



Meeting the Challenge of Alzheimer's Disease and Related Disorders

A Vision Focused on the Individual, Humanism, and Excellence

**REPORT OF THE COMMITTEE OF EXPERTS FOR
THE DEVELOPMENT OF AN ACTION PLAN ON
ALZHEIMER'S DISEASE AND RELATED
DISORDERS
HOWARD BERGMAN, M.D., CHAIR**

May 2009

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NOTICE

This report is not binding on the Ministère de la Santé et des Services sociaux and does not represent its policy. It represents the opinion of the Committee of Experts for the Development of an Action Plan on Alzheimer's Disease and Related Disorders.

The content of this report is the responsibility of its authors and has been presented unabridged out of respect for the authors and the members of the Committee of Experts.

May 6, 2009

The Honourable Yves Bolduc
Minister of Health and Social Services
Government of Québec

**Subject: Report of the Committee of Experts for the Development of an Action Plan
on Alzheimer's Disease and Related Disorders**

Dear Minister:

In December 2007, Québec's Minister of Health and Social Services gave the present Committee of Experts the mandate to develop an action plan on Alzheimer's disease and related disorders. Today, this committee and I are proud to present you with the results of our work.

This report proposes a ministerial action plan comprising seven priority actions, with 24 recommendations on how to carry them out. This report also presents a strategy for implementing the plan, with five related recommendations.

We wish to thank you for the confidence that you have placed in us, and we want you to know that we have received excellent co-operation from all of the people and organizations concerned.

Respectfully yours,

Howard Bergman, M.D.
Chair, Committee of Experts

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DEDICATION

Throughout our work on this action plan, we never forgot for whose sake we were developing it: people with Alzheimer's disease and related disorders and their families. The members of the Committee of Experts devote a significant portion of their professional practices to these individuals, so it is no exaggeration to say that this disease affects us too, and all the more so because we are recommending a profoundly humanistic approach focused on the individual and on excellence in care.

We therefore dedicate this report first and foremost to people who have Alzheimer's disease or related disorders, to whom we owe respect, dignity, excellent care, and humaneness in all circumstances, as well as to the family members who support them every day with kindness, courage, and self-sacrifice.

We also dedicate this report to all the professionals and staff of Québec's health-care system, community organizations, and the private sector, whose professionalism and dedication are beyond question; to all volunteers working in associations such as the Federation of Quebec Alzheimer Societies, who give generously of their time and energy; and to the researchers who, driven by the hope of a future breakthrough, strive to better understand this illness so as to better treat those who live with it.

**Report of the Committee of Experts for
the Development of an Action Plan on
Alzheimer’s Disease and Related Disorders**

Foreword	iv
Executive Summary	v
Section 1	1
Alzheimer’s Disease and Related Disorders: A Major Public Health Problem	1
Section 2	7
Alzheimer’s Disease and Related Disorders: Major Achievements and Challenges for Québec	7
Section 3	10
A Societal Approach Centred on the Individual, Humanism, and Excellence	10
Section 4	12
Priority Actions	12
Priority Action 1	12
Raise awareness, inform, and mobilize	12
Priority Action 2	16
Provide access to personalized, co-ordinated assessment and treatment services for people with Alzheimer’s and their family/informal caregivers	16
Priority Action 3	31
In the advanced stages of Alzheimer’s, promote quality of life and provide access to home-support services and a choice of high-quality alternative living facilities.	31
Priority Action 4	38
Promote high-quality, therapeutically appropriate end-of-life care that respects people’s wishes, dignity, and comfort	38
Priority Action 5	44
Treat family/informal caregivers as partners who need support	44
Priority Action 6	49
Develop and support training programs	49
Priority Action 7	54
Mobilize all members of the university, public, and private sectors for an unprecedented research effort	54
Section 5	60
Strategy for implementing the report of the Committee of Experts	60
Conclusion	65
Bibliography	i
Appendix 1: Recommendations	vii
Appendix 2: Members of the Committee and Sub-Committees	xxxiv
Appendix 3: Alzheimer’s and related diseases: definitions	xxxvi
Appendix 4: Criteria for orienting sufferers to second-line specialists and the use of neuroimaging technologies	xl
Appendix 5: Risk factors and protective factors, the prevention and treatment of Alzheimer’s disease: recommendations of the Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia	xli
Appendix 6: Alternative living environments	lviii

FOREWORD

The Committee of Experts for the Development of an Action Plan on Alzheimer's Disease and Related Disorders was established in December 2007 with a specific mandate: to develop and propose an action plan on Alzheimer's disease and related disorders for Québec's Ministry of Health And Social Services (MSSS). The mandate called for this plan to cover all aspects of this subject, from research and prevention to end-of-life care. As soon as the committee was formed, it was therefore divided into sub-committees to examine these various aspects, and each sub-committee then recruited additional experts in the areas that it would be examining. The committee then set about defining the main problems that had to be considered with respect to Alzheimer's disease and related disorders. By determining the causes of these problems, the committee was able to better assess possible solutions that could be translated into priority actions.

From the outset, the committee strived to develop innovative recommendations, stated in accessible language so as to enlist the support of the public as well as the professionals and staff of Québec's health and social services system. The committee is well aware of how challenging it is to develop relevant, realistic recommendations that go beyond generalities.

To confirm the accuracy and relevance of our analyses and the appropriateness of the priority actions that we were proposing, the committee members met with many individuals and organizations that deal with Alzheimer's and related disorders. Committee members held discussions not only with managers and professionals from Quebec's health and social services institutions and Ministry of Health and Social Services, but also with associations such as the Federation of Quebec Alzheimer Societies, foundations and other organizations such as the Québec Seniors' Council (*Conseil des aînés du Québec*), and with many representatives of community organizations, the private sector, and the research community. To promote collaboration and mutually rewarding exchanges, the committee forged ties with committees of experts from other Canadian provinces and from other countries comparable to Canada, such as France, England, and Australia.

As Chair of the Committee of Experts, I wish to thank the committee members for their dedication and perseverance. I also want to thank the members of the sub-committees, as well as the members of the support group: Pierre Bouchard, Isabelle Lussier, and Elizabeth Iacono.



Howard Bergman, M.D.
Chair of the Committee of Experts

May 2009

Report of the Committee of Experts for the Development of an Action Plan on Alzheimer's Disease and Related Disorders

Executive Summary

Alzheimer's disease and related disorders:^a the urgent need to act

Alzheimer's disease is a neurodegenerative disease whose impact on Québec society, already considerable, is growing dramatically as a result of the aging of Québec's population. Though Alzheimer's disease can affect people below age 65, the risk of developing the disease increases rapidly with age, particularly from age 80 on. It is estimated that nearly one baby boomer in five will develop Alzheimer's disease in his or her lifetime. As of 2009, 100 000 Quebeckers had this disease; by 2015, 120 000 will have it, and by 2030, 160 000. The number of cases of Alzheimer's newly diagnosed each year is also growing very quickly: from almost 23 000 in 2009, it will rise to 28 000 in 2015 and 43 000 in 2030.

The impact of this disease on resources at all levels of the health care system is enormous. The estimated cost of all care provided to Alzheimer's patients in Canada in the year 2000 was \$5.5 billion. But no statistic can adequately describe the effects of Alzheimer's on people who have it, on their families, and especially on family members and other persons who serve as their informal caregivers, the vast majority of whom are elderly women.

And yet the effects of this disease and the complex set of problems surrounding it are greatly underestimated, as witness the Canadian budget for Alzheimer's research, which is estimated at only 15% of the budget for cancer research and 29% of that for research on heart disease. There are a variety of well funded programs to help manage chronic illnesses such as cancer, cardiovascular disease, lung disease, and diabetes, but there is no integrated clinical approach to Alzheimer's disease, and scant resources are devoted to it.

The urgent need to act is now recognized internationally. France, England, Scotland, Australia, and New Zealand have all produced national Alzheimer's action plans. In December 2008, the European Union asked member countries to develop and implement national Alzheimer's strategies and action plans. Several Canadian provinces have already implemented strategic plans for dealing with Alzheimer's in their jurisdictions.

^a For some years, use of the term "dementia" has been challenged by various groups, in particular the Federation of Quebec Alzheimer Societies. This term, historically associated with insanity, can lead to exclusion of and discrimination against people who have dementia-type illnesses. In the present report, we have taken special care to use the term "dementia" only when there is no other, acceptable word. When we refer to the state of health of people who have cognitive disorders associated with neurodegenerative disease, we instead mainly use the phrase "Alzheimer's disease and related disorders". But when, for the sake of conciseness, we use the expression "Alzheimer's disease" or "Alzheimer's" alone, it should be understood to mean "Alzheimer's disease and related disorders".

It was against this background, in December 2007, that Québec's Minister of Health and Social Services established a Committee of Experts and gave it a mandate to develop and propose a ministerial action plan covering all aspects of Alzheimer's disease and related disorders, from research and prevention to end-of-life care.

The committee's work

In carrying out its mandate, the committee has drawn constantly on the vast experience and expertise of its members. They met with many people and groups at all levels of the health and social services system, as well as with associations such as the Federation of Quebec Alzheimer Societies and representatives of the private sector.

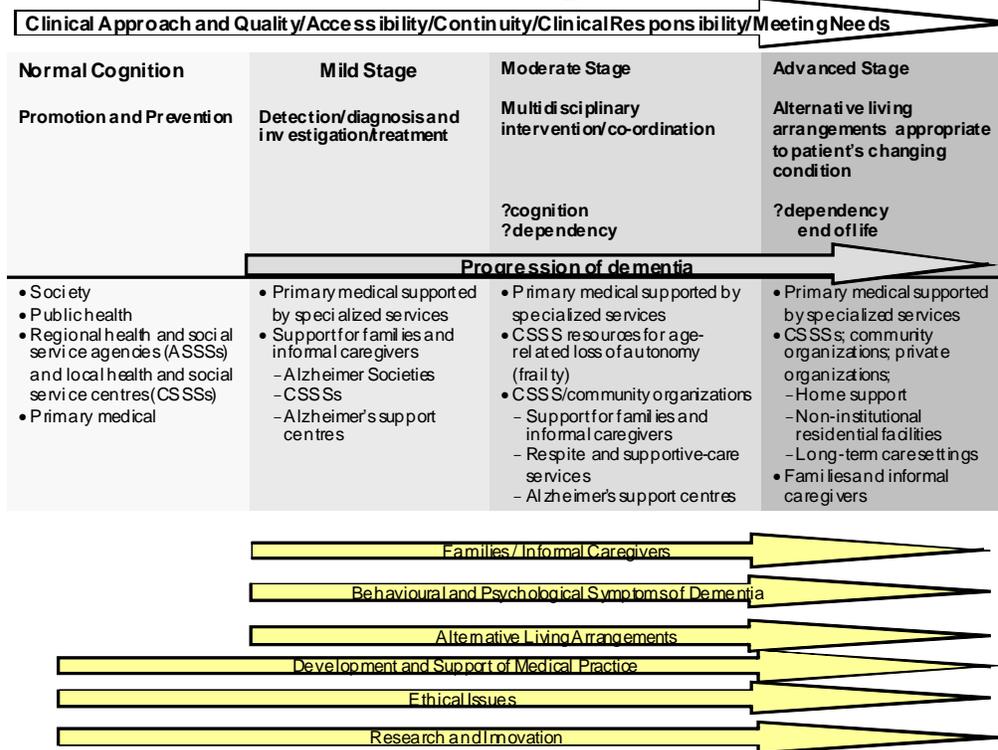
To begin its work, the committee identified existing achievements, problems, and underlying factors with regard to Alzheimer's disease and related disorders in Québec. The committee found evidence of real achievements, in the form of innovative experiments, improvements in quality of care, and development of new approaches both in research and in clinical practice. The committee believes that the Québec government's current policies, and in particular the reform of health and social services that it began several years ago, have provided a solid framework for the implementation of a ministerial action plan.

After examining and evaluating the current situation in depth, the committee identified the following key requirements for meeting the challenge of Alzheimer's successfully:

- increasing our knowledge of Alzheimer's and adopting different attitudes toward people with Alzheimer's and their family and other informal caregivers;
- providing people with Alzheimer's and their family/informal caregivers with access to co-ordinated, personalized services in a user-friendly system, at all stages of the disease;
- enhancing quality of life and care for people with Alzheimer's in alternative living facilities;
- enhancing quality of life and quality of care at end of life for people with Alzheimer's;
- enhancing quality of life and care for family/informal caregivers;
- enhancing training and motivation for professionals and support staff;
- conducting research that contributes to high-quality treatment and care.

Figure 1 is a diagram of the working framework adopted by the committee. This framework is built not around organizational structures or institutions, but around meeting the needs of people with Alzheimer's and those close to them, at every successive stage of the disease. This framework incorporates a number of cross-cutting themes, including families/informal caregivers, behavioural and psychological symptoms of dementia (BPSD), alternative living arrangements, development and support of medical practice, ethical issues, and research and innovation.

Figure 1



The approach that we, the members of the committee, propose is focused on the individual and based on humanistic values and excellence in all respects. Our approach therefore places the dignity of people with Alzheimer's and respect for their choices front and centre. Our approach also requires that all solutions to be implemented must be grounded in evidence-based findings from clinical and other research conducted in Quebec, elsewhere in Canada, and abroad.

For our proposed solutions to be effective, co-operation among all parties concerned, in the public and private sectors, is vital. The aim is not to create an "Alzheimer's care system," but to identify the specific nature of the problem and to bring about judicious, coherent changes in the ongoing activities and structures of the current health and social services system to address it.

Seven priority actions, 24 recommendations

Our proposed ministerial action plan comprises seven priority actions, with 24 recommendations on how to carry them out. These actions and recommendations reflect a vision that is innovative but also realistic. The committee hopes that the public and the professionals and staff of the health and social services system will perceive the coherence and appropriateness of these actions and recommendations and hence rally in support of the plan. The seven priority actions have been stated in language that will make them accessible to the general public and not only to members of the health care system. Each priority action is further broken down into three sets of elements: the challenges to be met, the objectives to be achieved, and the committee's recommendations on how to achieve them.

Priority Action 1 - Raise awareness, inform, and mobilize

The objectives of Priority Action 1 are to promote a better understanding of Alzheimer's disease and related disorders, a respectful attitude towards people with Alzheimer's and their families, and support for the necessary changes, both among the public and within government, the health and social services system, community organizations, and the private sector. This priority action is designed to raise awareness of the importance of taking steps to reduce Alzheimer's risk factors and promote Alzheimer's protective factors so as to delay the onset of the disease and mitigate its effects.

The **two recommendations** for carrying out this priority action involve implementing a strategy to raise awareness, provide information, and mobilize support. The first recommendation is that the government, in partnership with the Federation of Quebec Alzheimer Societies, the academic community, and the private sector, should disseminate information on all aspects of Alzheimer's disease and the issues related to it. The second recommendation is that the Quebec Public Health Service (*Direction de la santé publique du Québec*) should make this strategy one of its priorities and focus it on the risk factors and protective factors associated with Alzheimer's disease.

