostics;
- ▶ normes s'appliquant à tous les programmes et à tous les services;
- ▶ soutien aux malades et à leur famille;
- ▶ programmes et services complets à l'intention des malades, au niveau des collectivités et dans les établissements;
- ▶ prise en charge des cas et coopération interdisciplinaire;
- ▶ équité de l'accès aux programmes et aux services dans tout le Manitoba;
- ▶ questions d'ordre humain et financier incluant le recrutement, le maintien et la rémunération de l'effectif;
- ▶ recherche et évaluation continues et rigoureuses.

Le groupe directeur reconnaît que changer les mécanismes traditionnels ayant trait aux soins donnés aux personnes atteintes de démence et à leur famille constitue un défi. Le présent rapport suggère des mesures qui marquent un départ positif vers l'obtention des meilleurs soins possibles pour les Manitobains et Manitobaines atteints de la maladie d'Alzheimer ou d'une démence connexe.

Travaillons ensemble à obtenir de l'aide aujourd'hui et à garder un espoir dans l'avenir.

BACKGROUND TO STRATEGY DEVELOPMENT

In June 2000, Manitoba Health established a Committee to develop an Alzheimer Strategy for Manitoba. The Committee chose the structure of a Steering Group to coordinate the Strategy development and several Working Groups to work on identified topic areas. The Steering Group was co-chaired by Manitoba Health and Alzheimer Society of Manitoba. Other key participants included individuals with expertise in dementia related areas from Regional Health Authorities (RHAs), the Manitoba Seniors Directorate, the Manitoba Society of Seniors and the University of Manitoba's Centre on Aging.

The Steering Group's mandate was to develop a Strategy that would focus on the best possible care and support throughout the health care continuum for those Manitobans affected by Alzheimer Disease and related dementias, their families and other caregivers.

Over the course of 2 years, the Steering Group established fourteen Working Groups with individuals that represented the interests of persons with Alzheimer Disease and related dementias. Specifically, representation included provincial and national organizations, medical and other health care professions, clergy, persons affected by the disease and their families, caregivers and other interested stakeholders, to address the spectrum of Alzheimer Disease and related dementias throughout the health care continuum. (See Appendix E). Each Working Group was comprised of at least one Steering Group member and was free to expand its membership to obtain the appropriate knowledge and expertise as required to address the topic.

Summary of Process

The Steering Group undertook an intensive consultative process that was divided into two phases. The first phase involved four Working Groups that each examined one stage on a continuum of the disease progression:

1. Pre-diagnosis to diagnosis
2. Diagnosis to direct service
3. Direct service to personal care home (PCH) placement
4. PCH to death

Overlap between the stages was expected and served to ensure a comprehensive approach. A fifth Working Group conducted a literature review, liaised with the other four Working Groups to supply information and reference requests, and researched and reported on similar initiatives in other parts of Canada and the world.

The Working Groups primarily concentrated on needs assessment and inventory of services.

- ▶ Over 3,000 individuals were surveyed using specially designed questionnaires for Regional Health Authorities, staff of personal care homes, general and specialist physicians, individuals diagnosed with dementia, family members of residents in personal care homes who were diagnosed with Alzheimer Disease or related dementias and the general public. Individuals had the opportunity to give their comments/opinions related to the disease, awareness, knowledge, diagnosis, technology, special services, care, supports, skills and education.
- ▶ Thirty focus groups and information meetings with the general public, caregivers, professionals and persons with dementia and their families were held in Winnipeg, Brandon, and some rural areas.
- ▶ Policies, strategic plans, government documents, and systems information on dementia care at the regional, national, and international levels were reviewed. Sources of information included regional surveys, web sites, government documents, published literature/reviews and personal contacts.

The Working Groups collated, analyzed the data, and prepared reports from the surveys, focus groups and meetings. At the end of the first phase, a workshop was held to bring all Steering Group and Working Group members together to identify, analyze, understand in depth, prioritize service gaps and issues and begin the process of documenting potential means for addressing these gaps and issues.

The gaps and issues identified through the first phase were organized under nine topic headings that formed the basis of the work that was to be completed in the second phase. The Steering Group worked with nine new Working Groups to further develop and refine the gaps and issues, and describe actions to reach the goals. All participants from both phases were then brought together at a second workshop to give them the opportunity to validate the work that had been done and make changes to the actions.

A Strategy for Alzheimer Disease and Related Dementias in Manitoba containing nine priority Strategic Issues with Goals and Actions is the result of this process.

A STRATEGY FOR ALZHEIMER DISEASE AND RELATED DEMENTIAS IN MANITOBA

In this Report to Manitoba Health, the Alzheimer Strategy Steering Group recommends a Strategy that contains nine Strategic Issues with related Goals and Actions to guide the development of an implementation plan. The strategy embraces a philosophy that assures quality person-centred care across the continuum of services for individuals with dementia.

Alzheimer Disease and Related Dementia Strategy Philosophy

- ▶ All persons are unique and have intrinsic value, which is not diminished by dementia.
- ▶ All persons have the right to dignity, respect, and to participate fully in their environment.
- ▶ Recognizing that dementia changes a person's capacity to interact with his/her environment, the focus of efforts and resources is to optimize the person's self worth and personal strengths.
- ▶ Living requires making choices, and persons with dementia have the right to choices that involve personal risk.
- ▶ Services and supports are designed and delivered in a way that is integrated, collaborative, and mutually respectful of all persons involved, including: person with dementia, family, informal caregivers and all health care providers.

Strategic Issue 1:

Education for professionals, paraprofessionals, family, individuals, communities and the general public.

In order for people with dementia to have an optimum quality of life, they, their communities, their families, friends and neighbours (hereafter referred to as family) and those staff who are involved with them as they progress through their disease must be informed and educated.

The findings from the Strategy's broad consultation indicated that it is widely believed that education programs do not provide adequate information and opportunity for skill development around the care for people with dementia from diagnosis throughout the continuum of the disease. Specialty programs and advance practice programs are the exception.

Goals:

- ▶ Education for the general public, individuals, families and professionals/paraprofessionals on:
 - Increased awareness of the range of available services and support for people with dementia and their caregivers.
 - How to access services as well as how to effectively utilize the information to navigate the system.
 - Signs and symptoms of Alzheimer Disease and related dementias and how this disease and being diagnosed affect individuals and their quality of life.
- ▶ Education for professional and paraprofessionals on:
 - Appropriate support for people with dementia and their caregivers to access services and effectively navigate the system.
 - Appropriate advice for individuals and families on matters related to the effects of having and on being diagnosed with Alzheimer Disease and related dementias.
 - Development and maintenance of individual skills and knowledge of medical treatment options and other interventions, as well as planning, supporting and providing care for people with dementia and their families.

Actions:

- ▶ Ensure that education programs:
 - Are ongoing and reviewed yearly.
 - Use consistent language and up-to-date information.¹
 - Use clear, accurate consistent underlying message and philosophy.
 - Use multiple communication approaches to target a variety of audiences including interpretive services, multi-media — printed, visual, audio and electronic means of communication.
 - Provide opportunities for skill development using multiple approaches to learning e.g. mentoring, role modeling, and experiential exercises.
- ▶ Design and intensify public awareness initiatives that educate about the disease, reduce stigma, provide knowledge of how to access appropriate services and build community capacity and target specific communities/populations (e.g. Aboriginal, French language, children).
- ▶ Coordinate production and distribution of regional/community resource listings that include printed, visual, audio and electronic means of communication to ensure that they are accurate, available and widely distributed.
- ▶ Expand central information lines, programs/services that are widely advertised and staffed to allow Manitobans access to information, resources and service 24 hours/7 days a week.²
- ▶ Provide centres that offer “one stop shopping” for health services and community development/capacity building.³
- ▶ Increase delivery of workshops for families and people with dementia to all Manitoba communities.
- ▶ Increase resources to produce, distribute and widely circulate standardized print material for awareness, information and education.
- ▶ Support the development of basic/core learning outcomes related to dementia for all levels of curricula for health related disciplines.

1 The Alzheimer Society of Manitoba currently provides this resource and with additional resources, could meet the goal.

2 Expansion of existing services such as Alzheimer Society HELPLINE, Healthlinks and the Seniors Directorate line could meet the goal.

3 The Winnipeg Regional Health Authority Access Centre model describes this kind of centre.

- ▶ Increase opportunity for specialized education through certificate programs or specialized programs.⁴
- ▶ Develop and implement standardized multi-level orientation and educational in-services packages that address more in-depth learning for acute care, long-term care and community settings.
- ▶ Develop and maintain a centralized listing of skilled human resources that can be accessed for in-service education or informal consultation.

⁴ The Dementia Training Program endorsed through the Ontario government through Algonquin College is an example.

Strategic Issue 2:

Guidelines for diagnosis.

Information gained in the Strategy development process points to the need for timely diagnosis, a standardized diagnosis and follow-up protocol, and continuing education of general practitioners and family practice physicians regarding best practice, diagnosis and treatment information.

Goals:

- ▶ Education for physicians on:
 - Assessment and management of people with dementia.
 - Early recognition and appropriate management of people with dementia.
 - Development of clear assessment plans that respect the time constraints of primary care and lead to accurate diagnosis of the cause of the cognitive decline.
 - Development of management plans utilizing available resources.