Priority Action 2—Provide access to personalized, co-ordinated assessment and treatment services for people with Alzheimer's and their family/informal caregivers

The objectives of Priority Action 2 are as follows: to improve and simplify access to a process for assessing cognitive function and diagnosing dementia; to provide access to integrated case management as soon as a diagnosis is made; to innovate through effective, flexible co-ordination of the services required by people with Alzheimer's and their families; and to adapt the proposed service structure and approach to local and regional circumstances.

The central idea behind our **three recommendations** for achieving these objectives is to organize services according to the chronic-care management model and the collaborative practice model. The first step in doing so will be to establish partnerships between physician-and-nurse teams on the one hand and people with Alzheimer's and their families on the other. These partnerships will be established in stages, with Family medicine groups (FMGs) and network clinics (NCs) as the initial settings. This service structure, in which the nurse responsible for continuity of Alzheimer's patient services acts as the "care navigator," will enable the disease to be detected, diagnosed and treated.

To play their role effectively, the physician-and-nurse partnerships with people with Alzheimer's and their families must be able to count on some vital elements of support and must have fast, easy, flexible access to a varied range of specialized resources. Examples include psychosocial resources such as Alzheimer's support centres (ASCs), clinical resources such as cognition clinics and teams specializing in behavioural and psychological symptoms of dementia (BPSD), programs specifically designed for people who have both Alzheimer's and age-related loss of autonomy (PALV programs), and facilitated hospital stays and optimized transitions in the event of hospitalization. The health and social service centres (CSSSs), in co-operation with their regional health and social service agencies, will be responsible for ensuring that services are organized so as to take specific local and regional circumstances into account.

Priority Action 3 - In the advanced stages of Alzheimer's, promote quality of life and provide access to home-support services and a choice of high-quality alternative living facilities.

The objective of Priority Action 3 is to enable families to continue to care for loved ones in the advanced stages of Alzheimer's in their homes if they wish to do so. When families opt for an alternative living arrangement, they should be offered a varied choice of facilities designed for people with Alzheimer's and staffed by highly motivated, well-trained employees and managers who encourage family involvement.

The committee offers **five recommendations** for achieving these goals. The first recommendation aims at keeping people in advanced stages of Alzheimer's in their homes. The age-related loss of autonomy (PALV) programs provided by Québec's community and social services centres (CSSSs) must be better adapted to manage Alzheimer's disease and must have the required resources and well-trained personnel to do so. This recommendation also calls for use of home automation to adapt the living environment, foster autonomy, and prevent accidents.

The remaining four recommendations deal with alternative living facilities. The purpose of these recommendations is to create and maintain diversified facilities adapted to the realities of Alzheimer's disease, as well as to provide the professional support that all of these facilities, both public and private, must receive from the CSSSs and from the regional departments of general medicine (DRMGs). These facilities must also be able to rely on motivated, well-informed professional and support staff. There is also a need to increase staffing ratios to improve the quality both of medical and nursing care and of supportive care and attention. The idea is to help alternative living facilities to develop strategies and programs that reflect the realities of Alzheimer's and to ensure that the families of the people living in these facilities are encouraged to become involved.

Priority Action 4—Promote high-quality, therapeutically appropriate end-of-life care that respects people's wishes, dignity, and comfort

The objective of Priority Action 4 is to improve the quality of end-of-life care, particularly in Québec's hospitals and residential and long-term care centres (CHSLDs). To achieve this objective, we will have to examine our approach in light of best practices and research findings while respecting the wishes of people with Alzheimer's and their families. Our approach to end-of-life care must improve quality of care and include education for families and training for health professionals.

Our **five recommendations** for this priority action involve developing various clinical guidelines and tools, along with a public-awareness strategy. This strategy should cover the natural progression of the disease, the inevitable complications at end-of-life, the available choices of palliative care, and advance health care directives (living wills). Likewise, we recommend that families be offered training and educational materials about the end of life for people with Alzheimer's. We also recognize the need to train institutions' professionals and support staff (through college and university programs, on-the-job training, and continuing education programs) and to implement measures at all institutions to improve the quality of end-of-life care. In this regard, we propose an approach based on families' satisfaction with the care provided and the use of suitable guidelines for detecting pain.

Priority Action 5—Treat family/informal caregivers as partners who need support

The objective of Priority Action 5 is to treat family and other informal caregivers as clients who are themselves entitled to services. From a proactive and preventive standpoint, these caregivers also must receive psycho-educational and other services to help them navigate their way through the health care system and community agencies and cope better with the manifestations of the disease.

The first and most important of our **three recommendations** for this priority action is that an Alzheimer’s support centre (ASC) should be established in the service area of each CSSS (or group of CSSSs) by creating a community partnership led by the regional Alzheimer’s society in co-operation with the CSSS. The ASC is a neighbourhood facility that is easily accessible to caregivers, and a community space for providing information, training, and access to services for people in the early stages of Alzheimer’s as well. Though volunteers play a central role in the ASC, the ASC must also be able to rely on the co-operation and resources of the CSSS.

We also recommend that Family medicine groups and CSSSs maintain files on family/informal caregivers and use a specific assessment tool for this purpose. These caregivers must be able to count on flexible respite and supportive-care services, day and night, for short and longer periods, both planned jointly in advance and in emergencies. It is also essential for government to strengthen and add flexibility to the social and financial measures designed to support caregivers.

Priority Action 6—Develop and support training programs

The objective of Priority Action 6 is to recognize that investment in training is one of the strategies needed to enhance the quality of care and the role of managers, professionals and care providers, while also contributing to their recruitment and retention.

Our **four recommendations** for this priority action target all of the persons involved—policymakers, managers, professionals, and other staff—through training programs delivered in various settings, such as colleges and universities and on the job (both at the start of employment and later on).

Of these four recommendations, two are the most central. First, we propose that the Québec Ministry of Health and Social Services (MSSS) mobilize the academic community, professional associations, professional colleges, the pharmaceutical industry, and the Alzheimer Society to pool their expertise and resources in a co-ordinated, collective effort to establish a wide-ranging continuing education program for the professionals concerned, in accordance with certain very specific priorities. Second, we propose that the MSSS, in co-operation with the academic community, regional health and social service agencies, and health and social service centres (CSSSs), develop an Alzheimer’s training plan for support staff in community organizations, in public and private alternative living facilities, and in residential and long-term care centres (CHSLDs). Our two other recommendations are to develop a strategy for college and university training on the subject of aging (and more specifically of Alzheimer’s disease), and to develop an Alzheimer’s training plan tailored to the needs of managers and policymakers.

Priority Action 7–Mobilize all members of the university, public, and private sectors for an unprecedented research effort

The objectives of Priority Action 7 are as follows: to promote planning, organization, and support for interdisciplinary research into all aspects of Alzheimer’s disease; to enable people with Alzheimer’s and their families to express their needs and influence research efforts; to ensure rapid, complete dissemination of best practices; and to expand research capacity in all areas and approaches.

Of our **two recommendations**, the central one is to set up a consortium to promote and fund research into all aspects of Alzheimer’s disease. This consortium should be affiliated with the Québec Fund for Health Research (*Fonds de la recherche en santé du Québec*, FRSQ) and should receive substantial annual funding from the public sector (provincial and federal funding agencies and departments), the private sector (companies in the pharmaceutical, biotechnology, and information technology industries), and the community sector (Alzheimer societies, community organizations and foundations). We also recommend that article 21 of the Civil Code of Québec be amended; this article seeks to protect persons who are incapable of giving their consent for research, but in its current form, it also constitutes an impediment to research on how to help people with Alzheimer’s and their families.

Strategy for implementing the ministerial action plan

For the ministerial action plan to be implemented successfully, a strategy will have to be put in place based on leadership, free flow of information, support for implementation, development of clinical tools and practice guidelines, and the establishment of a culture of quality assurance and continuous improvement of services.

Our **five recommendations** for the implementation strategy focus on the responsibilities of the Québec Ministry of Health and Social Services (MSSS). We recommend that the MSSS respond quickly to the report of the Committee of Experts, determine when implementation of the action plan will begin, and allocate the funding needed to implement it gradually over six years (from now until 2015). Alzheimer’s disease constitutes a top-priority challenge for the health and social services system. Alzheimer’s must be recognized as a chronic disease and, as such, be incorporated into the Ministry’s 2010-2015 action plan, into the Québec plan for the management of chronic diseases, into the Québec public health program, and into management and accountability agreements.

Central to our recommendations is to create a ministerial strategic team tasked with implementing and monitoring the implementation of the ministerial action plan. In parallel, the regional health and social service agencies (ASSSs) and the health and social service centres (CSSSs) must formulate their regional and local plans with the support of this ministerial team. Back at the level of Québec as a whole, the MSSS, in co-operation with the academic community, must quickly establish a group of experts to design clinical guidelines and tools for Alzheimer’s disease and ensure that they are updated regularly in collaboration with the future Québec Institute for Excellence in Health and Social Services (*Institut national d’excellence en santé et services sociaux*, INESSS).

Section 1

Alzheimer's Disease and Related Disorders: A Major Public Health Problem

1. The nature of Alzheimer's disease and related disorders

Alzheimer's disease and related disorders^b are degenerative brain conditions manifested by the progressive, irreversible deterioration of cognition. Individuals generally present with memory loss and diminished reasoning skills, leading to the gradual loss of their ability to perform the tasks of daily living. As the disease progresses, cognitive deficits are accompanied by behavioural and psychological symptoms of dementia (BPSD) that disturb both these individuals and the people around them.^c

- 1.1. Alzheimer's disease is the main cause of dementia, accounting for 64% of all cases.¹ Other types of dementia include multi-infarct (vascular) dementia, fronto-temporal dementia, and Lewy body dementia.
- 1.2. These dementias can take anywhere from 3 to 20 years to run their course. They are characterized by progressive deterioration of physical and cognitive functions, ultimately leading to death (see Appendix 3).

2. A society that is concerned but ambivalent about Alzheimer's disease

- 2.1. The risk of developing Alzheimer's disease, like that of developing cancer and cardiovascular diseases, is one of the main sources of anxiety for Canadians, particularly those above age 45.²
- 2.2. Cognitive disorders, and in particular memory impairments, are another major source of anxiety for many people. Filmmaker Luis Buñuel (1900-1983) expressed this concern quite eloquently:

^b For some years, use of the term "dementia" has been challenged by various groups, in particular the Federation of Quebec Alzheimer Societies. This term, historically associated with insanity, can lead to exclusion of and discrimination against people who have dementia-type illnesses. In the present report, we have taken special care to use the term "dementia" only when there is no other, acceptable word. Whenever we refer to the state of health of people who have cognitive disorders associated with neurodegenerative disease, we instead mainly use the phrase "Alzheimer's disease and related disorders". But when, for the sake of conciseness, we use the expression "Alzheimer's disease" or "Alzheimer's" alone, it should be understood to mean "Alzheimer's disease and related disorders".

^c Behavioural and psychological symptoms of dementia (BPSD) refer to symptoms of impaired perception, thinking, mood, and behaviour that frequently appear in people who have Alzheimer's disease.

One has only to begin losing one's memory, if only in dribs and drabs, to understand that memory is the very essence of life. A life without memory cannot be truly lived; intelligence without possibility of expression is not really intelligence. Our memory is what makes our coherence, our reasoning, our feelings, and even our actions possible. (free translation)

- 2.3. Yet at the same time, films from Québec and English Canada, such as *La Brunante*, directed by Fernand Dansereau, and *Away from Her*, directed by Sarah Polley, show the value of the human relationships and human potential that are still present at all stages of the disease.
- 2.4. Alzheimer's disease remains poorly understood by the public. Myths and prejudices tend to stigmatize people with Alzheimer's and cause them to become isolated. The reason for this stigmatization is the psychiatric nature of the disease, which affects mainly elderly people and for which there is as yet no pharmacological cure. Here is how one woman with Alzheimer's talks about this issue, as quoted in a media release from the Alzheimer Society of Canada:

"Some people make incorrect assumptions that if we have Alzheimer's disease we are not capable people. Some people wouldn't know how to treat me normally anymore and, frankly, I want to be known as Marilyn, not "Marilyn with Alzheimer's disease."

3. A complex disease that is affecting more and more people

- 3.1. It is estimated that nearly one baby boomer in five will develop Alzheimer's disease.³
- 3.2. Nearly 33% of all Canadians know somebody who has Alzheimer's, and over 20% have a family member who has the disease.²
- 3.3. Alzheimer's disease is not part of normal aging, but its prevalence increases with age: 33% of people age 80 and over have the disease,^{1,4} and this is the age group that is growing fastest in Québec. Among Québeckers age 65 and over:
 - in 2009, 100 000 had the disease, and this figure will rise to 120 000 in 2015, and to 200 000 in 2030;^d
 - about 23 000 people will develop the disease in 2009, and the number of new cases per year will rise to 28 000 in 2015 and 43 000 in 2030.^e

^d The calculation of prevalence (the number of people who have the disease) is based on data from the Quebec Institute for Statistics (*Institut de la statistique du Québec*, ISQ) publication *Perspectives démographiques, Québec et régions, 2001-2051*, 2003 edition, (Scenario A) and on weighted estimates of prevalence by age group according to the Canadian Study of Health and Aging (CSHA) ("Study methods and prevalence of dementia". *Canadian Medical Association Journal* 1994;150:899-913; Ebly EM, Parhad IM, Hogan DB, Fung TS. "Prevalence and types of dementia in the very old: results from the Canadian Study of Health and Aging." *Neurology* 1994;44:1563-1565).

^e The calculation of incidence (the number of people who newly develop the disease each year) is based on data from the ISQ (*Perspectives démographiques, Québec et régions, 2001-2051*, 2003 edition, [Scenario A]) and on the CSHA ("The Incidence of Dementia in Canada". *Neurology* 2000; 55:66-73).

Moreover, according to projections based on studies and estimates from other countries, approximately 2 250 Québeckers below age 65 now have the disease.^f

3.4. Alzheimer's is a highly complex disease:

- up to 80% of people with Alzheimer's have at least one other chronic disease, such as diabetes, hypertension, cancer, depression, or heart or lung disease.⁶ Over 60% of patients present with three or more concomitant diseases;⁷
- many people with Alzheimer's develop acute conditions, such as heart disease and infectious diseases, hip fractures, etc.;^{8,9}
- increasing numbers of elderly persons are dying from Alzheimer's disease or have the disease.⁸ According to the World Health Organization (WHO), in high-income countries, Alzheimer's disease ranks six among the main causes of death.¹⁰

4. Major human and societal impacts

4.1. Impacts on people who have Alzheimer's

- According to the WHO, Alzheimer's disease is one of the main causes of disability among elderly people in high-income countries.¹¹

4.2. Impacts on their families and other informal caregivers

- In 70% of Alzheimer's cases, women, most of them elderly, act as informal (non-professional) caregivers.¹²
- Alzheimer's disease is a major source of psychological and social exhaustion. It has major effects on caregivers' health and financial status.^{13,14}

She lays her hands on my head, she runs her fingers through my hair. She asks me to look at her. She asks, "Why are you crying?" [...] Once outside, he continues, I can still hear in my mind the voice of this woman who gave me life and who now emerges from the depths of her dementia to worry about her child, to remind him of her love and give him her wishes and kisses for the New Year. It breaks my heart.
(translation)

- Jacques Boulerice, *La mémoire des mots—Alice au pays de l'Alzheimer*, Éditions Fides, page 183.

^f This calculation of prevalence in Québeckers below age 65 is based on data from the United Kingdom, which estimates that 981 people out of 100 000 aged 45-64 have Alzheimer's disease (Harvey RJ, Skelton-Robinson M, Rossor MN. "The prevalence and causes of dementia in people under the age of 65 years". *J Neurol Neurosurg Psychiatry* 2003;74:1206-1209) and from the ISQ (*Perspectives démographiques, Québec et régions, 2001-2051*, 2003 edition, [Scenario A]).

^g Mortality in Québec from Alzheimer's disease, 2000-2004. Statistics Canada. CANSIM, Table 102-0551^{1,2,18} (Site consulted on 29-10-08).

4.3. Tremendous pressure on the health system and on society

- A very high proportion of the people receiving home services from Québec's age-related loss of autonomy program (PALV), and the majority of Québec seniors residing in assisted-living and other alternative living facilities, have Alzheimer's disease.
- Up to 80% of the people living in Québec's residential and long-term care centres (CHSLDs) have Alzheimer's.¹⁵
- According to U.S. data, the cost of medical and hospital services is three times higher for someone who has Alzheimer's than for an elderly person who does not have the disease.¹⁶ Alzheimer's disease ranks second among the neurological diseases on which the Canadian medical system spends the most.¹⁷
- In acute-care hospitals, Alzheimer's patients account for 9% of all patients age 65 and over,^h and 9% of all patients with diabetes or heart failure also have Alzheimer's disease.
- From 2001 to 2006, the number of hospitalizations in acute-care hospitals among people with Alzheimer's rose by 26%, compared with only 1% among people in the same age group who did not have Alzheimer's. In addition, Alzheimer's patients' length of stay was twice as long as non-Alzheimer's patients'.

4.3.1. Alzheimer's disease costs society dearly. In Canada, in 2000, the estimated cost of all care provided to people with Alzheimer's totalled \$5.5 billion.^{18,19} And that does not include the considerable indirect costs, particularly in the form of lost income for family caregivers, who often have to shorten their work weeks or use vacation days to care for their loved ones who have Alzheimer's.

4.3.2. Despite all these pressures, in Québec as well as in other provinces and countries, funding for Alzheimer's research is far lower than funding for research on other diseases. In Canada, in 2007-2008, the Canadian Institutes of Health Research (CIHR) provided \$26 million worth of funding for Alzheimer's research, compared with \$170 million for cancer research and \$91 million for research on cardiovascular disease. Thus, the budget for Alzheimer's research amounted to only 15% of the budget for cancer research and 29% of the budget for research on heart disease.¹

^h Analyses of data on hospitalizations of users age 65 and over with Alzheimer's disease or dementia. Banque sur les clientèles hospitalières (MED-ÉCHO), 2001-2002 and 2005-2006.

ⁱ Search on grants and bursaries funded by the CIHR. 2007-2008 funding; Keywords: Alzheimer's, cancer, cardiovascular system. [Online: <http://webapps.cihr-irsc.gc.ca/funding>].

5. A troubling situation in Québec and elsewhere, and a global effort to tackle it

- 5.1. Québec is not the only jurisdiction that is seeing major demographic changes and a marked increase in the number of people with Alzheimer's disease. Other Canadian provinces and other countries are experiencing the same situation and have taken steps to respond to it.
- 5.2. Both the Organization for Economic Co-operation and Development (OECD) and the National Audit Office of the United Kingdom have taken stock of the situation by comparing the approaches that various countries advocate for dealing with people with Alzheimer's and their families.^{20,21}
- 5.3. France, England, Scotland, Australia and New Zealand are among the countries that have drawn up action plans to meet the challenges posed by the disease.^{22,23,24,25,26,27,28} In December 2008, the European Union asked all of its member countries to develop and implement national Alzheimer's strategies and action plans.²⁹
- 5.4. In Canada, most provinces, including Ontario, the Maritime provinces and the Western provinces, have implemented strategic plans for dealing with Alzheimer's.^{30,31,32,33,34,35}
- 5.5. Worldwide, awareness of the importance of Alzheimer's disease and its impact is growing. It is therefore essential for Québec to adopt an action plan now to meet the challenges of the years to come.

6. The urgent need to act and the prospect of real change

- 6.1. We must act now to gradually prepare Québec society and the Québec health and social services system to meet a dual challenge:
 - the large increase in the number of people with Alzheimer's disease in Québec;
 - the development of drugs that will truly change the course of the disease.
- 6.2. Improving the way that services are organized and developing appropriate psychological and social interventions for people with Alzheimer's and their caregivers can have a truly beneficial effect on their quality of life, thereby reducing the impact of Alzheimer's on the health care system.
- 6.3. Delaying the onset of the disease by five years could, within the span of a generation, halve the total number of persons who develop it, thus reducing the burden on families and society.³⁶
 - In Québec and elsewhere, much effort is being devoted to prevention and research, as well as to the development of drugs that could significantly slow the progression of Alzheimer's disease.

6.4. With their wealth of experience, knowledge, and commitment, the members of the Committee of Experts wish to contribute to the implementation in Québec of a ministerial action plan that will make a difference in the lives of the people who must cope with Alzheimer's disease: not only the individuals who have it, but their families as well.

Section 2

Alzheimer's Disease and Related Disorders: Major Achievements and Challenges for Québec

1. Recent major achievements in Québec

Québec can point to some valuable achievements in the battle against Alzheimer's disease and related disorders.

1.1. With regard to care, Québec has recently put some innovative solutions in place, and there are more to come. Here are a few examples.

- Innovative pilot projects and organizational strategies designed for people with cognitive impairments have been implemented at the following health and social service centres (CSSSs) in Québec: CSSS du Suroît, CSSS de Vaudreuil-Soulanges, CSSS du Haut-Saint-Laurent, CSSS Lucille-Teasdale, and CSSS Laval.
- Long-term care units and buildings specially designed for frail persons with cognitive impairments have been opened (Pavillon des Bâisseurs, CSSS de Bordeaux-Cartierville-Saint-Laurent).
- A number of specialized outreach clinics for people with cognitive impairments have been opened in university hospital settings, including memory, cognition, and geriatric psychiatry clinics.
- Regional Alzheimer societies have been established and are providing services in many regions of Québec.
- Community organizations and groups of such organizations have made major contributions by taking innovative approaches to provide alternative living arrangements (such as Maison Carpe Diem) and respite and supportive-care services (such as Le Baluchon) that represent an especially effective response to the needs of people with Alzheimer's and their families.
- The private sector has substantially increased and diversified the services that it offers, creating residential settings that cater to several types of clients who cannot live independently, mostly because of cognitive impairments.

1.2. With regard to clinical guidelines and standards, substantial efforts have been made to improve the quality of services in Québec.

- Québec's clinical and scientific communities have made major contributions to the development of Canadian clinical guidelines and standards on cognitive impairment (notably, at the Canadian Consensus Conferences on Diagnosis and Treatment of Dementia).³⁷
- Québec's Ministry of Health and Social Services (MSSS) has introduced the practice of making visits to residential and long-term care centres (CHSLDs) and other residential facilities to assess service quality.

- Special programs have been introduced to provide CHSLD managers with training on how to improve the quality of the living environment in residential and long-term care settings.

1.3. With regard to research, Québec is showing genuine leadership.

- Research into age-related cognitive impairment, and particularly into Alzheimer’s disease and related disorders, represents one of the “poles of excellence” of health research in Québec. Québec-based teams are conducting research in this area in a highly interdisciplinary fashion, and many of them are regarded as leaders both nationally and internationally. This stature is the result of the critical mass of researchers who are working at research centres and in research groups that are funded by the Québec Fund for Health Research (*Fonds de la recherche en santé du Québec*, FRSQ) and that belong to its Québec Network for Research on Aging. This network brings together all of the most important players doing research at Québec universities into the prevention, causes, identification, and treatment of cognitive impairment in the elderly. Alongside this outstanding university-based research, Québec’s pharmaceutical industry is making a major contribution to research on Alzheimer’s disease and related disorders.

1.4. With regard to government policy, Québec’s Ministry of Health and Social Services (MSSS) has made a number of official commitments.

- Reform the Québec health care system:
 - introduced a population-based, multi-levelled approach that will henceforth govern the delivery of services in the health and social service system;
 - created integrated service networks through the health and social service centres (CSSSs) and implement clinical projects aimed at specific groups of clients and specific health problems;
 - reformed primary medical services by establishing Family medicine groups (FMGs) and network clinics (NCs);
 - created integrated university health networks (RUISS).
- Establish policies on health and social services for the elderly:
 - published ministerial guidelines on services for frail seniors in 2001.³⁸ These policy guidelines serve as the basis for organizing the services provided to this substantial portion of Québec’s population. The measures set out in these guidelines emphasize integrating and providing access to a range of appropriate services in accordance with evolving practices and high quality standards;
 - adopted Québec’s 2005-2000 action plan on services for frail seniors, subtitled “A Call for Solidarity”.³⁹

- Hold public consultations on seniors' living conditions (an initiative of the Québec Ministry for Families and Seniors:
 - published the report "Préparons l'avenir avec nos aînés" (let's prepare the future with our seniors) in March 2008;⁴⁰
 - introduced co-ordinated policies on assistance and support measures for informal caregivers;
 - developed a caregivers-support project jointly with a charitable organization.
- Began in-depth consultations and discussions on Alzheimer's disease, particularly with the Federation of Quebec Alzheimer Societies and the Québec Seniors' Council (*Conseil des aînés du Québec*).⁴¹

2. Major challenges

Despite all these positive achievements with regard to care and services provided, clinical practice, research, and government policy, Québec still has some major challenges to meet in all these areas. To meet these challenges successfully, Québec must give priority to carrying out some wide-ranging structural initiatives.

Specifically, the challenges are as follows:

- increase knowledge of Alzheimer's disease and adopt different attitudes towards people with Alzheimer's and their family/informal caregivers;
- enhance access to co-ordinated, personalized services for people with Alzheimer's and their caregivers, in a user-friendly system, at all stages of the disease;
- enhance quality of life and quality of care in alternative living facilities;
- enhance quality of life and quality of care at end of life;
- enhance quality of life and quality of care for family/informal caregivers;
- train and motivate professionals and support staff;
- conduct research that contributes to high-quality treatment and care.

Section 3

A Societal Approach Centred on the Individual, Humanism, and Excellence

The approach proposed by the Committee of Experts is centred on the individual, grounded in humanistic values, and based on excellence in all respects. Hence this approach places the dignity of people with Alzheimer's disease and respect for their choices front and centre. The solutions to be implemented under this approach must not be improvised. On the contrary, they must be grounded in evidence-based findings from clinical and other research conducted in Quebec, elsewhere in Canada, and abroad. For these solutions to succeed, the involvement and contribution of all players concerned, in both the public and the private sectors, is vital.

1. Act with respect for the dignity and choices of people with Alzheimer's and their families

- Recognize the inherent value of every individual.
- Establish a relationship centred on the individual rather than on the illness.
- Promote the autonomy, independence and participation of the individual and his or her family.
- Ensure that people with Alzheimer's and their families are treated respectfully as regards such issues as the right to know the diagnosis, the choice of treatment, the use of genetic testing, assessment of driving ability, decisions about choice of living arrangements and end-of-life care, responsibility for finances, and participation in research.
- Provide the best possible quality of life for people with Alzheimer's and their families in living environments adapted to their needs, abilities, and expectations.
- Provide access to excellence in pharmacological treatment and in all approaches and interventions, while respecting the expectations and choices of people with Alzheimer's and of their families.
- Encourage the commitment and support of family/informal caregivers as partners in care, and recognize that they themselves need care and services.
- At the end of life, ensure that the dignity and choices of people with Alzheimer's and their families are respected.

2. Draw on emerging solutions, research findings, and Canadian and international experience, in the context of the Québec health and social services system.

- Emphasize a societal approach based on humanistic values, excellence, and quality of services.
- Organize medical, social, support, and residential services so as to give priority to this approach and to clinical responsibility, as well as to continuity of services that are specific and "sensitized" to Alzheimer's disease and reflect its complexity, given the high proportion of concomitant diseases in people with Alzheimer's.

3. Recognize and mobilize all sectors concerned and foster synergies among them

- On the basis of a shared overall vision, secure the participation of all players in accordance with their roles and responsibilities and with the resources at their disposal. These players and resources include the public health and social services system, private resources, not-for-profit organizations, advocacy and service organizations, universities (including university research settings), and private businesses.
- Promote an organizational culture characterized by planning responses to needs, empowering people, evaluating practices, ensuring accountability, and continuously improving quality and accessibility.

Section 4

Priority Actions

Priority Action 1

Raise awareness, inform, and mobilize

1. THE CHALLENGE: ACHIEVING AND COMMUNICATING A BETTER UNDERSTANDING OF THIS CONDITION

1. Despite the seriousness of Alzheimer's disease and its human and social impacts, knowledge about Alzheimer's among the general public—and even among the policymakers, managers, professionals, and other staff who deal with it—remains limited. Too many people still think that the symptoms of this disease are part of normal aging: for instance, 73% of Québeckers regard memory loss as a natural sign of aging.⁴² Failure to recognize the early signs and symptoms of Alzheimer's disease can delay diagnosis and treatment. In addition, people commonly underestimate the effects of this disease, which goes undetected in some cases but is overdiagnosed in others.
2. Because this disease remains poorly understood by the public, myths and prejudices tend to stigmatize people with Alzheimer's and cause them to become isolated. In a recent Québec survey, fear and shame were the two reasons that respondents cited most often for delaying seeking a diagnosis of the disease: these reasons were cited by 87% and 70% of the respondents, respectively.⁴² Such results show just how tenacious such prejudices remain today.
 - The prejudice and discrimination associated with Alzheimer's disease can be partly explained by the very nature of the disease. It is a disease almost solely of the elderly, in particular women, and is classified as a mental illness.
3. Defeatist attitudes regarding Alzheimer's disease are common among professionals as well as the general public. This is especially so with regard to assessment, treatment, and approaches to helping people with Alzheimer's and their families.
4. Health professionals and the general public continue to know very little about the risk factors for Alzheimer's disease or the protective factors that can delay its negative effects.⁴³ The same is true for the appearance of symptoms of depression and stress in family/informal caregivers.⁴⁴ In this regard, very little is being done as yet to apply and to disseminate information about best practices for prevention and health promotion. But if the knowledge already available were properly applied, it could help delay the onset of the disease, possibly slow its progression, and also ensure a better quality of life for caregivers.