Actions:

- ▶ Support physicians and other health practitioners/specialists by:
 - Providing easier access to supports such as specialty clinics, nurses and other resources including telehealth.
 - Using alternative health practitioners such as advanced practice nurses and clinical nurse specialists.
- ▶ Develop and distribute Manitoba Guidelines for diagnosis and management of dementia following the Alberta Medical Association Model or suitable alternatives.
- ▶ Simplify provincial prescribing practice policies by linking the ability to prescribe treatments without barriers with specialized Continuing Medical Education credits on Diagnosis and Management of dementia excluding designated specialist physicians (neurologists, geriatricians, psychiatrists). This provides incentives for further education and appropriate prescription practices.⁵

⁵ See Alberta Medical Association Guidelines for Cognitive Impairment: Dementia – Diagnosis to Management. (Alberta Clinical Practice Guidelines Program Working Group, 2002)

Strategic Issue 3:

Standards across all programs and services.

The following needs were clearly expressed in the development of the Strategy:

- ▶ A person-centred approach that is consistent throughout all programs and services.
- ▶ Standard language, definitions and explanations of Alzheimer Disease and related dementias and its effects.
- ▶ Coordinated operation of community and facility-based service systems.
- ▶ Standard practices and guidelines that support optimum quality of care including:
 - specialized training and education for caregivers (paid and unpaid)
 - support for caregivers (paid and unpaid)
 - individualized assessment, individualized person-centred support/care planning
 - meaningful programs and activities
 - specialized human resources
 - supportive physical design
 - transportation
 - decision-making
 - respecting individual choice
 - prevention and response to abuse
 - restraint-free environment
 - end-of-life care

Goals:

- ▶ A philosophy that supports consistent use of a person-centred approach throughout all dementia care programs and services.
- ▶ A standard language, definitions and explanations for dementia and its effects. This should include a biopsychosocial definition of dementia and planning tools that use person-centred language focusing on capacity rather than limitations.
- ▶ Service coordination that eliminates fragmentation and adverse impact of the service system on people with dementia and their caregivers through the progression of the disease to the end-of-life care.
- ▶ Standard practices and guidelines that support optimum quality of care.

Actions:

- ▶ Adopt and commit to the philosophy recommended by the Manitoba Alzheimer Strategy Steering Group in order to change current culture.
- ▶ Develop communication strategies that are respectful, utilize consistent terminology and support the philosophy of self preservation.
- ▶ Investigate needed changes to legislation regarding liability issues in order to support the philosophy of persons with dementia having the right of choice respecting personal risk.
- ▶ Establish an independent advocate process to represent persons with dementia and their supporters.
- ▶ Establish policies, standards and monitoring protocols to promote a healthy and positive environment utilizing ongoing research to maximize a restraint-free lifestyle.
- ▶ Develop a provincial “Bill of Rights” for persons in care in line with the recommended philosophy.
- ▶ Establish standards that include meeting the needs of people with dementia and families from identification of symptoms through progression of the disease to end-of-life care.

Strategic Issue 4:

Family and individual support.

Services and supports are organized around principles that often conflict with the individual needs of persons with the disease and their family. Timing is not always appropriate and is sometimes triggered by events that are not transparent to the individuals concerned, may not be desired/requested and in some cases, require eligibility criteria that are not clear or understood. The service system must become more respectful of this mismatch in order to support families and individuals in their attempts to understand what their needs are and how services can be delivered to meet these needs.

There is a need for:

- ▶ Access to a range of information and support programs that are flexible and timely to meet the varied and changing needs of individuals and their caregivers.
- ▶ More flexible options for families to choose their own care providers.
- ▶ Knowledgeable, flexible and sensitive health care providers, empowered to practice a person-centred approach in providing support and delivering services.

Goals:

- ▶ Flexible, timely, accessible information and support for the individual, their family and/or support network.
- ▶ Improved capacity for service and support at the local, community levels.

Actions:

- ▶ Expand support groups and counselling services for people with dementia and their family (including informal supports).⁶
- ▶ Increase the capacity within communities to support people with dementia. This may be attained by:
 - Adopting a health team model⁷ to develop capacity within communities to address seniors' health needs.
 - Involving communities to help neighbours for example: elderly persons' housing and seniors blocks recruiting volunteers from within to provide supports to those having difficulties.

6 Possible expansion of the Alzheimer Society program, and/or expansion of the Seniors Health Resource Team model.

7 The Seniors Health Team model in Winnipeg Regional Health Authority Rivereast district is an example.

- ▶ Provide services/programs in blocks with high senior population (public and private).
- ▶ Provide all programs and services that are timely, flexible and recognize the needs of the person with dementia and their family and assess needs of caregiver alongside person with dementia.
- ▶ Provide resources that are available to respond to needs.
- ▶ Explore financial support options for families providing care for people with dementia including but not limited to an improved self or family-managed care model.
- ▶ Explore new community housing models and options that meet varied needs of people with dementia.
- ▶ View family caregivers as acting within a “partnership continuum” rather than clients within the health care system. (Lysne, 2002).

Strategic Issue 5:

Comprehensive programs and services for individuals at the community and facility levels.

Changes to available programming, both in facility-based, and community/home care programs are required to make them more comprehensive and responsive to needs. In particular, programming for leisure/recreation and respite, needs to be expanded to provide access to those who require the services.

Goals:

- ▶ Meaningful leisure and recreational opportunities that match individual capacities of persons with dementia.
- ▶ Respite programs that meet the needs of individuals and families caring for persons with dementia.
- ▶ Flexible, dependable, accessible programming, which compensates for changing abilities and promotes functioning within their environment (e.g. physical, social, cultural) in the community or personal care home.

Actions:

- ▶ Ensure that all programs and services have access to affordable and flexible transportation.
- ▶ Develop/expand leisure programs.
 - Expand programs that partner with other organizations (e.g. friendly visiting programs, buddy programs, mobile programs).
 - Integrate leisure programming with other community programs.
 - Develop more flexibility in day/leisure programs (i.e. in seniors blocks).
 - Explore the idea of a “leisure van” that could travel to communities.
 - Develop range of programs to accommodate changing abilities.
 - Augment mainstream recreation programming to increase accessibility for people with dementia.
- ▶ Develop and expand day program opportunities for people with dementia in a variety of sites.
- ▶ Support and promote intergenerational programming.

- ▶ Provide a variety of flexible respite both in and out of personal care home settings, including but not limited to:
 - Expanding the use of the “swing bed” program (Fellman & Gibbs, 2001) where a facility designates a certain number of beds as respite.
 - Simplifying the process to access respite.
 - Ensuring consistent availability of flexible respite options.
 - Exploring and implementing respite innovations such as: including both the caregiver and the person with Alzheimer Disease and related dementias in a program together, holiday camp, home respite from 24 hour to 2 weeks to facilitate caregiver’s absence,⁸ flexible program times (day, evening, weekend), mobile respite and activity/recreation programs, family-managed respite.
- ▶ Provide equitable access to long-term beds: for both short-term treatment and long-term stay for individuals with significant aggressive responses.

8 Baluchon Program – Verdun Quebec.

Strategic Issue 6:

Case management and interdisciplinary collaboration.

There is a need for a model of care that improves access to services and utilizes all available expertise. Task-centred procedures may maximize efficiencies from the provider perspective in an acute medical setting, but for the persons with Alzheimer Disease and related dementias and their families, who are dealing with a long-term disease process, this leads to redundancy and depersonalization/disempowerment. Generally, complex issues are not dealt with in sufficient depth to minimize excess disability thus creating unnecessary dependency and lack of communication between members of the health care team (including the person with the disease and the family).

Goals:

- ▶ Person-centred models in screening, triage and referral services.
- ▶ Ongoing case management educational opportunities supported by a solid philosophy that builds on the individuals' current knowledge and skill base.
- ▶ Case management and interdisciplinary processes and methods that lead to better communication and collaboration.

Actions:

- ▶ Create a mechanism to assign and coordinate a case management approach throughout the course of illness in all cases when formal supports and services are initiated.
- ▶ Identify a health care provider on the clients' health care team as a coordinating person to help guide the clients and their families through the health care system. This person would serve as a case manager and facilitate access to and linkage of services.

Strategic Issue 7:

Equitable access to programs and services across Manitoba.

There is a need for equitable access to assessment, physician specialist services, diagnostic and support services in all areas of the province. All Regional Health Authorities tend to have some components in some communities; but there are inconsistencies both among, and within health authorities and few services appear to be universally or consistently available.

There is a need for regional Dementia Services Plans, which describe:

- ▶ Numbers of persons diagnosed as having dementia, residing in the region.
- ▶ Treatment and care requirements/needs.
- ▶ Current capacity of regional resources to meet those needs.
- ▶ Future/long-term management plans.

Goals:

- ▶ Improved ability of each Regional Health Authority to respond to needs of people with dementia and their caregivers.
- ▶ Enhanced ability of physicians and the health care team to respond in a timely and appropriate manner to the health care needs of people with dementia.

Actions:

- ▶ Develop and implement a set of “core” dementia services that specify appropriate access.
- ▶ Improve resource allocation to achieve equitable access and appropriate interventions.
- ▶ Implement a provincial single point of entry to services.
- ▶ Develop more Community Resource Centres or dementia care specialists who practice at an advanced level to provide resource and support to health care providers, patients and their families.
- ▶ Establish crisis intervention services to respond to dementia issues.⁹

9 Mental Health Mobile Crisis Teams/Programs in Manitoba Regional Health Authorities.

- ▶ Invest in technology as an adjunct to on-site assessment. Technology such as voicemail, e-mail, advanced tele-communications, facilitate collaborative communication that is not limited by traditional time and distance constraints. Teleconferencing or Audiovisual linkages, which involve a number of people being connected via the phone or videos at the same time so that all persons can hear each other and contribute to the discussion.
- ▶ Develop partnerships with educational facilities and encourage student experiences especially in rural and northern settings. Training in special populations and interdisciplinary care are fundamental to the care of vulnerable populations including persons with dementia.

Strategic Issue 8:

Human and financial issues including recruitment, retention and remuneration.

“Dementia care requires sufficient and qualified staff, appropriate activity programming, and various environmental features as described in the literature and research” – *Special Care Unit Working Group Report to Manitoba Health, 1999*. Increasing knowledge regarding the specific needs of individuals with dementia and their families points to the need for a different staff mix than was previously believed to be appropriate. Staffing decisions have not kept pace in response to this new information.

There is a need for sufficient number and mix of health care providers with the appropriate qualifications to meet the needs of individuals in the community, in supportive housing and personal care home environments. There is also a need to support those health care providers through the emotional task of providing person-centred care.

Goals:

- ▶ Sufficient number and mix of health care providers with the appropriate qualifications to meet the changing needs of individuals with dementia and their families in the community, supportive housing and PCH environments.
- ▶ Supportive and empowering work environment for health care providers to provide quality person-centred care through workplace culture changes, education initiatives and better coordination of services.
- ▶ Best practice incentives related to medical assessment of persons with dementia.
- ▶ Incentives to support employment in community and supportive housing environments.

Actions:

- ▶ Develop and implement standards/provincial guidelines related to staff mix and qualifications to deliver the necessary care to individuals with dementia and their families.
- ▶ Develop and implement plans to change culture and attitudes around care of people with dementia.
- ▶ Define practice expectations.
- ▶ Develop performance outcome measures to be used for team performance measurement.

- ▶ Ensure educational opportunities for health care providers are available.
- ▶ Develop resources to support the emotional needs of health care providers.
- ▶ Develop alternate physician payment system, given the time required for assessments.
- ▶ Investigate and address salary/benefit inequities for health care providers across the continuum of care that impedes care provision in certain environments.

Strategic Issue 9:

Ongoing, rigorous research and evaluation.

At the current time there is no systematic synthesis and dissemination of information on best practice and research in Manitoba. Many services and programs are implemented without an evaluation component. There is a need to conduct local (provincial and regional) outcome-based program evaluation with mechanism to communicate best practices.

Bio-medical, psycho-social, and service efficacy (best practice in treatment and care) research is needed in Manitoba. The topics to be researched are diverse and require the involvement of a number of different disciplines and perspectives. At the current time the different access requirements of Manitoba Health, the Regional Health Authorities, and specific programs create a barrier for the conduct of research.

Goals:

- ▶ Up-to-date, comprehensive and appropriate information about best practices in treatment and care of those with Alzheimer Disease and related dementias, with province-wide access to those working and interested in this field.
- ▶ An evaluation component for all services and programs for people with dementia and their caregivers.
- ▶ A recognized centre of excellence for bio-medical and psycho-social research on dementia in Manitoba.

Actions:

- ▶ Establish or expand a resource¹⁰ to collect, synthesize and disseminate information on best practice and research related to dementia. Such a resource would:
 - Act as a central repository for information related to dementia.
 - Conduct literature searches for specific purposes.
 - Provide synthesis information.
 - Translate findings so that they may be utilized in practice.
 - Proactively provide ongoing communication/dissemination of information to highlight advances in this field using diverse formats such as website, e-mail and newsletters.

¹⁰ The Crane Library, a national library, located within Deer Lodge Centre can meet this goal with additional resources.

- ▶ Develop and undertake a communication strategy to advise organizations and individuals of the availability, and how to access this resource.
- ▶ Require that new programs include an outcome-based evaluation component prior to funding and that there are funds available to cover the costs of such evaluations.
- ▶ Begin a process whereby existing services and programs would be required to systematically record information and evaluate their activities.
- ▶ Develop a resource with expertise in various types of program evaluations so that organizations can receive assistance to conduct the necessary evaluations.
- ▶ Conduct on a regular basis province-wide educational workshops on program evaluation and use of best practice related to dementia care.
- ▶ Establish a province-wide Working Group to identify minimum data requirements related to dementia and make recommendations to ensure that information is systematically collected and can be used for evaluation purposes. This Working Group would review existing data collection tools used by Manitoba Health, the Regional Health Authorities, Provincial Network of Psychogeriatrics Program Specialists and Alzheimer Manitoba to determine the information currently collected on dementia, examine restrictions based on various acts related to health information and consider technology needs.
- ▶ Ensure broad dissemination of local service/program evaluations.
- ▶ Increase research funding targeted to dementia by developing partnerships between governments, the private sector and non-government organizations. This funding may be used for such things as operating grants, personnel awards and infrastructure support.
- ▶ Develop co-ordinated access guidelines/policies to provide researchers with a streamlined process of gaining access to people with dementia, existing program data, etc. This will require the establishment of a Working Group to review existing guidelines/policy and to make recommendations.
- ▶ Facilitate the development of a Research Interest Group that will share information and seek ways to encourage/enhance/advocate for research on dementia.
- ▶ Promote dementia research conducted in Manitoba in order to increase visibility and awareness.

Enjeu Stratégique N° 1 :

Éducation des intervenants professionnels et paraprofessionnels, des malades et de leur famille, des collectivités et du grand public

Pour que les personnes atteintes de démence puissent jouir d'une qualité de vie optimale, elles-mêmes, leur collectivité, leur famille, leurs amis et leurs voisins (ci-après appelés la famille), ainsi que les intervenants qui les accompagnent tout au long de leur maladie, doivent être formés et informés.

La vaste consultation menée par le comité a indiqué que l'on croit généralement que les programmes d'éducation ne fournissent ni l'information ni l'occasion adéquates pour parfaire les connaissances nécessaires pour donner des soins aux personnes atteintes de démence, et ce, à partir du moment où le diagnostic est posé, pendant tout le continuum des soins. Les programmes spécialisés et les programmes de pratique avancée sont l'exception.

Buts :

- ▶ Éducation du grand public, des malades, de leur famille, des intervenants professionnels et paraprofessionnels visant :
 - une sensibilisation accrue à la gamme de services offerts et au soutien aux malades et aux soignants;
 - un accès aux services et une utilisation efficace de l'information afin de trouver son chemin dans le système;
 - les signes et les symptômes de la maladie d'Alzheimer et des démences connexes et la façon dont ces maladies peuvent affecter les personnes atteintes et influencer sur leur qualité de vie.
- ▶ Éducation des intervenants professionnels et paraprofessionnels visant :
 - un soutien approprié aux malades et aux soignants pour leur permettre d'avoir accès aux services et de trouver efficacement leur chemin dans le système;
 - des conseils appropriés aux malades et à leur famille sur des sujets liés au fait d'avoir la maladie d'Alzheimer ou une démence connexe;
 - le perfectionnement des compétences et des connaissances individuelles relatives aux traitements médicaux et autres interventions possibles, ainsi que la planification et la prestation des soins et le soutien aux malades et à leur famille.

Mesures :

- ▶ S'assurer que les programmes d'éducation :
 - sont continus et révisés tous les ans;
 - utilisent un langage cohérent et une information à jour;¹
 - s'articulent sur un message et une philosophie sous-jacents qui sont clairs, exacts et cohérents;
 - utilisent de multiples approches de communication, de façon à cibler des publics variés, dont les services de présentation et les médias imprimés, visuels, audio et électroniques;
 - créent des possibilités de perfectionnement professionnel en utilisant de multiples approches d'apprentissage, par exemple le mentorat, l'imitation de rôles et des exercices expérimentaux;
- ▶ élaborent et fortifient des initiatives de sensibilisation publique ayant pour but d'informer sur la maladie, de réduire la stigmatisation des malades, d'informer sur l'accès aux services appropriés, de renforcer les capacités communautaires et de cibler des publics bien précis comme, par exemple, les Autochtones, les francophones, les enfants;
- ▶ coordonnent la production et la distribution de répertoires des ressources régionales ou communautaires, incluant des communications imprimées, visuelles, audio et électroniques, de façon à assurer leur exactitude, de même que leur accessibilité par une large distribution;
- ▶ développent les lignes, les programmes et les services centraux d'information qui sont largement publicisés et bien dotés en personnel afin de permettre aux Manitobains et Manitobaines un meilleur accès à l'information et aux ressources, et ce, 24 heures sur 24, sept jours sur sept;²
- ▶ offrent, par le truchement de certains centres, un guichet unique vers les services de santé et le renforcement des capacités communautaires;³
- ▶ organisent des ateliers à l'intention des malades et de leur famille dans toutes les communautés de la province;

1 La Alzheimer Society du Manitoba travaille actuellement dans ce sens et, à l'aide de ressources additionnelles, pourrait atteindre le but.