5. Alzheimer's disease is not perceived as a priority health challenge of the same importance as cancer, cardiovascular disease, diabetes and chronic lung diseases. It is still far from receiving adequate political and financial support from public and their elected representatives.

2. OBJECTIVES

1. **Promote, among the public, government, the health and social services system, community organizations, and the private sector:**
 - a better understanding of Alzheimer's disease and its effects on people with Alzheimer's and their families;
 - an attitude of respect for people with Alzheimer's and their families, free from prejudice and discrimination;
 - realistic but positive expectations based on the hope of improving the approach to treating people with Alzheimer's and caring for them and their families;
 - support for the necessary changes to the way that services are organized within the health and social services system;
 - support to help policymakers, managers, professionals, and other staff in the health-care system to develop their skills in dealing with Alzheimer's, and support for the definition of optimal care practices;
 - ongoing support for more research on all aspects of the disease;
 - recognition and support for funding efforts by the public, the private sector, and government.
2. **Raise awareness of the importance of promoting measures to reduce risk factors and enhance protective factors, and of devoting the necessary resources to these tasks. Such measures can help to delay the onset of the disease and mitigate its effects, thus reducing its prevalence.**

3. RECOMMENDATIONS

1. **We recommend that Québec's Ministry of Health and Social Services, together with its Ministry of the Family and Seniors and in partnership with the Federation of Quebec Alzheimer Societies, the academic community, and the private sector, develop and implement a strategy for raising awareness, disseminating information, and mobilizing resources to meet the challenges posed by Alzheimer's disease.**

This strategy must:

- address all aspects of the disease, including promotion of protective factors, mitigation of risk factors, identification of early signs of the disease, treatment, support resources, services for people with Alzheimer's and their family/informal caregivers, alternative living arrangements, behavioural and psychological symptoms of the disease, later stages of the disease, way of dealing with end of life, and research and assessment;
- include efforts to fight ageism and discrimination against people with Alzheimer's and to raise awareness of the roles, contributions, and efforts of family/informal caregivers;
- be based on validated knowledge and on the systematic application of best practices;
- be implemented by means of a variety of information-dissemination initiatives, such as an annual Québec-wide Alzheimer's information and awareness campaign, information brochures, and support for organizations that assist in and support the promotion of this information;
- provide mechanisms for the public to access information, such as a specific website containing a section for family/informal caregivers.

2. We recommend that the Québec Public Health Service (*Direction de la santé publique du Québec*) develop a strategy for raising awareness, disseminating information, and mobilizing resources regarding the major protective factors and risk factors associated with Alzheimer's disease.

This strategy must:

- be one of the priorities of Québec's Director of Public Health and be incorporated into Québec's provincial public health program and regional public health action plans, as well as into health promotion and disease prevention campaigns;
- be designed to stimulate the interest and involvement of the public and of community organizations;
- have the official backing of the regional health and social service agencies (ASSSs), local health and social service centres (CSSSs), Family medicine groups (FMGs) and all primary medical practitioners;
- be grounded in evidence-based knowledge and research findings, and on the systematic implementation of what experts consider best practices, a few examples of which are as follows:³⁷
 - prevention, detection and early management of hypertension, hyperlipidemia, and diabetes to help reduce the risks of developing Alzheimer's disease or of aggravating its symptoms';
 - steps to improve children's educational attainment and prevent head injuries, to reduce the risk of their developing Alzheimer's disease or related disorders later in life;

- encouragement of healthy lifestyles, including physical, intellectual, and social activity, good eating habits, not smoking, and consuming alcohol in moderation, all of which can help to reduce the risks of developing Alzheimer's disease or of aggravating its symptoms.

Priority Action 2

Provide access to personalized, co-ordinated assessment and treatment services for people with Alzheimer's and their family/informal caregivers

1. THE CHALLENGE: CREATING THE CONDITIONS NECESSARY FOR ACCESS TO HIGH-QUALITY CARE AND SERVICES

1. People with Alzheimer's disease and their families often have difficulty in accessing the health care and support services that they need. Health and social services professionals often are not fully aware of the range of care and services available and do not know how to guide individuals and their families to them. The results are strong feelings of frustration and a failure to make optimal use of the care and services that are in fact available.
2. Problems of access take various forms.
 - Limited access to assessment and diagnostic services: only a small percentage of people who are experiencing cognitive problems receive adequate clinical assessments. In addition to long waiting times, these individuals come up against the limits of many health professionals' training with regard to Alzheimer's disease. As a result, only a small percentage of the people who have Alzheimer's disease or a related disorder receive an accurate final diagnosis. An even smaller percentage are treated in accordance with a systematic clinical approach comparable to that used for other chronic diseases: appropriate pharmacological treatment, use of validated care protocols, other types of clinical interventions, optimal supportive care through the involvement of a care navigator or case manager, and so on. Also, the diagnosis of Alzheimer's is often communicated to individuals and their families in an unsatisfactory way that leaves them feeling helpless and frustrated.
 - Limited access to interventions for treatment and management of the behavioural and psychological symptoms of dementia (BPSD)^j: in addition to impaired cognitive function, a high proportion of Alzheimer's patients present with behavioural and psychological symptoms such as heightened anxiety, depressed mood, repeating words or questions, wandering, agitation, sexual disinhibition, and verbal or physical aggression. These symptoms are sometimes quite significant, but very rarely are they or their effects on the individuals themselves and the people around them managed in any systematic way. This situation is a major source of dysfunction, both for people with Alzheimer's and for their families.

^j BPSD (behavioural and psychological symptoms of dementia) means the symptoms of disturbed behaviour, perceptions, thoughts, and mood that frequently occur in people with Alzheimer's disease.

- Even more limited access to psychosocial services: Alzheimer's disease is not only a source of cognitive deficits and behavioural changes. It is also a source of psychological, social, and legal challenges both for the individuals who have it and for their families. At present, too little attention is paid to such important issues as assessing the ability of people with Alzheimer's to manage their assets, take care of themselves, drive a vehicle, and manage their stress.
 - Difficulty in accessing crisis services: People with Alzheimer's not only have this particular chronic disease, but can also experience acute episodes of other chronic diseases (such as pneumonia, heart failure, and other illnesses) that must be treated urgently. Likewise, these people's family members, who also are dealing with the consequences of Alzheimer's disease, may experience acute distress and discouragement that also require a rapid response. But our health care system is not good at responding rapidly, and above all appropriately, to such crises experienced by people with Alzheimer's and those close to them.
3. A number of factors may account for these difficulties of access.
- The great complexity of Alzheimer's as a health condition: Alzheimer's is a complex disease that requires many interactions both within the health and social services system and with organizations outside it. Co-morbidity is very common. Up to 80% of Alzheimer's patients have other conditions such as hypertension, arthritis, diabetes, heart disease, and depression. This makes medical and interdisciplinary monitoring and follow-up more complex. Moreover, because Alzheimer's disease and related disorders are not yet recognized as chronic diseases, few resources are devoted to them, and unlike most other chronic diseases, particularly cancer, they are not dealt with through an integrated clinical approach.
 - Prejudices that remain very strong: prejudices, apathy, and insufficient knowledge, both among the public and within the health and social services system, delay the request for a first assessment. These attitudes and behaviours are often examples of ageism ("That's normal at her age," or "There's nothing to be done about it.").
 - Broadly inadequate training: primary health-care workers have little training in the nature of Alzheimer's disease, its etiology, diagnosis and treatment, and the management of its consequences for patients and their families. These workers make little use of validated clinical guidelines. This is a major problem, because these shortcomings greatly limit the knowledge and clinical skills of physicians, nurses, and other health professionals. As a result, they are less able to recognize symptoms, investigate, diagnose, initiate treatment, and take steps to deal with the behavioural and psychological symptoms of the disease.

- Lack of flexibility and incentives: the structure, policies, and procedures of the health-care system and its institutions do not afford the flexibility needed to manage such a complex disease as Alzheimer's. The same goes for the way that primary medical services, including Family medicine groups, are organized: in addition to insufficiently flexible policies, there are insufficient incentives for preventing and managing the disease. These shortcomings make it harder to provide assessment and regular monitoring and follow-up to people with Alzheimer's and support to their families. These shortcomings are amplified by shortages of the required medical professionals: primary-care physicians, geriatricians, geriatric psychiatrists, and behavioural neurologists.
- An incomplete range of services in local health and social service centres (CSSSs): the resources currently allocated to CSSSs do not cover all of the types of interventions required to respond adequately to the increased needs of people with Alzheimer's and their caregivers.
- Lack of co-ordination and integration of the activities of the various parties involved: shortcomings are commonly seen in the integration of the activities of primary-care physicians, CSSS staff, and community organizations. This lack of co-ordination and integration on the very front line works against consistency, effectiveness, efficiency, and continuity in the care provided.
- Inappropriate home-support services: home-support services are not sufficiently tailored to the specific characteristics of Alzheimer's disease. At present, these services focus all too often on compensating for limitations in activities of daily living (ADL) and home living activities (HLA). Home-support workers pay too little attention to the clinical approach to the disease and to mobilizing the patients' abilities.
- A shortage of specialized resources: even in regions where specialized secondary services, such as cognition clinics and geriatric psychiatry departments, do exist, there are not enough of them to meet special needs and to provide rapid support to primary-care providers.

2. OBJECTIVES

1. Improve and simplify access to a process for assessing cognitive function and diagnosing Alzheimer's.

This process must be set in motion as soon as a clinician suspects memory problems, or as soon as the individual or his or her family expresses the fear that there may be such problems. The approach must be based on identifying and detecting cases, and not on

screening. The assessment process must be triggered by the degree of clinical suspicion, in accordance with the recommendations of the three Canadian Consensus Conferences on Diagnosis and Treatment of Dementia that have been held since 1989.^k

- The Consensus Conferences recommend that assessment and initial treatment be carried out by primary-care physicians with the support of the required specialists (such as geriatricians, neurologists, and psychiatrists). Primary-care physicians, when they are well trained, equipped with the necessary tools, and well supported, can perform the work of assessment and diagnosis very well, just as they do for other chronic diseases such as diabetes and heart failure. The Consensus Conferences have recommended very specific criteria for referring dementia patients from primary to secondary care providers and for using technologies such as computer tomography (CT scans) (see Appendix 4).
- Though there are currently no curative pharmacological treatments for Alzheimer's disease, improving access to the assessment and diagnosis process is still important, for the following reasons.
 - If the observed memory problems are not caused by Alzheimer's or a related disorder, and are part of normal aging, then the assessment and diagnosis process provides relief and comfort to the person and his or her family.
 - Early diagnosis enables people with Alzheimer's and their families to plan for the future, take part in decisions regarding care, and address legal issues.
 - Drugs available today do have a positive effect on the disease, even though this effect is symptomatic and may seem limited. In 10 years, it is possible and even likely that a drug will have been developed that can change the course of the disease.
 - Early diagnosis makes it possible to initiate a set of pharmacological, psychosocial, and environmental interventions that can benefit patients and their families. The goals are to optimize the patients' potential, to act on the progression of their illness, and to improve their own and their family members' well-being and quality of life.
 - Early assessment and diagnosis also allows better treatment of concomitant diseases and makes it possible to anticipate and possibly prevent complications associated with acute illness and hospitalization.

^k Screening, using current tools and in the absence of very specific clinical and biological markers, would lead to "false positives": persons identified as potentially having Alzheimer's disease, but whose cognitive status was actually normal. This situation would create anxiety in these people and their families and lead to inappropriate assessments and possibly to inappropriate treatments.

2. Provide access to integrated case management as soon as Alzheimer's is diagnosed.

As soon as people are diagnosed with Alzheimer's disease, they must be given fast access to a comprehensive process for managing their illness. According to the recommendations of the 3rd Canadian Consensus Conference (Appendix 5), in addition to assessment and diagnosis, this process must include:

- communicating and explaining the diagnosis to the individuals and their families;
- pharmacological treatment;
- treatment of risk factors;
- treatment of concomitant diseases;
- detection and treatment of depression and anxiety;
- psychosocial and environmental interventions, including advice on nutrition and physical exercise, advice on legal issues, assessment of ability to drive, and so on;
- assessment and intervention plans for family/informal caregivers, using specific, appropriate tools;
- referral to interdisciplinary professional primary-care services at health and social service centres (CSSSs) and community agencies, and co-ordination of these services as required;
- referral to secondary and tertiary services, as required;
- regular monitoring and follow-up.

3. Innovate through effective, flexible co-ordination of necessary services for people with Alzheimer's and their families.

People with Alzheimer's disease and their families need fast and easy, but effectively and flexibly co-ordinated access to primary-care services in their communities and to specialized services not far from where they live. This co-ordination is vital to the quality and continuity of the required care and services. We must therefore innovate and find effective, flexible ways to:

- develop a lasting relationship of trust between every person diagnosed with Alzheimer's and his or her family, on the one hand, and a professional assigned to ensure continuity of service, on the other, as soon as the diagnosis is made;
- anticipate the various stages of the disease, respond to constantly changing needs, and act rapidly in crises;
- focus interventions on achieving the full potential of people with Alzheimer's and ensuring their integration into society, rather than simply on compensating for their disabilities;
- respond appropriately to needs arising out of the behavioural and psychological symptoms of dementia;

- navigate through the health-care system to provide quicker access to primary, secondary, and tertiary preventive, curative, rehabilitative, and end-of-life services;
 - facilitate transitions, be they temporary (such as an acute-care hospitalization) or more permanent (such as a move to an alternative living facility).
4. **Adapt the proposed service structure and approach to local and regional circumstances.**

It is important to take into account the ways that needs and available resources vary with the geographic setting (major metropolitan area, smaller city, rural area, and so on). While we must of course consider how Québec’s health-care system as a whole is currently structured, we must also strive to adapt the proposed service structure and approach to local and regional realities. The local health and social service centres and regional health and social service agencies must be given the flexibility needed to implement the committee’s recommendations in light of their local and regional situations, while still satisfying the same requirements as regards expected overall results.

3. RECOMMENDATIONS

1. **We recommend the implementation of a service structure based on the chronic-care model⁴⁵ and the collaborative-practice model.⁴⁶ This new structure should be introduced gradually, starting in Family medicine groups (FMGs) and network clinics (NCs).**

Here are the key elements of this new service structure.