2 L'expansion de services existants comme la Alzheimer Society HELPLINE (ligne secours), Healthlink et la ligne d'aide de la Direction générale des services aux personnes âgées pourrait permettre d'atteindre le but.

3 Le modèle adopté par le Centre d'accès de l'Office régional de la santé de Winnipeg décrit ce genre de centre.

- ▶ augmentent les ressources de production et de distribution afin de diffuser sur une grande échelle des imprimés normalisés favorisant la sensibilisation, l'information et l'éducation;
- ▶ soutiennent l'élaboration d'un programme prioritaire d'apprentissage de base lié aux démences, à tous les niveaux des programmes d'études dans le domaine de la santé;
- ▶ améliorent l'accès à une éducation spécialisée, grâce à des cours sanctionnés par un certificat et à des programmes de spécialisation;⁴
- ▶ élaborent et mettent en œuvre des programmes d'orientation et d'éducation qui sont normalisés, multiniveaux et donnés à l'intérieur des services, et qui visent un apprentissage plus approfondi sur le plan de soins de courte et de longue durée, et dans le cadre des collectivités;
- ▶ élaborent et tiennent à jour un répertoire centralisé de ressources humaines spécialisées auxquelles on peut s'adresser pour de la formation donnée à l'intérieur des services ou pour des consultations amicales.

⁴ Le programme de formation relative à la démence offert par le Algonquin College et appuyé par le gouvernement de l'Ontario peut servir d'exemple.

Enjeu Stratégique N° 2 :

Directives concernant l'établissement des diagnostics

L'information recueillie pendant le processus d'élaboration de la stratégie indique la nécessité d'établir un diagnostic en temps opportun, de normaliser un diagnostic ainsi qu'un protocole de suivi, d'offrir de la formation continue aux généralistes et aux omnipraticiens en matière de pratique exemplaire, de diagnostic et de traitement.

Buts :

- ▶ Éducation des médecins relativement à :
 - l'évaluation et à la prise en charge des personnes atteintes de démence;
 - la détection précoce et à la prise en charge appropriée des personnes atteintes de démence;
 - l'élaboration de plans d'évaluation clairs qui respectent les contraintes de temps qu'imposent les soins de première ligne et conduisent à un diagnostic exact de la cause du déclin des fonctions cognitives;
 - l'élaboration de plans de prise en charge qui utilisent les ressources disponibles.

Mesures :

- ▶ Soutenir le travail des médecins et autres praticiens et spécialistes de la santé en :
 - facilitant l'accès à des ressources telles que les cliniques spécialisées, le personnel infirmier et Télésanté;
 - ayant recours à des praticiens de la santé tels que les infirmières exerçant à un niveau avancé et les infirmières cliniciennes spécialisées;
- ▶ élaborant et distribuant les directives manitobaines concernant l'établissement des diagnostics et la prise en charge des personnes atteintes de démence d'après le modèle mis de l'avant par l'association médicale de l'Alberta ou tout autre modèle approprié;
- ▶ simplifiant les politiques provinciales encadrant la pratique en matière d'ordonnance par l'établissement d'un lien entre la faculté de prescrire des traitements sans entrave et les crédits que procure la formation médicale continue sur le diagnostic et la prise en charge des personnes atteintes de démence, à l'exclusion des médecins spécialistes désignés (neurologues, gériatres, psychiatres). Une telle approche encourage le perfectionnement professionnel et la mise en place de pratiques appropriées en matière d'ordonnance.⁵

5 Voir les *Guidelines for Cognitive Impairment : Dementia – Diagnosis to Management* adoptées par la Alberta Medical Association. (Alberta Clinical Practice Guidelines Program Working Group, 2002)

Enjeu Stratégique N° 3 :

Normes s'appliquant à tous les programmes et à tous les services

Les besoins suivants ont été clairement exprimés lors de l'élaboration de la stratégie :

- ▶ une approche axée sur la personne qui est cohérente dans tous les programmes et tous les services;
- ▶ l'utilisation d'un vocabulaire, de définitions et d'explications normalisés pour traiter de la maladie d'Alzheimer, des démences connexes et de leurs conséquences;
- ▶ le fonctionnement coordonné des systèmes de services axés sur les collectivités et de ceux axés sur les établissements;
- ▶ des pratiques et des directives standard qui appuient une qualité optimale des soins, incluant :
 - de la formation spécialisée à l'intention des personnes soignantes (rémunérées et non rémunérées);
 - un soutien aux personnes soignantes (rémunérées et non rémunérées);
 - une évaluation personnalisée et la planification de soins et d'aide personnalisés axés sur la personne;
 - des programmes et des activités constructifs;
 - des ressources humaines spécialisées;
 - un aménagement rationnel de l'équipement;
 - le transport;
 - le processus décisionnel;
 - le respect des choix individuels;
 - la prévention des abus et la façon d'y remédier;
 - un milieu sans contention;
 - les soins au terme de la vie.

Buts :

- ▶ Une philosophie qui appuie l'utilisation cohérente d'une approche axée sur la personne dans tous les programmes et les services de soins aux personnes atteintes de démence;
- ▶ un vocabulaire, des définitions et des explications normalisés pour traiter de la démence et de ses conséquences; cette approche devrait inclure une définition biopsychosociale de la démence et des outils de planification qui s'articulent sur un langage axé sur la personne qui met l'accent sur les capacités plutôt que sur les limites;
- ▶ une coordination des services qui élimine la fragmentation et les effets néfastes du système de services sur les personnes atteintes de démence et sur leurs soignants tout au long de l'évolution de la maladie jusqu'à sa phase terminale;
- ▶ des pratiques et des directives standard qui appuient une qualité optimale des soins.

Mesures :

- ▶ Adopter et s'engager à suivre la philosophie recommandée par le groupe directeur du Comité chargé de la stratégie relative à la maladie d'Alzheimer et aux démences connexes afin de faire évoluer les mentalités.
- ▶ Élaborer des stratégies de communication qui respectent les malades, s'articulent sur une terminologie cohérente et soutiennent l'idée de conservation de soi.
- ▶ Examiner les changements souhaitables aux dispositions législatives ayant trait aux questions de responsabilité, afin de soutenir l'idée selon laquelle les personnes atteintes de démence ont le libre choix en ce qui concerne les risques pouvant les menacer.
- ▶ Instaurer un processus permettant la nomination de mandataires pour défendre les intérêts des personnes atteintes de démence et de ceux qui les soutiennent.
- ▶ Établir des politiques, des normes et des protocoles de suivi contribuant à un milieu sain et positif utilisant la recherche continue afin de favoriser un mode de vie sans contention.
- ▶ Élaborer une « Charte des droits » provinciale pour les personnes qui reçoivent des soins qui s'aligne sur la philosophie recommandée.
- ▶ Établir des normes qui répondent aux besoins des personnes atteintes de démence et de leur famille pendant toute la progression de la maladie, c'est-à-dire à partir de l'observation des symptômes jusqu'au terme de la vie.

Enjeu Stratégique N° 4 :

Soutien aux malades et à leur famille

Les services et les mesures de soutien sont organisés autour de principes qui entrent souvent en conflit avec les besoins individuels des personnes atteintes de démence et de leur famille. Le moment choisi pour intervenir n'est pas toujours opportun et est parfois déterminé par des circonstances qui ne sont pas claires pour les personnes concernées. L'intervention peut donc ne pas être désirée et, dans certains cas, peut même renvoyer à des critères d'admissibilité qui ne sont pas clairs ou ne sont pas compris. Le système de services doit se montrer plus respectueux des besoins individuels afin d'aider les familles et les malades à comprendre quels sont leurs besoins et de quelle façon la prestation de services peut contribuer à y répondre.

Il est nécessaire :

- ▶ d'avoir accès à une gamme de programmes d'information et de soutien qui sont flexibles et interviennent en temps opportun afin de répondre aux besoins changeants des malades et de leurs soignants;
- ▶ d'offrir plus de souplesse aux familles qui veulent choisir leurs propres fournisseurs de soins de santé;
- ▶ de pouvoir compter sur des fournisseurs de soins de santé qui possèdent les connaissances, la souplesse et la sensibilité requises, et qui ont le pouvoir de pratiquer une approche axée sur la personne dans les mesures de soutien et dans les services qu'ils offrent.

Buts :

- ▶ Rendre souples et accessibles l'information et les mesures de soutien destinées aux malades, aux familles ou au réseau de soutien, et les offrir en temps utile;
- ▶ améliorer la capacité des services et des mesures de soutien aux niveaux local et communautaire.

Mesures :

- ▶ Augmenter le nombre de groupes de soutien et de services de counseling à l'intention des personnes atteintes de démence et de leur famille (y compris le soutien informel).⁶

⁶ L'expansion possible du programme de la Alzheimer Society et l'expansion du modèle de l'équipe ressource en santé des personnes âgées.

- ▶ Augmenter, au sein des collectivités, la capacité de soutenir les personnes atteintes de démence. Ce résultat peut être atteint en :
 - adoptant le modèle d'équipe de soignants⁷ afin de développer au sein des collectivités la capacité de s'occuper des besoins en santé des personnes âgées;
 - encourageant les collectivités à aider les voisins. Par exemple, des aînés vivant dans des habitations pour personnes âgées qui recrutent des bénévoles dans leurs propres rangs afin de venir en aide à ceux d'entre eux qui éprouvent des difficultés.
- ▶ Offrir des services et des programmes dans les immeubles où les aînés forment une part importante des occupants (immeubles relevant tant du secteur public que privé).
- ▶ Offrir en temps utile tous les programmes et tous les services qui sont flexibles, reconnaître les besoins des personnes atteintes de démence et de leur famille et évaluer parallèlement les besoins des soignants.
- ▶ Fournir les ressources disponibles afin de répondre aux besoins.
- ▶ Explorer les possibilités d'aide financière pour les familles qui fournissent des soins aux personnes atteintes de démence, y compris mais non exclusivement, celles ayant adopté un modèle amélioré d'autogestion ou de gestion familiale des soins.
- ▶ Examiner les nouveaux modèles et les nouvelles options en matière de logement communautaire qui répondent aux besoins variés des personnes atteintes de démence.
- ▶ Voir les soignants familiaux comme des « partenaires dans le continuum des soins » plutôt que comme des clients à l'intérieur du système de soins de santé (Lysne, 2002).

⁷ Le modèle de l'équipe ressource en santé des personnes âgées du quartier de Rivereast, à Winnipeg (Office régional de la santé de Rivereast), peut servir d'exemple.

Enjeu Stratégique N° 5 :

Programmes et services complets à l'intention des malades, au niveau des collectivités et dans les établissements

Les modifications aux programmes disponibles, tant les programmes fondés sur les soins en établissement que ceux fondés sur les soins à domicile ou dans la collectivité, doivent rendre ces programmes plus exhaustifs et plus sensibles aux besoins. En particulier, les programmes de loisir et de répit doivent être agrandis afin de les rendre accessibles à tous ceux qui en ont besoin.

Buts :

- ▶ Offrir des activités de loisir fructueuses qui s'harmonisent aux capacités individuelles des personnes atteintes de démence;
- ▶ offrir des programmes de répit qui répondent aux besoins des personnes et des familles qui prennent soin de personnes atteintes de démence;
- ▶ offrir des programmes souples, fiables et accessibles qui s'ajustent au déclin des capacités et favorisent le fonctionnement des malades dans leur environnement (physique, social, culturel) au sein de la collectivité ou dans un foyer de soins personnels.

Mesures :

- ▶ S'assurer que tous les programmes et tous les services donnent accès à des transports qui sont à un prix abordable et offrent un service flexible.
- ▶ Développer les programmes de loisir.
 - Étendre les programmes qui fonctionnent en partenariat avec d'autres organismes (par exemple des programmes de visites amicales ou de surveillance mutuelle, des programmes mobiles).
 - Intégrer les programmes de loisir dans les autres programmes communautaires.
 - Améliorer la souplesse des programmes de loisir et des programmes de jour (c.-à-d. dans des immeubles occupés par des personnes âgées).
 - Explorer l'idée d'une « fourgonnette de loisir » qui pourrait se rendre dans diverses communautés.
 - Élaborer un éventail de programmes afin de s'ajuster au déclin des capacités.
 - Augmenter le nombre de programmes de loisir grand public afin de les rendre plus accessibles aux personnes atteintes de démence.

- ▶ Développer les possibilités d'offrir en divers endroits des programmes de jour à l'intention des personnes atteintes de démence.
- ▶ Soutenir et promouvoir les programmes intergénérationnels.
- ▶ Fournir des soins de relève variés tant à l'intérieur qu'à l'extérieur des foyers de soins personnels, y compris, mais non exclusivement :
 - étendre le recours au programme de « lit tampon » (Fellman & Gibbs, 2001), qui permet à un établissement de réserver un certain nombre de lits aux soins de relève;
 - simplifier le processus permettant d'avoir accès aux soins de relève;
 - assurer un choix cohérent et souple de soins de relève;
 - Examiner et mettre en œuvre des mesures innovatrices en matière de soins de relève, comme : réunir le fournisseur de soins aussi bien que la personne atteinte de la maladie d'Alzheimer ou d'une démence connexe dans un même programme; organiser des camps de vacances; offrir des soins de relève à domicile pour une durée allant de 24 heures à deux semaines afin de permettre au fournisseur de soins de s'absenter plus facilement;⁸ offrir des programmes à horaire variable (jour, soir, fin de semaine), des programmes mobiles de soins de relève, d'activités et de loisir, des programmes de répit administrés par la famille.
- ▶ Rendre équitable l'accès aux lits pour soins de longue durée : pour les malades qui peuvent réagir de façon très agressive tant à des traitements de courte durée qu'à des séjours prolongés.

8 Le programme Baluchon – Verdun (Montréal) (Québec).

Enjeu Stratégique N° 6 :

Prise en charge des cas et coopération interdisciplinaire

Il est nécessaire d'opter pour un modèle de soins qui améliore l'accès aux services et a recours à toute l'expertise disponible. Les procédures axées sur la tâche à accomplir peuvent maximiser l'efficacité, du point de vue du fournisseur de soins dans un milieu très médicalisé, mais, pour la personne atteinte de la maladie d'Alzheimer ou d'une démence connexe et sa famille, qui font face à un long processus morbide, cette façon de faire conduit au double emploi, à la dépersonnalisation et à la perte d'autonomie. En règle générale, les questions complexes ne sont pas traitées avec suffisamment de profondeur pour minimiser la déficience exceptionnelle, ce qui crée une dépendance inutile et entraîne un manque de communication entre les membres de l'équipe soignante (incluant le malade et sa famille).

Buts :

- ▶ Élaborer des modèles axés sur la personne dans les services de présélection, de sélection et d'aiguillage.
- ▶ Offrir des possibilités éducatives, dans la prise en charge continue des cas, qui prennent appui sur une philosophie solide, elle-même fortifiée par les connaissances et les compétences individuelles actuelles.
- ▶ Élaborer des processus et des méthodes interdisciplinaires et de prise en charge des cas qui conduisent à une meilleure communication et à une meilleure collaboration.

Mesures :

- ▶ Créer un mécanisme d'affectation et de coordination pour la prise en charge des cas pendant le cours de la maladie dans tous les cas où des mesures de soutien et des services formels sont institués.
- ▶ Désigner un fournisseur de soins au sein de l'équipe soignante pour servir de coordonnateur et guider le client, ainsi que sa famille, à travers le réseau des soins de santé. Cette personne s'occuperait de la gestion du cas et favoriserait l'accès aux services et les liens entre ceux-ci.

Enjeu Stratégique N° 7 :

Équité de l'accès aux programmes et aux services dans tout le Manitoba

Il est nécessaire de rendre équitable l'accès aux services d'évaluation, d'un médecin spécialiste, de diagnostic et de soutien dans toute la province. Tous les offices régionaux de la santé ont tendance à offrir des services partiels dans certaines collectivités, mais il y a des incohérences tant à l'intérieur des offices régionaux qu'entre eux, et peu de services semblent être universellement accessibles et invariablement accessibles.

Des plans de services régionaux pour les personnes atteintes de démence sont nécessaires. Ils devraient contenir les renseignements suivants :

- ▶ le nombre de personnes atteintes de démence qui habitent la région;
- ▶ les besoins et les exigences concernant les traitements et les soins;
- ▶ la capacité actuelle des ressources régionales de répondre à ces besoins;
- ▶ les plans de gestion futurs et à long terme.

Buts :

- ▶ Améliorer la capacité de chacun des offices régionaux de la santé de répondre aux besoins des personnes atteintes de démence et à ceux de leurs soignants.
- ▶ Augmenter la capacité des médecins et de l'équipe soignante de répondre de manière appropriée et en temps utile aux besoins en soins de santé des personnes atteintes de démence.

Mesures :

- ▶ Élaborer et mettre en application un ensemble de services « de base » à l'intention des personnes atteintes de démence qui précisent les voies d'accès appropriées.
- ▶ Améliorer l'attribution des ressources afin de parvenir à un accès équitable et à des interventions appropriées.
- ▶ Mettre en œuvre un guichet provincial unique vers les services.
- ▶ Développer plus de centres de ressources communautaires ou former plus de spécialistes des soins aux personnes atteintes de démence qui pratiquent à un niveau avancé afin d'offrir les ressources et le soutien nécessaires aux fournisseurs de soins, aux malades et à leur famille.

- ▶ Établir des services d'intervention en situation de crise afin de s'occuper des questions liées à la démence.⁹
- ▶ Investir dans la technologie comme dans un moyen auxiliaire de l'évaluation sur place. Des technologies comme la boîte vocale, le courriel et les télécommunications de pointe facilitent la communication faite en collaboration, qui n'est pas assujettie aux contraintes traditionnelles de temps et distance. La téléconférence ou les liaisons audiovisuelles, qui impliquent la participation simultanée d'un certain nombre de personnes reliées entre elles, de façon que chacune puisse entendre les autres et prendre part à la discussion.
- ▶ Développer des partenariats avec des établissements d'enseignement et encourager la participation des élèves, particulièrement dans les régions rurales et du nord de la province. La formation dans les populations ayant des besoins particuliers et les soins interdisciplinaires sont cruciaux pour soigner les personnes vulnérables, y compris celles atteintes de démence.