1.1 A physician-and-nurse partnership with patients and their families

In FMGs and NCs, the primary-care physician and the nurse responsible for continuity of patient services establish a partnership with each patient and his or her family to ensure access to the process of assessment, diagnosis, treatment, monitoring, and follow-up, as well as the quality and continuity of this process. The patient and his or her family are regarded as members of the team and participate actively in its decisions.

1.2 An Alzheimer’s nurse care navigator¹

In practice, the FMG nurse in charge of continuity of patient services plays the role of Alzheimer’s nurse care navigator. This role is entirely consistent with the definition of the role of the FMG nurse, as defined by the Ministry and the regional health and social service agencies.^{47,48} The Alzheimer’s nurse care navigator acts as care co-ordinator and advisor for patients and their families, liaises with the FMG’s other professionals, and interacts with specialized services such as cognition clinics, BPSD teams, Alzheimer’s

¹ In some English-language documents from Québec, this role is referred to as the “Alzheimer’s pivot nurse”.

support centres, and age-related loss of autonomy (PALV) programs. The Alzheimer's nurse care navigator, in co-operation with the physician and in accordance with established protocols, takes part in:

- identifying individuals who require cognitive assessments;
- conducting cognitive assessments (taking histories, administering cognitive tests);
- discussions leading to determination of the diagnosis;
- explaining the diagnosis and treatment to patients and their families;
- evaluating and developing plans for providing services to patients and their family/informal caregivers, including personalized recommendations on the diagnosis, treatment, support measures, legal issues, driving a car, and so on;
- referring patients to community and specialized services, as required;
- referring patients to age-related loss of autonomy (PALV) programs when they need more complex home-support or case-management services, because the services of such programs must be available. It should be stressed that FMG nurses acting as Alzheimer's nurse care navigators do not replace PALV program case managers and do not play their role.

In short, the Alzheimer's nurse care navigator becomes the primary contact for people with Alzheimer's and their families and ensures that the required care and services are delivered by the right person at the right place and the right time.

1.3 Vital support elements to facilitate the physician-and-nurse partnership with patients and their families

- Intensive, specialized training about the disease, for physicians, nurses, and other members of the team;
- Use of clinical guidelines and other standardized tools:
 - to assess, diagnosis, and treat persons with Alzheimer's;
 - to assess and provide services to their family/informal caregivers.
- Additional human resources as required, such as nurses for patient monitoring and follow-up, and psychosocial professionals, depending on the characteristics of the FMG's clientele, the number of clients with Alzheimer's, and the number of physicians;^m
- A revised and specific medical remuneration structure well suited to the work of identifying cases of this chronic disease and assessing, diagnosing, treating, and managing it;
- Elimination of the requirement to go through the exception drug status process to obtain coverage for Alzheimer's medications;

^m It is estimated that one physician can handle a caseload of 10 to 12 people with Alzheimer's disease, so one FMG with 10 physicians can handle an estimated 100 to 120 such patients. According to the Ministry and its agencies, an FMG with 10 physicians may have two to four nurses and possibly other health and psychosocial professionals, depending on the characteristics of its clientele (number of patients registered, number of elderly patients, difficulty of cases, and so on).

- Creation of a computerized registry of Alzheimer’s patients and their family/inform caregivers at the FMGs;
 - Fast access to the required technical platforms.
2. **We recommend that specialized resources be put in place to ensure that physician-nurse partnerships, as well as patients and their families, have fast, easy, flexible access to a varied range of resources.**

The accessibility of these resources must be in keeping with the changing needs of patients and their families and the progression of the disease. For example, after the diagnosis, it must be possible to quickly refer patients and families to an Alzheimer’s support centre (ASC), where they will receive information and education about the disease and about strategies for dealing with the difficulties associated with it. If the diagnosis or required treatment proves hard to establish, then there must be quick access to a cognition clinic. If behavioural and psychological symptoms of dementia are persistent or present problems that the FMG team cannot solve, then there must be reliable access to a specialized team that can intervene rapidly. If an individual’s functional abilities deteriorate and he or she needs more complex home-assistance or case-management services, an age-related loss of autonomy (PALV) program must be available.

2.1 Psychosocial resources

- **We recommend encouraging the creation of Alzheimer’s support centres (ASCs)** in the service areas of individual CSSSs or groups of CSSSs, by establishing partnerships of community groups under the leadership of regional Alzheimer societies (see Priority Action 5: Treat family/informal caregivers as partners who need support).
- **Ensure fast, flexible access to other psychosocial resources for patients and their families.**
 - For patients:
 - socialization and stimulation activities, in accordance with the stage of the disease;
 - on an individual basis, at home, in groups, in day centres, and in community agencies.
 - For caregivers (see Priority Action 5: Treat family/informal caregivers as partners who need support).

2.2 Cognition clinics

1. **We recommend that individual CSSSs or groups of CSSSs, with the support of the regional health and social service agencies, set up local or regional cognition clinics.** We must ensure that there is at least one cognition clinic in the service area of every regional hospital. Every FMG will be linked with a designated cognition clinic. The CSSS (or group of CSSSs with the support of the regional agency) will be able to choose whether to create a new cognition clinic or enhance an existing one.

These cognition clinics can be located in hospital centres or in other clinical settings, such as neurologists' offices or associated medical clinics. The regional agency or the CSSS will be responsible for ensuring that the FMGs have access to the cognition clinics. Where distances or limited staff availability pose problems, a cognition clinic should be designated to provide telehealth consultations.

Conditions for the success of cognition clinics:

- well-trained staff with the necessary expertise;
- access to the appropriate technology;
- a suitable method of remuneration, specific to Alzheimer's disease, for physicians in family medicine and other specialties who work as consultants to the clinic;
- a recognized process and approaches, based on proven facts, along with quality standards and indicators that allow a comparative analysis of cognition clinics;
- mechanisms and criteria for referral to the clinic that are explicit, harmonized, and well known to health professionals.

The cognition clinic's **mandate**:

- support the established partnership and meet the needs of team members in complex detection, diagnosis and treatment situations; access to the cognition clinic, including access for advice by telephone, must be fast and easy;
- provide training and education to FMG and other health professionals who are involved in treating patients in the clinic's service area.

The cognition clinic **team**:ⁿ

- one specialist physician (geriatrician, neurologist, geriatric psychiatrist, family physician, etc.) who has been trained to diagnose and treat Alzheimer's disease;
- one nurse clinician;
- one neuropsychologist;
- one co-ordinator.

2. We recommend that every integrated university health network (RUIS) establish a more specialized cognition clinic, with the following mandate:

- provide support to local and regional cognition clinics in very complex cases;
- offer continuing-education activities to the professionals at local and regional cognition clinics;
- ensure that the process and approaches used by all the local and regional cognition clinics in that university health network's service area are compatible and of high quality;
- help regional health and social service agencies to ensure that the local and regional cognition clinics' professional services provide sufficient coverage of needs in their service areas, including setting up telehealth services in the university health network's service area;
- assume leadership in developing research within the university health network's service area;
- develop clinical guidelines, clinical tools, and a web site with a portal for clinicians;
- take part in creating training programs (see Priority Action 6: Develop and support training programs);
- take part in assessing clinical methods and technologies in the field of Alzheimer's disease and related disorders.

2.3 Teams to manage behavioural and psychological symptoms of dementia (BPSD)

1. **We recommend that individual CSSSs or groups of CSSSs, with the support of their regional health and social service agencies, set up outreach teams to deal with moderate to severe BPSD.** These teams' services should be available to FMGs, to Alzheimer's support centres, to age-related loss of autonomy (PALV) programs, and to all residential facilities, including private facilities and residential and long-term care centres (CHSLDs).

ⁿ In determining the number of professionals (physician, nurse, neuropsychologist, etc.) required on the clinic team, needs and numbers of professionals available in the service area will be taken into account.

Depending on the resources in the area served, the CSSS or group of CSSSs may either create a new outreach team or designate an existing team, specializing in geriatric medicine, geriatric psychiatry, or another appropriate discipline, to play this role. If management of common BPSD is handled by primary-care teams (FMGs, ASCs, PALV programs), then the professionals and other care providers on these teams will need to receive appropriate training. The BPSD outreach team must then be available to help primary-care teams deal with persistent, moderate, and severe BPSD.

Conditions for the success of BPSD outreach teams:

- well-trained staff with the necessary expertise;
- a suitable method of remuneration for physicians working on the team;
- availability and flexibility of the required resources, plus a flexible method of operation that allows needs to be met in a rapid, timely fashion;
- a recognized process and approaches, based on proven facts, along with quality standards and indicators that allow a comparative analysis of BPSD outreach teams;
- mechanisms and criteria for referral to the team that are explicit, harmonized, and well known to health professionals.

The BPSD outreach team's **mandate**:

- assess and diagnose people presenting with behavioural and psychological symptoms of dementia, in their own living environment;
- working with the attending team, develop an individualized pharmacological, psychosocial, and environmental treatment plan;
- contribute to the implementation of the intervention plan by providing either clinical support or training and education to local primary-care teams;
- provide short- and medium-term monitoring and follow-up until the problem has stabilized.

The BPSD outreach **team members**:^o

- one physician (geriatric psychiatrist, geriatrician, or general practitioner) who is an expert in the diagnosis and treatment of BPSD;
- one nurse;
- one psychosocial clinician;
- one co-ordinator.

^o In determining the number of professionals (physician, nurse, neuropsychologist, etc.) required on the BPSD team, needs and numbers of professionals available in the service area region will be taken into account.

2. We recommend that every integrated university health network (RUIS) assemble a specialized geriatric psychiatry team with the following mandate:

- provide support to local BPSD outreach teams in very complex cases;
- offer continuing-education activities to local BPSD outreach teams;
- ensure that the process and approaches used by all local BPSD outreach teams in that university health network's service area are compatible and of high quality;
- help regional health and social service agencies to ensure that the local and regional BPSD teams' professional services provide sufficient coverage of needs in their service areas, including setting up telehealth services in the university health network's service area;
- assume leadership in developing research within the university health network's service area;
- develop clinical guidelines, clinical tools, and a web site with a portal for clinicians;
- take part in creating training programs (see Priority Action 6: Develop and support training programs);
- take part in assessing clinical methods and technologies in the field of BPSD.

2.4 Alzheimer's-specific age-related loss of autonomy (PALV) programs

We recommend that the CSSSs ensure that their PALV programs are better adapted to the management of Alzheimer's disease and have well-trained staff and the necessary resources. (See Priority Action 3: In the advanced stages of Alzheimer's, promote quality of life, provide access to home-support services, and provide the choice of high-quality alternative living facilities.)

2.5 An easier hospital stay and optimal transitions when Alzheimer's patients are hospitalized for acute care^p

We recommend that, when Alzheimer's patients are hospitalized for acute care, the CSSS (and, in the case of a university hospital, the integrated university health network), take the necessary steps to facilitate their hospital stays and ensure optimal transitions when they are admitted and when they are discharged.

^p These recommendations will have to be harmonized with those of the Committee of Experts on appropriate approaches to care and services for the elderly in hospital settings.

The **conditions for success** will be as follows:

- Ensure that hospitals quickly recognize patients with cognitive impairments and Alzheimer's disease, by ensuring that at the time of admission, information is transmitted quickly from the FMG (and from the PALV program, if the patient is involved in one);
- Prevent, detect, and treat delirium;
- Involve family members and the FMG's Alzheimer's nurse care navigator right away:
 - keep them informed and involve them in treatment decisions and discharge planning;
- Make sure that the services of a qualified team are available for consults at the hospital, especially with regard to BPSD;
- Provide an appropriate care structure for safely assessing and treating patients who have Alzheimer's, especially when they present with BPSD;
- Provide professionals and other staff with continuing education regarding Alzheimer's disease, delirium, BPSD, and end-of-life care, to deal with the growing numbers of people admitted to hospital who have Alzheimer's and the complex nature of co-morbidity.

3. **Service structure adapted to local and regional circumstances**

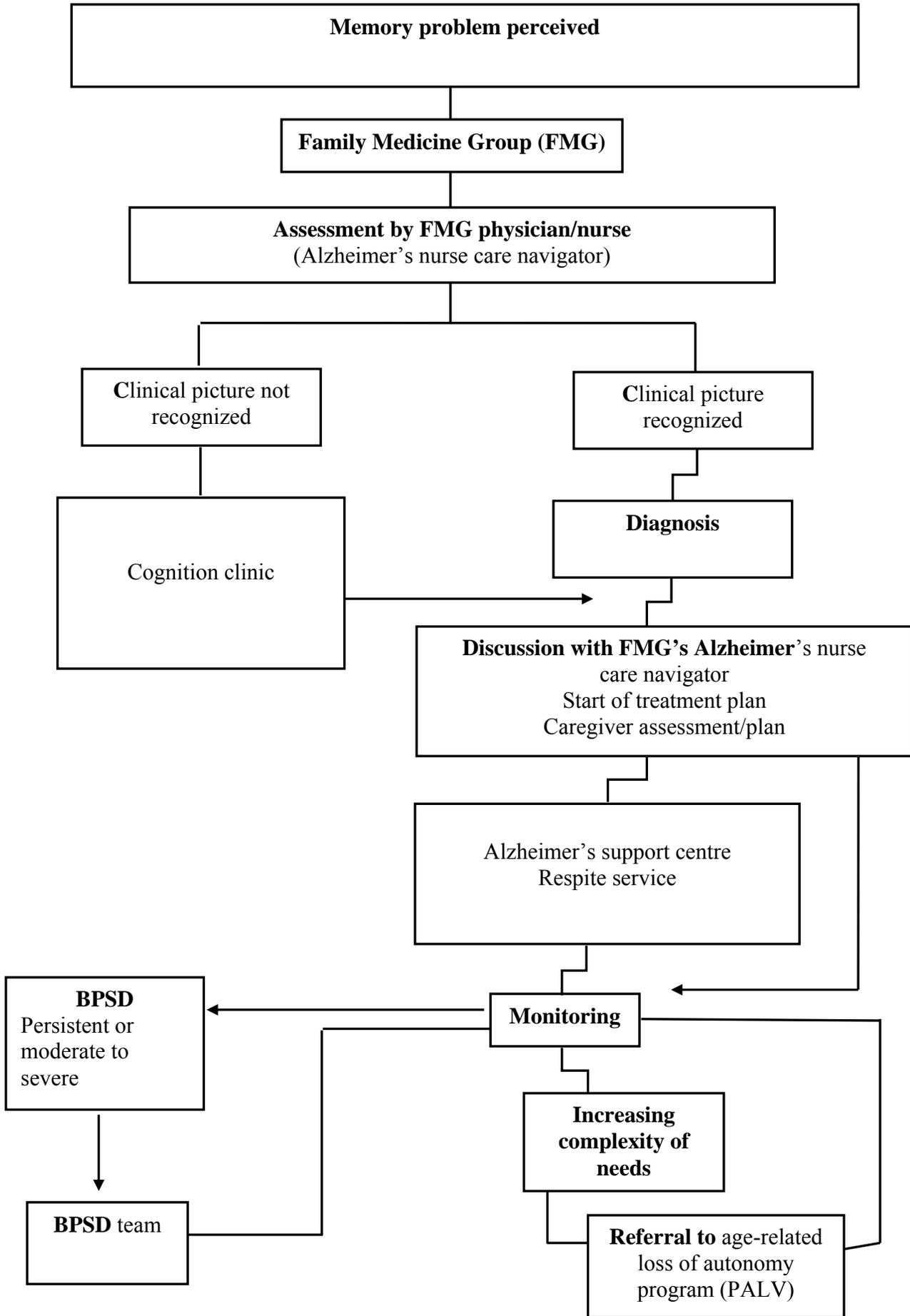
We make the following recommendations.