9 Les équipes mobiles d'intervention d'urgence au sein des offices régionaux de la santé du Manitoba.

Enjeu Stratégique N° 8 :

Questions d'ordre humain et financier incluant le recrutement, le maintien et la rémunération de l'effectif

« Les soins aux personnes atteintes de démence nécessitent un personnel qualifié et en nombre suffisant, des programmes d'activités appropriés et diverses caractéristiques propres au milieu, conformément à ce qui est décrit dans la documentation et les rapports de recherche. » — *Rapport présenté à Santé Manitoba par le groupe de travail de l'unité prothétique, 1999* (traduction libre). Le progrès des connaissances au sujet des besoins spécifiques des personnes atteintes de démence et de leur famille montre la nécessité d'une combinaison de soignants et d'intervenants différente de celle que l'on croyait appropriée. Les décisions en matière de dotation en personnel n'ont pas suivi le rythme de cette nouvelle information.

Il est nécessaire d'avoir un nombre et une combinaison suffisants de fournisseurs de soins de santé qualifiés afin de répondre adéquatement aux besoins des personnes, et ce, au sein des collectivités, dans les logements avec services de soutien et les foyers de soins personnels. Il est également nécessaire de soutenir les efforts de ces fournisseurs de soins de santé pour leur permettre d'accomplir la tâche, difficile sur le plan émotif, de fournir des soins axés sur la personne.

Buts :

- ▶ Avoir un nombre et une combinaison suffisants de fournisseurs de soins de santé qualifiés afin de répondre adéquatement aux besoins changeants des personnes atteintes de démence et de leur famille, et ce, au sein des collectivités, dans les logements avec services de soutien et les foyers de soins personnels.
- ▶ Offrir un milieu de travail positif et favorisant l'autonomie afin que les fournisseurs de soins de santé puissent donner des soins de qualité axés sur la personne, grâce à des changements dans la culture du milieu de travail, à des initiatives en matière d'éducation et à une meilleure coordination des services.
- ▶ Encourager les pratiques exemplaires relativement à l'évaluation médicale des personnes atteintes de démence.
- ▶ Encourager et soutenir l'emploi au niveau des collectivités et des logements avec services de soutien.

Mesures :

- ▶ Élaborer et mettre en œuvre des normes et des lignes directrices provinciales relativement aux combinaisons de personnel et à la qualification de celui-ci en vue de pouvoir fournir les soins nécessaires aux personnes atteintes de démence et à leur famille.
- ▶ Élaborer et mettre en œuvre des plans en vue de changer les mentalités et les attitudes à propos des soins aux personnes atteintes de démence.
- ▶ Déterminer les attentes en matière de pratique.
- ▶ Élaborer des instruments de mesure du rendement qui serviront à mesurer la performance de l'équipe soignante.
- ▶ S'assurer que les fournisseurs de soins de santé ont des possibilités de formation.
- ▶ Développer des ressources pour soutenir les besoins émotifs des fournisseurs de soins de santé.
- ▶ Mettre au point un système parallèle pour payer les honoraires des médecins, étant donné le temps nécessaire pour faire les évaluations.
- ▶ Examiner les iniquités salariales qui frappent les fournisseurs de soins de santé tout au long du continuum des soins et s'y attaquer; ces iniquités nuisent à la prestation de services dans certains milieux.

Enjeu Stratégique N° 9 :

Recherche et évaluation continues et rigoureuses

À l'heure actuelle, il n'y a pas au Manitoba de synthèse ni de diffusion systématique des normes de pratiques exemplaires et des travaux de recherche. De nombreux services et programmes sont mis en œuvre sans être dotés d'un mécanisme d'évaluation. Il est nécessaire d'évaluer les programmes locaux (provinciaux et régionaux) basés sur les résultats et de disposer d'un mécanisme de communication des pratiques exemplaires.

Le Manitoba a besoin de recherche biomédicale et psychosociale, et dans le domaine de l'efficacité des services (pratiques exemplaires dans le traitement et les soins). Les sujets de recherche sont diversifiés et nécessitent la participation de personnes venant d'horizons divers et pratiquant différentes disciplines. Au moment présent, les exigences concernant l'accès aux soins, tant celles fixées par Santé Manitoba, par les offices régionaux de la santé que par certains programmes, font obstacle à la recherche.

Buts :

- ▶ Offrir de l'information à jour, complète et appropriée sur les pratiques exemplaires dans le traitement des personnes atteintes de la maladie d'Alzheimer ou d'une démence connexe et dans les soins à leur donner. Cette information devrait être accessible à l'échelle de la province aux personnes qui travaillent dans ce domaine.
- ▶ Mettre en application un mécanisme d'évaluation pour tous les services et tous les programmes destinés aux personnes atteintes de démence et à leurs soignants.
- ▶ Ouvrir un centre d'excellence reconnu pour la recherche biomédicale et psychosociale sur la démence au Manitoba.

Mesures :

- ▶ Établir ou élargir une ressource¹⁰ ayant pour but de collecter, de synthétiser et de diffuser l'information sur les pratiques exemplaires et la recherche liées aux démences. Une telle ressource :
 - agirait à titre d'organe d'archivage pour l'information liée aux démences;
 - chercherait de la documentation à des fins particulières;
 - fournirait de l'information de synthèse;

10 La Crane Library, une bibliothèque nationale située dans le Deer Lodge Centre, pourrait atteindre le but grâce à des ressources additionnelles.

- traiterait les résultats de recherche de façon qu'ils puissent être mis en pratique;
 - communiquerait et diffuserait de l'information dynamique et continue afin de souligner les progrès accomplis dans ce domaine, en employant des outils tels que le site Web, le courriel et le bulletin.
- ▶ Élaborer et lancer une stratégie de communication afin d'informer les organismes et les personnes sur la disponibilité de cette ressource et la manière d'y avoir accès.
 - ▶ Exiger que les nouveaux programmes comportent un volet d'évaluation basée sur les résultats avant de les financer et qu'il y a des fonds suffisants pour couvrir le coût de telles évaluations.
 - ▶ Entreprendre un processus par lequel les services et les programmes existants seraient tenus d'enregistrer systématiquement l'information et d'évaluer leurs activités.
 - ▶ Développer une ressource ayant une expertise dans divers types d'évaluation de programmes afin que les organismes puissent recevoir de l'aide pour effectuer les évaluations nécessaires.
 - ▶ Organiser de façon régulière, à l'échelle de la province, des ateliers éducatifs sur l'évaluation de programme et le recours aux pratiques exemplaires dans le domaine des soins aux personnes atteintes de démence.
 - ▶ Mettre sur pied un groupe de travail à l'échelle de la province qui déterminerait les exigences minimales en matière de renseignements sur la démence, et ferait des recommandations visant la collecte systématique de l'information et l'utilisation de celle-ci à des fins d'évaluation. Ce groupe de travail réviserait les outils de collecte de données existants — employés par Santé Manitoba, les offices régionaux de la santé, le réseau provincial des spécialistes des programmes psychogériatriques et Alzheimer Manitoba — pour déterminer l'information actuellement recueillie sur la démence, examiner les restrictions fondées sur diverses lois liées à l'information en matière de santé et évaluer les besoins technologiques.
 - ▶ Assurer une large diffusion des évaluations des services et des programmes locaux.
 - ▶ Augmenter le financement accordé à la recherche sur la démence en élaborant des partenariats entre les gouvernements, le secteur privé et les organismes non gouvernementaux. Ce financement pourrait prendre la forme de subventions de fonctionnement, de bourses au personnel et de mesures de soutien des infrastructures.

- ▶ Élaborer des directives et des politiques coordonnées afin de fournir aux chercheurs un processus rationalisé leur donnant accès aux personnes atteintes de démence, les données sur les programmes existants, etc. Cette mesure exigera la mise sur pied d'un groupe de travail qui aura pour tâche de réviser les directives et les politiques existantes et de faire des recommandations.
- ▶ Faciliter la création d'un groupe de recherche fondé sur la communauté d'intérêts qui partagera l'information et cherchera des moyens d'encourager et d'accentuer la recherche sur la démence.
- ▶ Promouvoir la recherche sur la démence au Manitoba afin d'accroître la visibilité et la sensibilité.

APPENDIX A: A DESCRIPTION OF ALZHEIMER DISEASE AND RELATED DEMENTIAS

Dementia is a syndrome consisting of a number of symptoms that include loss of memory, judgment and reasoning, and changes in mood and behaviour. These symptoms may affect a person's functioning at work, in social relationships or in day-to-day activities. Sometimes symptoms of dementia can be caused by conditions that may be treatable, such as depression, thyroid disease, infections or drug interactions.