3.1 The CSSSs, in co-operation with their regional health and social service agencies, should be responsible for implementing the recommendations and, most important, for adapting them to the characteristics and needs of the populations they serve, the configuration of their service areas, the availability and organization of their health and social services, the availability and expertise of their primary professional resources (including FMG teams), their specialized resources, and their community resources.

Here are some examples.

- In areas where there are few or no FMGs, existing groups of physicians will have to be relied on to implement the recommendations.
- A nurse from a CSSS's chronic-disease program might be assigned the role of Alzheimer's nurse care navigator, working with a group of physicians who practice in one or more offices or at a local community service centre (CLSC).
- The functions of the cognition clinic and the BPSD team could be combined into a single team.
- Certain programs could be delivered jointly by more than one CSSS.
- Certain programs could rely on telehealth technology.

3.2 Every regional health and social services agency, in co-operation with its CSSSs, should set up an advisory committee whose mandate would be, first, to analyze the strengths and weaknesses of the region's service structure and available resources, and second, to co-ordinate, monitor and follow up on the implementation of the recommendations.



Priority Action 3

In the advanced stages of Alzheimer's, promote quality of life and provide access to home-support services and a choice of high-quality alternative living facilities.

1. THE CHALLENGE: IN THE ADVANCED STAGES OF ALZHEIMER'S, REDUCE OBSTACLES TO PATIENTS' QUALITY OF LIFE.

In addition to the general problems of access to services mentioned earlier (see Priority Action 2: Provide access to personalized, co-ordinated assessment and treatment services for people with Alzheimer's and their family/informal caregivers), people who reach the advanced stages of Alzheimer's face very specific obstacles, especially when they wish to continue to live at home for as long as possible and when they must leave their home for an alternative living environment.

1. Home support

- Nature of needs
 - When people with Alzheimer's reach the advanced stages of the disease, their needs become increasingly complex and require more intensive, highly co-ordinated services. Behavioural and psychological symptoms of dementia (BPSD) increase, as does the need for monitoring and follow-up. The individuals' clinical condition affects their physical abilities and makes them depend more on other people for activities of daily living. These individuals may contract acute illnesses, and co-existence of other chronic illnesses is common.
- Shortcomings in services provided
 - Access is still limited to intensive assistance measures to help keep people at home in the advanced stages of Alzheimer's disease. The number of hours of service offered is limited. There is little flexibility in the nature and modalities of help and respite services.
 - Family/informal caregivers receive little support and gradually become exhausted. They often face crises: social crises, intense BSPD, medical emergencies, and so on. These situations demand a fast, appropriate response, but in reality, the response is often very hard to obtain and inappropriate when it does come.

2. Alternative living facilities

- Nature of needs:
 - The prevalence of Alzheimer's disease is increasing with the ageing of the population. There is still no effective treatment to combat the progression of the disease. In addition, social support for people in the advanced stages of the disease is limited: a greater number of people are living alone, families

are smaller, and home-support services for people needing an around-the-clock presence are very limited. A rising demand for alternative living facilities can therefore be expected.

- The needs of people with Alzheimer's change over time.
 - At the start, they need a normalizing, more stimulating environment, such as a house or a hotel. These facilities can take the form of seniors' residences, operated by various legal entities (private for-profit, private not-for-profit, not-for-profit organizations, co-operatives, and so on.) Environments of this type can also be found in some public residential and long-term care centres (CHSLDs).
 - If people with Alzheimer's engage in wandering or aggressive behaviours, then they may need a more secure, safer environment. Alternative living facilities may be appropriate, or a special-care unit may meet their needs.
 - As people with Alzheimer's grow increasingly dependent for their activities of daily living, they need an environment that is better organized to provide physical care, such as a traditional long-term care unit.
- Some people with Alzheimer's have needs that are still not met appropriately in traditional geriatric-medicine settings—particularly people below age 65, couples who do not want to live apart even though one of the partners has been admitted to an alternative living facility, and, lastly, patients in special cultural circumstances.
- In addition, the declining number of spaces in the public sector is gradually increasing people's out-of-pocket expenses for such accommodations.
- Shortcomings in services provided
 - In recent years, the policy objectives of the Ministry of Health and Social Services have been to encourage home support, limit the number of spaces in public residential and long-term care centres, and rely on private-sector and not-for-profit organizations to offer a greater variety of residential accommodations. In addition, the Ministry sees its mission as being to organize support for persons with limited autonomy (frail persons) by providing the health services, social services, and assistance services that come under its mandate, regardless of where these people reside.
 - In practice, few alternative living facilities can meet all the needs of people with Alzheimer's. They are thus forced to move from one setting to another as their behavioural symptoms become more of a problem or their physical dependency becomes too great. The lack of continuity in the approach to care and the individual's diminished capacity to adapt often make these experiences painful, both for the people with Alzheimer's and for their families.

- The quality of care and access to health and social services vary greatly from one facility to another. In particular, management of BPSD is often lacking, even though this problem is virtually always present in most alternative living settings. The Ministry is attempting to improve quality of care by conducting service quality assessment visits, but so far, these visits are generally limited to public institutions and to Ministry-licensed private institutions. In addition, there are few consulting services that specialize in improving existing settings and creating new ones.
- Many alternative living facilities have difficulty in providing personalized care that respects people's distinctive characteristics and needs. For example, the established routine regarding mealtimes and bedtimes in such facilities often goes against residents' personal habits. A number of institutions have made efforts to take a more flexible approach, but much remains to be done in this regard.
- Several factors may explain why it is so difficult to provide personalized care:
 - staff are not selected well enough; there is not enough insistence on the necessary capacity for empathy, flexibility and patience;
 - staff do not receive adequate training in the approach to take when dealing with behavioural and psychological symptoms of dementia;
 - staff do not receive adequate supervision;
 - head nurses' jobs are becoming increasingly demanding, so they have less time to observe and train the staff who work for them;
 - insufficient numbers of staff, which encourages institutional routines and generates resistance to care on the part of patients.
- Staff turnover is another common problem, because as a result of it, care is very often provided by staff who do not know their patients well. This problem is observed mainly in larger facilities where staff turnover tends to be high. Difficult working conditions militate against the retention of skilled, trained staff, who prefer to move to different settings or other types of work. This turnover problem also exists in private residential facilities, where salaries are not always competitive with those in the public sector.
- The difficulties in accessing primary and secondary-care physicians and nurses who are qualified to treat people with Alzheimer's also contribute to staff burnout, repeated hospitalizations, and frequent changes in alternative living facilities.
- The waiting time to be admitted to an individual's chosen alternative facility can be long, which may mean a temporary stay in another residence that is often of inferior quality.

- Admission to an alternative setting that is undesired or unsuited to the person's needs can lead to a failure to fit into that setting, resulting eventually in relocation to a new setting and, in the meantime, frequent readmissions to hospital, with a heightened risk of functional decline.

2. OBJECTIVES

- 1. Enable families who want to do so to continue to care for loved ones in advanced stages of Alzheimer's in their homes.**
- 2. Offer a varied choice of alternative living facilities suited to the needs of people in the advanced stages of Alzheimer's.**
- 3. In facilities where a majority of the residents have Alzheimer's, design and implement programs and services that are more specifically aimed at people with this disease.**
- 4. Encourage development of staff and managers who are well trained and motivated to meet the challenges of caring for people at all stages of the disease.**
- 5. Inform, support, and encourage the involvement of families and other informal caregivers.**

3. RECOMMENDATIONS

- 1. To support families who want to care for loved ones in the advanced stages of Alzheimer's in their homes, we make the following recommendations.**

1.1 Every CSSS should ensure that its age-related loss of autonomy (PALV) program is better suited to the management of Alzheimer's disease and has well trained staff and the resources required to do the following.

- Give people who have Alzheimer's fast, flexible access to the PALV program once they have been referred to it by the FMG/patient-and-caregiver partnership. Once the disease has reached such an advanced stage that the individual and his or her caregivers need a complex combination of services from the PALV program, case-management becomes appropriate. Each such case must be managed in co-operation with the FMG and psychosocial resources, in particular the Alzheimer's Support Centre, as well as with any respite and alternative living resources that may be involved.
- Co-ordinate access to all psychosocial services and respite resources, for the sake of continuity.
- Respond rapidly to crises, for example, by having the BPSD team intervene.
- Help families to co-ordinate private services in accordance with their choices and particular needs.

1.2 The Ministry of Health and Social Services should support the use of home automation—a combination of electronic, computer and telecommunications technologies—to equip residences so as to promote autonomy and prevent accidents.

- The Ministry, in partnership with universities and the private sector, must define the role of home automation, evaluate its consequences, and encourage its incorporation into treatment plans.
- The technologies used for home automation are varied and can be helpful in many different situations that are common among people with Alzheimer's, in particular those involving isolation, falls, running away, wandering, and anxiety. Examples of these technologies include fall detectors, videotelephones, remote monitoring of biological parameters, behaviour measurement devices (sensors), audible reminder devices (for taking medication, for example), memory function stimulation, anti-runaway devices (such as door contacts, bracelets, tracking devices, and geolocators), and devices for countering anxiety (ranging from light-sensitive automatic lighting to robot pets).
- Many aspects of these technologies require government action, whether to further their development, enhance their usefulness and effectiveness, or fund them and incorporate them into intervention plans. It is also essential to consider the ethical issues that these measures raise, because they involve weighing restrictions on human freedom and dignity against the safety of people with Alzheimer's and those around them.

2. To improve services in alternative living facilities, we recommend as follows.

2.1 The Ministry of Health and Social Services, the regional health and social service agencies, and the local health and social service centres should encourage the creation and maintaining of diversified facilities that are adapted to the realities of Alzheimer's disease.

Alternative living facilities should be designed in accordance with principles that have been proven in recent experiments (see Appendix 6). We recommend as follows.

- Residents in the earlier stages of the disease should be accommodated in groups of six to 14, in spaces with an appropriate architectural design, and with staff who are trained in the psychological and physical needs of people with Alzheimer's.
- Promote the development of versatile alternative living facilities that can meet the needs of patients not only when they are in the early stages of Alzheimer's, but also when their needs change. If they begin to have persistent problems with wandering or aggressive behaviour, they will need a more secure environment. When they become more physically dependent or require palliative end-of-life care, they will need an environment with enhanced nursing care.
- Ensure that secure units are available for patients who display major physical aggression or disruptive behaviours that are incompatible with life on other care units. These secure units require a higher staff-to-patient ratio than conventional

units, as well as the services of a consulting psychiatrist. Patients could be admitted to such units temporarily or for long-term stays.

- Support the development and maintenance of affordable facilities through not-for-profit organizations (such as co-operatives, municipalities, and local Alzheimer's societies) and public-private partnerships.
- Encourage developers to situate these facilities close to or in the community, so that community members can provide assistance and support services, such as providing day care in their own homes, or assistance in the patient's home, or emergency/respite accommodations.

2.2 We make the following further recommendations.

- The CSSSs and the regional departments of general medicine (DRMGs) should provide the required professional support to the various alternative living facilities, not only regarding common medical and nursing problems, but also regarding the clinical approach to behavioural symptoms and for end-of-life care.
 - All alternative living facilities, both public and private and including private residences, should be subjected to regular service quality assessment visits focusing not only on safety issues but most of all on the humanization of care.
- 3. To train, motivate, and recognize the staff of alternative living facilities, we recommend as follows.**
- **Improve training for all staff in alternative living facilities, in particular support staff, and recognize the value of the work they do.**
 - This training should cover the fundamentals of caring for people with Alzheimer's, and particularly non-pharmacological approaches to behavioural and psychological symptoms of dementia, and should be based on a humanistic approach (see Priority Action 6: Develop and support training programs).
 - To recognize the important but frequently unacknowledged work of orderlies, adapt the suggestion in France's national Alzheimer's action plan and give orderlies who receive such training the title of "geriatric care assistants." These workers could then perform a wider variety of tasks, such as leading recreational activities and providing home support. The French plan also suggests a wage premium for these staff members.
 - **Increasing the ratios of caregiving staff** so as to improve the quality of medical care and supportive care, personalize these forms of care, and structure them in a more flexible way. This step will help to reduce staff burnout and frustration, improve patients' co-operation in the care that they receive, and reduce aggressive behaviour.⁴⁹

4. To provide families with better information and support and better encourage their involvement, we recommend as follows:

- in every alternative living facility, designate a resource-person who will be responsible for communicating regularly with families and be available to listen to their comments and answer their questions;
- provide this resource-person with training on the course of the disease, recommended clinical approaches, important aspects of communicating with families, and approaches to conflict mediation.

5. To encourage and help alternative living facilities to develop an orientation and programming that reflect the realities of Alzheimer's disease, we recommend that those facilities that have a significant proportion of residents with Alzheimer's disease do the following.

- Alternative living facilities in residential and long-term care centres (CHSLDs)
 - Regularly update the profiles of their residents who have Alzheimer's disease, specifying their characteristics and the length of their stay, according to their diagnosis.
 - Adjust the orientation, organization, and programming of their institutions to better reflect residents' actual clinical condition.
 - Set up interdisciplinary committees to improve the quality of care provided to residents with Alzheimer's.
 - Each institution's committee should be composed of clinicians and at least one representative of residents with Alzheimer's and their families.
 - Its mission should be to improve the quality of care, particularly by communicating the recommendations on best clinical practices within the institution.
 - This committee could include members of management, but should focus mainly on clinical issues.
 - Quality of care should be monitored through evaluations based on explicit criteria (such as rates of use of certain medications, rates of restraint, stimulation and maintenance of functional capacities, and pain relief), as well as through surveys of caregiving staff and surveys of families' satisfaction with the care given to their relatives.
- Other alternative living facilities
 - Provide these facilities with the consulting services and expertise that they need to apply clinical guidelines and other clinical tools that will help them to implement a care and management approach compatible with the changing needs of people with Alzheimer's (see Priority Action 8: Strategy for implementing the ministerial action plan).
 - Provide training on Alzheimer's disease to their staff and managers.

Priority Action 4

Promote high-quality, therapeutically appropriate end-of-life care that respects people's wishes, dignity, and comfort

1. THE CHALLENGE: DESIGN A BALANCED APPROACH AND PRACTICES

Currently, between 20% and 30% of people in Canada who die after age 65 have Alzheimer's disease or some other form of dementia during the last year of their life. The association between the end of life and dementia is growing. One reason is that the proportion of deaths from other causes is being reduced as the lives of people with cardiovascular disease and cancer are being extended. Another is increased life expectancy, which entails a direct risk of developing Alzheimer's disease.

Though a number of other diseases may develop or worsen as Alzheimer's progresses, in most advanced cases of Alzheimer's, the deterioration of the brain itself is usually the cause of death. In the United States, approximately 70% of all dementia-related deaths have been found to occur in nursing homes.⁵⁰ The main signs of imminent death are serious functional deterioration (for example, incontinence, and loss of the ability to walk or talk), difficulty in swallowing, and repeated bouts of fever. Characteristically, at this advanced stage of the disease, death occurs following pneumonia or feeding difficulties (denutrition and dehydration).

In the early stages of Alzheimer's, the main management objectives are to maintain optimal cognition and to improve the individual's quality of life as much as possible. As long as people with Alzheimer's and their families perceive their quality of life as acceptable, most of them will want to continue measures aimed at prolonging life. But as the disease progresses and quality of life diminishes with the onset of serious physical and mental disabilities, measures to prolong life become less desirable.

1. Alzheimer's disease as a cause of death: a little-known reality

Alzheimer's disease and related disorders are certainly among the main causes of death in the elderly, but often are not identified as such in the death certificates issued by physicians. Further evidence that deaths attributable to these causes are underestimated is that the Ministry's policy on end-of-life palliative care, published in 2005, does not even mention Alzheimer's disease or related disorders as causes of death.⁵¹

2. **Difficult ethical choices**

As Alzheimer's disease progresses and complications arise, the team providing care is increasingly faced with ethical dilemmas. Should it attempt to prolong life no matter what, or help the patient to experience a peaceful end of life? Every situation is different, and many factors must be considered, but patient autonomy is a recognized principle of medical ethics, so the wishes expressed by the patient should count the most. Because Alzheimer's patients generally cannot participate directly in medical decisions concerning them, the team must determine whether they have expressed their wishes either orally or in written documents such as advance directives, a living will, or a health-care proxy (known in Québec as a "mandate in case of incapacity"). In keeping with the personalized treatment approach, for a treatment decision to be appropriate, it must be based not only on scientific knowledge but also on the patient's condition, prognosis, values, and beliefs, as well as the care objectives that have been established with the patient or his or her representative. In this sense, the decision regarding end-of-life care must be based on a combination of different kinds of knowledge and considerations.

3. **The advantages and limitations of advance instructions**

In Québec, individuals may use a mandate in case of incapacity, advance directive, or other legal document to provide advance instructions concerning their care at end of life. In many respects, the usefulness of such documents is limited—for example, the instructions may be too general, or the individual may change his or her mind. But they can help the patient's representative—who may be a close relative or a legally designated "mandatary" (agent)—to guide the health-care team in making end-of-life treatment decisions. The proportion of people who do prepare such written advance instructions is rising steadily, but a significant number of people still do not. Fortunately, their wishes can generally be reconstructed from their known values and the opinions that they have expressed orally in the past.

4. **Divergence of opinions among families and health-care professionals regarding the appropriateness of palliative care in the advanced stages of Alzheimer's**

Increasingly, experts believe that the palliative-care approach originally developed for incurable cancers is just as appropriate for the advanced stages of Alzheimer's disease and related disorders. But whether out of ignorance or out of conviction, many physicians, nurses, other health-care professionals, and patients' representatives do not consider this option. They therefore take steps that encourage the continuation of treatment that often seems pointless. One example would be attempting cardiopulmonary resuscitation when the chances of success are practically nil and carry a high risk of injuring the patient. Another would be transferring a patient to the hospital for an assessment, or beginning an invasive treatment to prolong life for a few days or weeks, without first examining the objectives of such care or discussing a suitable palliative alternative.

5. Absence of clear guidelines on how to proceed in the advanced stages of Alzheimer's

The question of palliative care in the advanced stages of Alzheimer's disease is the subject of a growing number of scientific papers, which tend to support it as an appropriate option. But there is still no consensus on how care and services should be provided. For example, there is controversy about the advisability of antibiotic therapy in cases of potentially terminal pneumonia, as well as about artificial hydration and feeding when the patient becomes dysphagic or no longer eats sufficiently. The role of the mandatary (family member who acts as a proxy in taking medical decisions) is another subject on which opinions diverge. It is therefore no surprise how greatly practices can differ according to who is providing the care, and how much conflict end-of-life medical decisions can cause between health-care teams and families.

6. Insufficient training in ethics and palliative care for certain professionals

The Committee finds that many physicians and nurses do not have training in ethics and palliative care as they apply to Alzheimer's disease. These professionals do not always think to offer a palliative option in situations where it might be advisable, and they do not always recognize that less technological but more effective care might help patients to experience a more peaceful end of life.

7. Families' sometimes unrealistic expectations

Many families lack knowledge of the natural progression of Alzheimer's disease, the inevitable complications at end of life, and the various palliative-care options available. Some families have unrealistic expectations and, for fear that the patient may be abandoned, or for cultural or religious reasons, they ask that everything be done to prolong the patient's life. This attitude leads to added interventions and continued, possibly futile treatments, not to mention prolonging the patient's discomfort at the end of life. Many people think that choosing palliative care means deciding that nothing more can be done and leaving the patient to his or her fate. On the contrary, much can be done to make the patient more comfortable and provide better support for his or her family. Also, limiting care to making patients comfortable does not necessarily mean that they will die soon; they may continue to live for months, or even years.

8. Communication between health-care teams and families

Providing quality end-of-life care for people with Alzheimer's means maintaining their dignity, trying to make them as comfortable as possible both physically and psychologically, and respecting the wishes that they have expressed in writing or orally regarding the treatments that they receive. That is why health-care teams must always be attentive to the requests of families, who know their loved ones best. When the time

comes to choose among various treatment options (for instance, whether to prolong life or to provide comfort care only), physicians must not decide on the best course of action alone, but should instead strive to establish a consensus with their patients' representatives. The question that they must answer together is: what is the best thing to do for this person at this point in his or her life? Health-care teams must also be open to and show great respect for cultural and religious differences. Unfortunately, a number of studies have shown that communication between families and health-care teams is often difficult.

9. **Changing pharmacological care**

Many medications are prescribed for the elderly.⁹ Some of these medications are intended to provide comfort and are certainly useful. But many others are designed to prevent future medical complications, so that prescribing them becomes less appropriate when life expectancy is short and the treatment objective is simply to provide comfort care, rather than to prolong life. Moreover, taking medications can be a real burden, because many people have difficulty in swallowing all those pills. Also, as patients' cognition deteriorates, it becomes harder and harder for them to report any side effects. The apathy or agitation frequently observed at such times may be linked to the medication taken.

10. **Pain: a major challenge**

Detecting pain and discomfort in people who have Alzheimer's disease or related disorders is often difficult, because of the significant deterioration in their ability to express themselves orally. According to some authors, this explains why pain is underdiagnosed and undertreated in this population.

2. **OBJECTIVES**

1. **Encourage all citizens of Québec to prepare instructions regarding their end-of-life health care in the event that they are incapacitated.**
2. **Encourage the practice of documenting the desired intensity of treatment (level of care) for every person receiving treatment in health-care institutions, by means of discussions between health-care teams and patients or their representatives.**
3. **Evaluate and improve the quality of end-of-life care in Québec hospitals and residential and long-term care centres (CHSLDs).**

⁹ Approximately 95% of residents of Québec's residential and long-term care centres (CHSLDs) take medication. They receive up to four times more prescriptions for medications than their counterparts living at home. A typical CHSLD resident receives an average of seven different types of medications per day and has two or three "PRN" (*pro re nata*) medications, that is, medications administered as needed. Over one-third of all medications taken by CHSLD residents are psychotropic (Voyer, P and Mengue, GNP. "L'usage optimal des médicaments dans les CHSLD", in Voyer, P. (2006). *Soins infirmiers aux aînés en perte d'autonomie. Une approche adaptée au CHSLD*. Saint-Laurent (QC), ERPI. p.325-351. Online: <http://erpi.com/elm/6570.3551684490723710988.pdf>).

4. **Improve detection and treatment of pain and discomfort in persons unable to express themselves orally.**
5. **Create and publicize a guide to best medical and pharmacological practices for Alzheimer's patients at end of life.**
6. **Train physicians, nursing staff, and other professionals in ethical reasoning, palliative end-of-life interventions in cases of Alzheimer's disease, and the importance of giving families good support and keeping them well informed.**
7. **Inform families about the natural progression of Alzheimer's disease, the medical complications that commonly occur in its advanced stages, the treatment choices available, and the role of the family in the medical decision-making process. Explain the choice of palliative care in the advanced stages of Alzheimer's and reassure the public that palliative care is active care aimed at providing physical and psychological comfort and does not mean that the individual is being abandoned.**

3. RECOMMENDATIONS

1. **We recommend that the Ministry of Health and Social Services, drawing on the work that has already been done in Québec, develop an integrated approach to end-of-life care.**
 - The group to be set up to create clinical guidelines and other tools (see Priority Action 8: Strategy for implementing the ministerial action plan) must address the following end-of-life issues without fail, though it may address other such issues as well:
 - definition of end of life (factors indicating that death is imminent);
 - concept of comfort care;
 - roles of the physician and the patient's representative in medical decision-making;
 - appropriateness of cardiopulmonary resuscitation;
 - appropriateness of using technology to prolong life (artificial nutrition and hydration, repeated doses of antibiotics for recurrent infections, and so on);
 - prescribing medication when the treatment objective is comfort care;
 - the most effective ways of relieving pain and breathing problems in the terminal phase of Alzheimer's;
 - communicating with families;
 - cultural and religious differences regarding end-of-life care.

- The strategy for raising public awareness about Alzheimer’s (see Priority Action 1: Raise awareness, inform, and mobilize) should stress the issues mentioned in the preceding recommendation, together with the following ones:
 - the natural progression of Alzheimer’s disease;
 - the inevitable end-of-life complications;
 - the palliative-care choices available;
 - the usefulness of written advance end-of-life instructions and the choice of a representative legally empowered to ensure that the patient’s wishes are respected.
2. **We recommend that all health and social service centres (CSSSs), Family medicine groups (FMGs), network clinics (NCs), primary-care physicians, hospitals, and residential and long-term care centres (CHSLDs) provide families with education and educational materials about the end of life in cases of Alzheimer’s disease, drawing on tools that have already been developed in Québec.**
 3. **We recommend that universities and colleges, on-the-job training programs for new and current employees, and continuing professional development programs incorporate the following topics into the Alzheimer’s training that they provide to physicians, other professionals, and support staff at hospitals and CHSLDs (see Priority Action 6: Develop and support training programs): appropriate knowledge of end-of-life medical complications in Alzheimer’s patients and the various treatment choices, including palliative care. This training should also provide professionals with the tools they need to discuss treatment objectives and levels of care with patients and their representatives.**
 4. **We recommend that all health-care institutions concerned, and at a minimum all age-related loss of autonomy (PALV) programs, all CHSLDs, and all hospitals, take the following steps.**
 - Carry out a process to evaluate the quality of the end-of-life care that they provide. More specifically, by using a sample of cases to conduct a study of families’ satisfaction with this care, these institutions can verify their performance regarding various aspects of care, such as controlling symptoms, respecting patients’ and families’ wishes, maintaining personal dignity, and communicating with and providing support to families (a number of easy-to-use evaluation tools are available for this purpose). The institutions could then take corrective action on the basis of the weaknesses that their studies revealed.
 - Use appropriate tools to detect the pain and discomfort that people at the end of life cannot always express orally, and make sure to properly treat any pain or discomfort thus detected.
 5. **We recommend that every CHSLD create a pharmacological care committee, one of whose tasks would be to review the appropriateness of the prescriptions issued for residents of that institution, in light of the consensus of experts and the aforementioned clinical guidelines (see recommendation 1 above).**

Priority Action 5

Treat family/informal caregivers as partners who need support

1. THE CHALLENGE: SUPPORTING FAMILY/INFORMAL CAREGIVERS

Informal caregivers of people with Alzheimer's may include their spouses, their children, other family members, friends, and other persons who have chosen to provide support at some point in the course of the disease. It should be noted that 70% of all such family/informal caregivers are women.

These caregivers make a vital contribution. But the difficulties inherent in caring for someone with Alzheimer's put so much pressure on them that their own physical or psychological health may deteriorate. Hence, family/informal caregivers must be regarded both as partners and as persons who may require special support.

1. Lack of tools for assessing the status of family/informal caregivers

- The burden placed on family/informal caregivers, which increases as Alzheimer's disease progresses, is associated with psychological stress and physical health problems.^{52,53} These caregivers thus constitute an "at-risk" group within the health-care system.
- The services currently offered in Québec are centred mainly on the people who have Alzheimer's. Some countries, such as the United Kingdom and Sweden, have developed or are in the process of developing tools for assessing family/informal caregivers; the Carers Outcome Agreement Tool (COAT), developed in Sweden, is one example. No systematic tool for evaluating such caregivers' needs has yet been implemented in Québec, though an Ministry of Health and Social Services committee did make a recommendation to this effect in 2004.

2. Caregivers' reluctance to use services early on

- Studies conducted in Québec have shown that certain services offered to caregivers lack flexibility and continuity (for instance, respite services may be available only on a rigid schedule, and a different respite worker may come each time one is requested).^{54,55} Such shortcomings make these services less attractive to caregivers, who make relatively little use of them. This is especially true of respite services, even though caregivers identify them as their top need. According to the Alzheimer Society of Canada, only 3.4% of all caregivers use such services. The Canadian Study of Health and Aging has shown the same pattern. Caregivers thus often call on services only as a last resort, when they are exhausted.

- Studies also show that caregivers' needs vary according to the stage of the disease and the stage of their "career" as caregivers, and that the services provided to them must vary and be adjusted accordingly.⁵⁶ It is therefore important that we examine the issue of the time at which services are offered. Currently, caregivers make use of the services available to them (such as respite services and psycho-educational support groups) only when they have begun to show signs of psychological stress and exhaustion—often when the people for whom they are caring have reached the most advanced stages of Alzheimer's disease.
- Studies have shown that the benefits of programs for caregivers diminish as the disease progresses, at the very time that the caregiving itself becomes more demanding and the associated fatigue and psychological stress increase.^{57,58,59} Moreover, the longer that caregivers wait to seek support services, the greater the variety of services they need, and the more complex and costly these services become for the health-care system to provide.