Alzheimer Disease, the leading cause of dementia, accounts for 75 percent of all dementias in Manitoba. The features of Alzheimer Disease include a gradual onset and continuing decline of memory, as well as changes in judgment or reasoning, and inability to perform familiar tasks. The specific cause of Alzheimer Disease is unknown. At present, there is no cure for Alzheimer Disease and no treatment that will stop its progression. However, several medications are available that may be used to manage some of the symptoms. The treatments do not work for everyone and are effective for a limited time. However, by understanding the person's personality, life experiences, support systems and ways of coping, an approach to care that preserves the individual's quality of life can be created.

Related dementias (other than Alzheimer Disease) may be demonstrated through symptoms of sudden onset of memory loss, early behaviour problems, or difficulties with speech and movement. Causes may be related to vascular dementia, Creutzfeldt-Jakob Disease, Lewy body Dementia or Pick's Disease.

1. The Effects of Alzheimer Disease and Related Dementias

Alzheimer Disease and related dementias affect individuals differently and eventually impact all aspects of a person's life — how he or she thinks, feels and acts. Although the disease results in changes, it does not affect the person's ability to appreciate and respond to feelings such as joy, anger, fear, sadness or love. Social function is maintained late into the process of the disease.

It is difficult to predict the symptoms each person will have, the order in which they will appear or the speed of the disease's progression. The disease may affect the following:

1.1 Mental abilities

- ▶ A person's ability to understand, think, remember and communicate may be reduced.
- ▶ The ability to make decisions may be reduced.

- ▶ Simple tasks that have been performed for years may become more difficult or be forgotten.
- ▶ Confusion and memory loss, initially for recent events and eventually for long-term events, may occur.
- ▶ The ability to find the right words and follow a conversation may be affected.

1.2 Emotions and moods

- ▶ A person's ability to control mood and emotion may be lost or reduced.
- ▶ Some individuals have less expression, are more withdrawn or less active.
- ▶ As the disease progresses, the person may no longer recognize people or familiar places.

1.3 Behaviour

Changes in the brain may bring about changes in the way the person reacts to his or her environment. These actions may seem out of character for the person. Some common reactions include:

- ▶ Wandering from home
- ▶ Repeating the same action or words
- ▶ Hiding possessions
- ▶ Physical outbursts
- ▶ Restlessness
- ▶ Inappropriate sexual advances

1.4 Functional abilities

The disease may affect a person's physical co-ordination. As the disease progresses, there may be a gradual physical decline. These changes may impact on the person's ability to independently perform day-to-day tasks, such as eating, bathing and getting dressed.

1.5 Effects on family and caregivers

The effects of the disease on the individual also impact families and caregivers. Some caregivers may experience adverse effect on their health. Medical models often focus on the affected individual without recognizing the need to provide support to caregivers.

2. Prevalence of Alzheimer Disease and Related Dementias

The number of Manitobans age 65 years or older has increased from 12.1 percent of the total population in 1985 to 13.6 percent of the total population in the year 2001.

It is projected that by 2021, seniors age 65 years or over will constitute 18.8 percent of the population. (Statistics Canada, 2001).

The Canadian Study of Health and Aging estimates that there will be approximately 60,150 new cases of Alzheimer Disease and related dementias in Canada each year. (Canadian Study on Health and Aging Working Group, 2000).

It has estimated that, by 2011, there will be 475,000 Canadians with Alzheimer Disease and related dementias. By 2031, the number is expected to be 778,000. (Canadian Study of Health and Aging Working Group, 1994).

Prevalence rates for Manitoba have been calculated by researchers at the University of Manitoba's Centre on Aging, drawing on data collected for the Manitoba Study of Health and Aging.

The estimated number of Manitobans age 65+ affected by Alzheimer Disease and related dementias was 12,074. This represented 8.2 percent of Manitoba's population age 65+ or 1 in 12 individuals in this age group.

The prevalence rate was higher for women than for men:

- ▶ 1 in 10 females age 65+
- ▶ 1 in 18 males age 65+

Increasing age was associated with an increased likelihood of having Alzheimer Disease and related dementias:

- ▶ 1 in 37 between ages 65-74
- ▶ 1 in 11 between ages 75-84
- ▶ 1 in 3 age 85 and older

The researchers also found that Alzheimer Disease was the most common form of dementia; it accounted for 75 percent of all dementias in Manitoba.

These rates were very similar to the Canadian rates reported by the Canadian Study of Health and Aging.

APPENDIX B: SERVICES AND SUPPORTS FOR INDIVIDUALS WITH ALZHEIMER DISEASE AND RELATED DEMENTIAS IN MANITOBA

Manitoba provides a variety of programs and services throughout the province for seniors. Some programs and services are specific to individual Regional Health Authorities, but most are accessible and beneficial to individuals with dementia. A scan of the programs and services that are available to seniors in Manitoba revealed that apart from those provided by the Alzheimer Society of Manitoba, there are relatively few that are specifically designed for those individuals with Alzheimer Disease and related dementias. Currently individuals with dementia may access the following programs and services in Manitoba:

Manitoba Home Care Program

The Manitoba Home Care Program is a comprehensive, province-wide, universal program that provides Home Care to Manitobans of all ages based on assessed need and taking into account other resources available to the individual including families, community resources and other programs.

Individuals with Alzheimer Disease and related dementias benefit from the Home Care Program as the Program provides the opportunity for them to remain in their own home as long as safely possible with essential in-home support, thus minimizing changes in their surroundings and the risk of confusion. When living in the community is no longer a viable alternative, the Program provides coordination and support, for admission to health care facilities.

- ▶ **Self-Managed Care Option:** Self-managed care is an option within the Home Care Program through which individuals manage and arrange for their own personal care and home support services. Financial assistance is provided to assist eligible individuals in taking full responsibility for arranging, coordinating and managing those non-professional services required for meeting their assessed home care needs.
- ▶ **Family-Managed Care Option:** This option, similar to Self-Managed Care in which designated family members assume the care management responsibilities on behalf of the client, has extended the flexibility of this type of arrangement to more seniors.

- ▶ **Respite Care:** Respite Care provides a period of planned relief to families/caregivers who are committed to maintaining the person that they support in the community. Respite care can be provided in a personal care home, hospital, and adult day program or in the client's home.
- ▶ **Adult Day Program:** Adult Day Programming is a component of the Home Care Program. It is currently the result of joint planning between the Regional Health Authority, Manitoba Health and the sponsor. It assists individuals living in the community to maintain their independence for as long as possible. It promotes health maintenance and provides opportunities for recreational, social and peer interaction through organized group programming in a supportive environment to those who may be socially isolated. The program provides respite to caregivers who may themselves be frail and at risk.
- ▶ **Supportive Housing:** This option provides for the delivery of personal care, personal support services and essential home making services in a grouped community housing setting for individuals whose needs justify the availability of staff on a 24-hour basis.

Inpatient Psychogeriatric Units

The units provide short-term assessment and treatment on an inpatient basis.

Psychogeriatric Teams

Community-based psychogeriatric interdisciplinary teams provide specialized psychogeriatric services for elderly persons with mental health problems uniquely associated with aging. Services include; assessment, treatment, consultation and referral. In some communities, there are additional adjunctive services such as individual support and case management; practical assistance (proctors and support staff); specialized activity programming; caregiver support; and education to clients, families, health care providers and communities.

Memory Assessment Clinic

This ambulatory care clinic currently operating out of St. Boniface Day Hospital provides clinical patient assessment, research and education regarding Alzheimer Disease and related dementias. Physician referral is required.

Mental Health Resource Nurses in the Personal Care Home (or RPN in PCH)

These Registered Psychiatric Nurses work with personal care home residents, families and staff in several personal care homes in Manitoba.

Crisis Stabilization Units

The units provide short-term residential care to voluntary adult clients who require specialized services in the community but are not in need of hospitalization.

Seniors Centres

The Senior Centres provide a community focal point on aging where seniors come together and have access to educational, recreational, social and health promotion activities and services.

Community Seniors Resource Councils (Support Services to Seniors)

These Councils fund programming at the community level that promotes/supports independent community living for seniors. Services include congregate meal programs, home maintenance, transportation, safety checks, friendly visitors, shopping and personal emergency response systems. This program is unique to Manitoba and varies from community to community. They serve as a primary resource in many rural communities.

Long-term Care Personal Care Home Beds

Manitoba currently has 124 licensed personal care home facilities with a total of 9,805 beds. The ratio of long-term care beds per 1,000 individuals age 75 and over = 126.4.

Manitoba's Design Standards now call for smaller units where a home-like environment can be more easily promoted. (Manitoba Health, Capital Planning Branch and Health Programs, 1999). Age-related deficits and cognitive impairment are considered and compensated for in a specially designed and organized care environment. The potential for an improved quality of life for all residents is enhanced. Residents' safety and security is more easily achieved. Existing personal care homes are encouraged to apply the guidelines to the extent that is both practical and cost effective.

- ▶ **Special Care Units:** There are two designated units in Manitoba, one of which is located at Salem Home Inc. in Winkler, and the other at Bethania Mennonite Personal care Home Inc. in Winnipeg. These units provide specialized assessment for residents who require special interventions.
- ▶ **Special Needs Areas:** Some personal care homes have segregated areas for persons with Alzheimer Disease and related dementias.

Pharmacare

The Pharmacare program is a provincial program that provides assistance to reduce the financial burden of prescription drugs for residents of Manitoba, and ensures that seniors have access to medications necessary for the maintenance of their health.

The drugs which treat mild to moderate symptoms in the early stages of Alzheimer Disease are listed as “exception drug.” To obtain approval as a benefit, certain tests are done to determine if the drugs are likely to produce an improvement in symptoms. There is also a requirement for ongoing evaluation to ensure continued benefit to the individual. These drugs are not a cure and their effects are limited both in terms of who will benefit and how long the benefit will be sustained.

- ▶ ***The personal care home drug program:*** This program provides prescription drugs and related preparations covered under the Pharmacare program to residents of personal care homes on an as-required basis, as part of the per diem rate. Drugs from the “exception drug” status are available through this program if required criteria are met.

Geriatric Program Assessment Teams

Geriatric Program Assessment Teams (GPAT) respond to referrals from Physicians, Home Care case coordinators, Emergency Room staff, and from families within the city of Winnipeg. These clinicians have extensive experience in Geriatrics and undergo an extensive transition training process that allows each clinician to complete a comprehensive multidimensional assessment. The assessment allows the clinician to make decisions around a plan of care, referral to Day Hospital, in-patient services or community-based supports. All patients referred must be age 65 years and over as a Geriatrician directly supports the teams.

Geriatric Day Hospitals

The Day Hospitals provide interdisciplinary care to patients who are living in the community. They admit patients who require the services of at least two health disciplines.

Special Care Resource Teams

Special Care Resource Teams (SCRT) provide consultation, assistance with care planning, and education on the management of PCH residents with disruptive behaviours. The goal of the SCRT is to prevent crises related to residents with dementia, psychiatric disorder, affective disorder or cardio-vascular accident through early detection and intervention. Teams are comprised of a nurse, social worker and clerical support.

Seniors Health Resource Teams

The goal of the Seniors Health Resource Teams is “to enable seniors to live independently in the community by providing clinical services in the areas of primary care, health promotion, illness and injury prevention and chronic disease management that promotes quality of life.” Clinics situated in senior blocks and local senior centres offer individual health consultation and are followed up with home visits and treatment and support. The two teams located in Winnipeg are composed of primary health care nurses with expertise in gerontology, and either an occupational therapist or a nutritionist.

The Alzheimer Society of Manitoba

The Alzheimer Society of Manitoba is part of a national, community-based volunteer organization, whose mission is to alleviate the individual, family and social consequences of Alzheimer Disease and related disorders while supporting the search for a cure. As a province-wide organization, the Society seeks to achieve its mission through community awareness, individual, family and professional education, support programs and research funding.

The Centre on Aging

The Centre on Aging at the University of Manitoba serves as a focal point for the conduct and dissemination of research on aging in Manitoba and has a national and international reputation for research excellence. The Centre is one of 18 study centres participating in the Canadian Study of Health and Aging (CSHA), a national, longitudinal study focusing on cognitive impairment and aging. The CSHA has been significantly expanded in Manitoba to allow for province-wide data collection and province-specific analyses; this study is known as the Manitoba Study of Health and Aging.

APPENDIX C: DEFINITIONS

acetyl cholinesterase inhibitor: This class of drugs probably acts by inhibition of acetyl cholinesterase resulting in accumulation of acetylcholine; a naturally occurring substance that is believed to be deficient in the brains of persons with Alzheimer Disease. Some examples are: donepezil, galantamine, metrifonate, rivastigmine, tacrine.

alzheimer disease: The most common cause of dementia. (see dementia)

caregiver: A person who provides personal care or supervision to an individual who is incapacitated. Caregivers can be either formal (paid) or informal (unpaid). Informal caregivers are most often family members of the person receiving care.

case management: A model of service delivery that emphasizes attention to identifying, assessing and providing responses to the full range of service needs exhibited by an individual service recipient.

core services: Core services are those that each Manitoba Health Authority is expected to provide or provide access to for each resident in their jurisdiction. A document describing these core services can be found at <http://www.gov.mb.ca/health/rha/core.pdf>

dementia: “Dementia is a syndrome due to disease in the brain, usually of a chronic or progressive nature, in which there is impairment of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. Consciousness is not clouded. The cognitive impairments are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behavior or motivation. This syndrome occurs in Alzheimer Disease, in Cerebrovascular Disease, and in other conditions primarily or secondarily affecting the brain.” – *World Health Organization*

intergenerational: Something that involves people who belong to more than one generational grouping who need not be related to each other. For example, children and parents or grandparents and grandchildren.

home care: Care and treatment that is delivered in the home of the individual. Could be a private home or congregate living such as a group home.

paraprofessional: Health care workers with diploma, certificate or on-the-job training who work under the supervision and direction of a health professional.

person-centred approach: “Person-centered care focuses on the person, not the person’s disease, and dictates that care should be individualized to the uniqueness of the person, taking into consideration the skills, interests, and life stories of each (person)” (p.41) – *Harr, Robert Glenn: Kasayka, Roseann E. Person-centered dementia care. Assisted Living Today. June 2000; Vol.7 (No.5): p. 41-44.*

professional: Health worker who is a member of a regulated or self-regulated professional group.

related dementias: Related dementias are those with causes that may be related to vascular dementia due to a stroke, Creutzfeldt-Jakob Disease, Lewy body Dementia, Pick’s Disease... not Alzheimer Disease.

respite: “Respite care has been described as one or more services designed to provide caregivers with temporary periods of relief from caregiving duties.” – *Lawton et al. 1989.*

restraint: Restraint is any restriction of voluntary movement or freedom to ensure the safety of self, others or the environment.

- ▶ **physical or mechanical:** A manual or physical device attached or adjacent to the resident’s body that the individual cannot remove and which restricts freedom of movement or normal access to one’s body. This can include arm restraints, hand mitts, soft ties, geri-chairs that prevent rising, chair trays, seat and lap belts, bed rails, and wheelchair safety bars and brakes.
- ▶ **chemical:** Medication given with a specific and sole purpose of inhibiting a behaviour (e.g. pacing, wandering, restlessness, agitation, aggression or uncooperative behaviour) or movement and not required to treat the resident’s medical or psychiatric symptoms. This includes sedatives, hypnotics, antipsychotics, antidepressants or antianxiety medications.
- ▶ **environmental:** Barriers to free personal movement which serve to confine residents to specific areas, e.g. removal of a cane or walker. Isolation (e.g. restricted to their room) is also included in this category.

– *Manitoba Long Term Care Network*

restraint-free environment: A respectful care environment that acknowledges, addresses and seeks to meet the person’s needs while not diminishing their personhood by coercion or restraint.

single point of entry: A method of coordinating health service access so that eligibility can be determined and application initiated for several programs and services in one place rather than applying to each one individually.

specialized services: Services and programs that are specially designed to meet the needs of persons with dementia and their families.

swing beds: A model of personal care home respite that reserves a number of beds for use as respite beds for persons from the community and maintains a relationship with individuals after they return home.

transformative learning: “Transformative learning involves experiencing a deep, structural shift in basic premises of thought, feelings, and actions. It is a shift of consciousness that dramatically and permanently alters our way of being in the world.” – *Transformative Learning Centre*, <http://www.oise.utoronto.ca/~tlcentre/index.htm> – September 12, 2002.

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WEB SITES:

National Service Framework for Older People

<http://www.doh.gov.uk/nsf/oldermentalhealth.htm>

Impact Of Dementia

<http://www.eurohealth.ie/remind/impact.htm>

Alzheimer Society of Canada

<http://www.alzheimer.ca>

Alzheimer Society of Manitoba

<http://www.alzheimer.mb.ca>

Rural Areas: Problems and Solutions

[http:// www.alzheimer-europe.org/rural](http://www.alzheimer-europe.org/rural)

Planning Signposts for Dementia Care

<http://www.alzscot.org/policy/signposts/html>

Action on Dementia

<http://www.alzscot.org/>

Dementia as a Public Health Problem: its importance and related challenges

<http://www.eurohealth.ie/remind/>

APPENDIX E: ACKNOWLEDGEMENTS

Steering Group Members

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APPENDIX F: EXAMPLES OF RELATED BEST PRACTICE FROM MANITOBA AND OTHER JURISDICTIONS

- 1 The Alzheimer Society of Manitoba currently provides this resource and with additional resources, could meet the goal.
- 2 Expansion of existing services such as Alzheimer Society HELPLINE, Healthlinks and the Seniors Directorate line could meet the goal.
- 3 The Winnipeg Regional Health Authority Access Centre model describes this kind of centre.
- 4 The Dementia Training Program endorsed through the Ontario government through Algonquin College is an example.
- 5 See Alberta Medical Association Guidelines for Cognitive Impairment: Dementia – Diagnosis to Management. (Alberta Clinical Practice Guidelines Program Working Group, 2002).
- 6 Possible expansion of the Alzheimer Society program, and/or expansion of the Senior Health Resource Team model.
- 7 The Seniors Health Team model in Winnipeg Regional Health Authority Rivereast district is an example.
- 8 Baluchon Program - Verdun Quebec.
- 9 Mental Health Mobile Crisis Teams/Programs in Manitoba Regional Health Authorities.
- 10 The Crane Library, a national library, located within Deer Lodge Centre can meet this goal with additional resources.