3. Becoming a caregiver: a commitment with social and financial implications

- The caregiver's role has many repercussions personally, professionally, and socially. Caregivers often withdraw partly or completely from the labour market, which impedes their career advancement, causes them major financial losses, and makes it more difficult for them to return to their work environment once that becomes possible. In addition, they must often pay a major portion of the costs involved in caring for their aging relatives.
- There are now a greater number of financial support programs available to caregivers (refundable tax credits, for example), and these programs have been improved over the past few fiscal years. But these programs are often complex and hard for caregivers to access. Many caregivers are unaware of these programs or fail to take advantage of them.
- Currently, the top three priority needs that must be met for caregivers are respite care, psycho-educational support, and financial assistance.

2. OBJECTIVES

- 1. Enhance the Ministry of Health and Social Services policy on home support (*Chez soi : le premier choix - La politique de soutien à domicile*) by defining family/informal caregivers as clients who are entitled to receive services in their own right.**
- 2. In partnership with caregivers, design and implement a systematic tool for evaluating their needs and jointly develop a service plan.**
- 3. As soon as Alzheimer's is diagnosed, offer proactive, preventive services to caregivers, so that they can better navigate through the health-care system and community agencies network and better cope with the symptoms of their relatives' disease.**

4. **Facilitate access to psycho-educational and counselling services for caregivers in all parts of Québec.**
5. **Develop flexible respite and supportive-care services to help caregivers cope with the difficulties of their day-to-day lives as they care for people with Alzheimer's.**
6. **Make the social and financial programs for caregivers accessible and easy to use.**

3. RECOMMENDATIONS

1. **We recommend that as soon as someone is diagnosed with Alzheimer's at a Family Medicine Group or health and social services centre, a family/informal caregiver file be created, based on a partnership between the family/informal caregiver and the professional caregivers and including a tool for assessing the caregiver's needs and jointly developing a service plan.**
 - The family/informal caregiver file will make it possible to ensure the continuity, co-ordination, safety, and overall quality of the interdisciplinary measures to be taken until the person with Alzheimer's dies; this file should be reassessed and followed up on regularly (see Priority Action 2: Provide access to personalized, co-ordinated assessment and treatment services for people with Alzheimer's and their family/informal caregivers).
 - Introducing the family/informal caregiver file will require a change in professional caregivers' current practice, in which assessments and service plans are based on standardized criteria related mainly to the patient's state of health.
 - Professional caregivers will have to be given training on the partnership approach and on the problems experienced by family/informal caregivers. This training will enable these professionals to take family/informal caregivers' special needs into account so as to facilitate the partnership.
2. **In order to implement a range of services designed specifically for family/informal caregivers and suited to their needs, we recommend that the following steps be taken.**
 - 2.1 **Support the creation of an Alzheimer's support centre (ASC) in the service area of each CSSS or group of CSSSs, by creating a partnership of community groups under the leadership of the regional Alzheimer's society and with the co-operation of the CSSS.**
 - Under the leadership of the regional Alzheimer's society, the ASC enables the community to mobilize and facilitates the following tasks:
 - determining families' needs;
 - referring families to resources in the health and social services system and in the community;

- delivering direct services to individuals and groups;
- supporting society campaigns;
- combining initiatives to provide support for families.
- The ASC is a community facility that provides information, training, and access to services primarily for family/informal caregivers, but also for people in the early stages of Alzheimer's.
- Though volunteers play a central role in any ASC, certain professional resources from the CSSS are essential for establishing one. The ASC must be able to count on co-operation from the CSSS to do the following:
 - ensure that the ASC's projects mesh properly with the CSSS's services (for example, the professional team dealing with chronic diseases, the age-related loss of autonomy (PALV) program, the day centre, and temporary accommodation programs);
 - make use of the CSSS's professional resources;
 - enable the ASC to train human resources, including volunteers, in co-operation with colleges and universities.
- The ASC is a neighbourhood facility that is easily accessible to family/informal caregivers and that offers the following:
 - information and advice to individuals and groups, about Alzheimer's disease and the resources available (brochures, web sites, and so on);
 - information on how to access the psychosocial and psychosocial follow-up resources offered by the CSSS;
 - information on access to respite services;
 - emotional support, individually and in groups (support groups, relaxation courses, information on health promotion, social activities, and so on);
 - individual and group psycho-educational support (in person or on line):
 - programs for learning various skills related to psychosocial issues;
 - stress-management programs for family/informal caregivers;
 - programs regarding tools to use as they begin their role as caregivers, to learn how to navigate through the health-care system, share caregiving responsibilities within the family, communicate with the person with Alzheimer's, deal with behavioural problems, and so on;

- programs to teach various strategies for dealing with the residence where a family member with Alzheimer’s is living—for example, how to deal with caregiving staff, how to make visits enjoyable, and how to communicate with family members who are in the advanced stages of Alzheimer’s;
- community consultation and advocacy to promote the needs of people with Alzheimer’s and their family/informal caregivers in the community and to develop skills within the health-care system, the legal system, and so on;
- information on financial assistance available to caregivers.

2.2 Provide flexible respite and supportive-care services

- Caregivers must be able to rely on flexible respite and supportive-care services, day and night, for shorter and longer periods, whether planned and agreed to in advance or in emergencies.

2.3 Support the use of information and communication technologies

- The use of information and communication technologies will allow wider access to the various psycho-educational programs that will be offered, particularly in remote regions.

3. We recommend that the Government of Québec make social and financial support programs for family/informal caregivers stronger and more flexible, and inform caregivers about these programs:

- explore various mechanisms besides tax credits, which are available mainly to people with higher incomes, so as to expand the range of social and financial programs provided to family/informal caregivers;
- take the necessary steps to ensure that all family/informal caregivers are systematically informed of the social and financial programs available to them;
- ensure that these programs are clear and flexible enough to make them easy to understand and to access;
- for greater flexibility, where appropriate, provide direct allowances (also known as “service employment paycheques”);
- ensure that the various Québec ministries (Finance, Health and Social Services, Labour) work together to better co-ordinate all of the support programs offered to family/informal caregivers.

Priority Action 6

Develop and support training programs

1. THE CHALLENGE: SOME CATCHING UP TO DO

1. Currently, Alzheimer's remains a relatively neglected disease. It has received scant attention or energy from the health and social services system. Little effort has been invested in developing and transferring knowledge about this disease to professionals and support staff,^r even though the presence of qualified staff to work with people with Alzheimer's and their families is a major determinant of the quality of the care and services that they receive. For example, lack of training or inadequate training in the behavioural and psychological symptoms of dementia results in suboptimal management of this problem and overuse of antipsychotic drugs. This non-existent or inadequate training, and the resulting suboptimal quality of care, also lead to a devaluing of the work done by staff who deal with people with Alzheimer's and their families.

2. Training in and transfer of knowledge regarding Alzheimer's disease present special challenges, for the following reasons:
 - the great complexity and progressive nature of the disease, the intensity of the needs of individuals and their families at the disease's various stages, and the presence of behavioural and psychological symptoms of dementia and major basic physical needs;
 - the large number and wide variety of professionals and other staff involved in providing services;
 - the large number of policymakers, planners, and managers involved at all levels of the health and social services system;
 - the variety of settings in which services are delivered and the uneven availability of conditions suitable for training, such as in residential facilities, especially private ones.

3. Colleges and universities do not offer nearly enough courses and internships in the field of aging in general and Alzheimer's in particular. This shortcoming affects the academic and clinical training of all categories of human resources, from support staff to managers and professionals.

The same problem arises with regard to continuing professional development, at the time when people start a new job or enter a new professional practice, and thereafter.

^r This term covers orderlies, home support workers, and other workers who provide care.

- That said, some progress has been made in recent years. Medical school internships and residencies in family medicine, internal medicine, neurology, and emergency medicine now include placements in geriatrics, which may be compulsory or elective, depending on the school. The Ministry of Health and Social Services now also offers orderlies a special training program in working with the elderly. Unfortunately, these efforts are often fragmented. Most of the time, they do not reach the people who need them the most. Moreover, little incentive or recognition is given to encourage training, particularly about Alzheimer's disease.
- Few continuing education or professional development programs offer inter-occupational learning activities, even though care is actually given by teams from various occupations. This situation does not facilitate clear, harmonious sharing of roles and responsibilities.
- The health and social service centres staff who deliver age-related loss of autonomy programs (home care, CHSLDs, public alternative living facilities) deal with large numbers of people with Alzheimer's. But these centres provide few training and orientation activities for new employees and few opportunities for on-the-job training on this subject. In addition, little is known about what kind of investments private institutions are making in such training.
- Despite the marked rise in the numbers of people who are living with and dying of Alzheimer's disease, there is very little training in end-of-life care for this clientele. Many physicians and nurses lack training in medical ethics and palliative care as applied to Alzheimer's disease (see Priority Action 4: Promote high-quality, therapeutically appropriate end-of-life care that respects people's wishes, dignity, and comfort).
- Policymakers, planners, and managers have few opportunities to receive systematic training on Alzheimer's disease.
- Professional caregivers do not always have ready access to tools such as care guidelines, clinical tools, and web sites that bring together all the information needed to work intelligently with people with Alzheimer's and their families.

Lastly, despite the great efforts that have been made, particularly by the Canadian Consensus Conferences on Diagnosis and Treatment of Dementia, there is no recognized clinical guide for Alzheimer's disease (see Priority Action 8: Strategy for implementing the ministerial action plan).

2. OBJECTIVES

1. **Recognize investment in training as one of the strategies needed to enhance the quality of care and the role of managers, professionals, and caregiving staff and thereby contribute to their recruitment and retention.**
2. **Develop a picture of training in Alzheimer's disease both at colleges and universities and in introductory programs for new employees and on-the-job programs for other employees at care facilities.**
3. **Use the resulting data to guide training strategy and priorities when the future ministerial action plan is implemented.**
4. **Mobilize all sectors to develop and implement this training strategy, including the ministries concerned, colleges, universities, organizations that provide continuing professional development (such as professional orders, professional associations, and scholarly organizations), the private sector, the Federation of Quebec Alzheimer Societies, and other groups.**
5. **Design and use innovative methods and approaches to attract the greatest possible number of people to training sessions, especially people who are normally reluctant to take part in activities of this type.**
6. **Link training efforts to the development of clinical guidelines and tools.**
7. **Design and implement a variety of organizational, professional, and financial incentives, such as scholarships, bonuses, training certificates with credits, and the replacement of staff for training, in order to make training more attractive and facilitate recruitment and retention.**

3. RECOMMENDATIONS

1. **We recommend that the Québec Ministry of Education, Leisure, and Sport (MELS), in co-operation with the Québec Ministry of Health and Social Services (MSSS), develop a strategy to provide education on aging, and more specifically on Alzheimer's disease, at all colleges and universities in Québec.** The curriculum and programs that these institutions implement to provide academic training at the bachelor's, master's and doctoral levels, as well as continuing professional development, will enable professionals^s and other people working in this field to gradually upgrade their skills and keep them up to date thereafter.
 - The MSSS should put the appropriate incentives in place to attract and recruit health professionals to careers working with the elderly.

^s Particularly physicians, nurses, physiotherapists, occupational therapists, social workers, nutritionists, and psychologists

2. **We recommend that the MSSS mobilize universities,¹¹ professional associations and colleges, the pharmaceutical industry, and the Alzheimer Society to pool their expertise and resources in a coherent, collective effort to establish an extensive continuing professional development operation aimed at the main health professionals who provide care to Alzheimer’s patients.**
- This initiative should produce a “uniprofessional”, interprofessional training plan based on the stages of the disease, adapted to the various clinical settings, and including end-of-life medical interventions and the various treatment options, including end-of-life care (see Priority Action 4: Promote high-quality, therapeutically appropriate end-of-life care that respects people’s wishes, dignity, and comfort).
 - This training plan should be designed to reach as many professionals as possible, especially those who generally show no interest in continuing professional development.
 - This training plan should define strategies and methods for maintaining previously acquired knowledge and skills and transmitting new knowledge and skills, drawing mainly on the work of the Canadian Consensus Conferences.
 - These strategies should innovate by using a variety of methodologies, such as a web portal, e-learning, contributions from regional and national experts, train-the-trainer programs to train local expert coaches, visits to teaching institutions (academic detailing), on-the-job training by local coaches, use of telehealth, etc.
 - In the very short term, priority should be given to providing the following groups of professionals with training in the following topics:
 - Family Medicine Group physicians and nurses, in detection, diagnosis, treatment and follow-up;
 - BPSD team physicians, nurses and psychosocial clinicians, in detection, diagnosis, treatment, follow-up, and support in the community;
 - physicians, nurses, and psychosocial clinicians from residential settings, chiefly in BPSDs and end-of-life care.
 - The MSSS, regional health and social service agencies, and health-care institutions should provide innovative organizational, professional, and financial incentives to promote active participation in this training.

3. **We recommend that the MSSS, in co-operation with universities,[†] regional health and social service agencies, and local health and social service centres (CSSSs), develop an Alzheimer’s disease training program for support staff in community agencies, in public and private alternative living facilities, and in residential and long-term care centres (CHSLDs).**
 - This program should emphasize the fundamental aspects of caring for people with Alzheimer’s. It should focus especially on humanistic, non-pharmacological approaches to dealing with behavioural and psychological symptoms of dementia and providing end-of-life care.
 - To reach as many people as possible, this program should use a variety of innovative methods, such as e-learning and training in the workplace.

4. **We recommend that the MSSS develop a plan for raising awareness and providing training about Alzheimer’s disease to decisionmakers, including members of boards of directors, planners, and managers at the MSSS, regional health and social service agencies, CSSSs, and community organizations.**

[†] More specifically, integrated university health network (RUIS) cognition clinics, RUIS geriatric psychiatry teams, the Geriatrics Institutes at the University of Montreal and the University of Sherbrooke, the Centre of Excellence on Aging at Laval University, and the Division of Geriatric Medicine at McGill University.

Priority Action 7

Mobilize all members of the university, public, and private sectors for an unprecedented research effort

1. THE CHALLENGE: ENHANCE QUÉBEC'S ALREADY FORMIDABLE RESEARCH POTENTIAL

Alzheimer's research in Québec, despite the excellence of the individuals, organizations, and infrastructure devoted to it and its competitive advantage in terms of interdisciplinarity, has not yet reached maturity. But it has the potential to become a major source of new knowledge that can in turn generate new clinical practices and new ways of delivering health and social services, both nationally and internationally. Québec Alzheimer's research can thus rightly aspire to a leading role on the world stage.

1. Building linkages among all types of research settings, clinical settings, industry, and users is still proving difficult.

One of the keys to the success of a Québec policy on Alzheimer's disease research will be the ability to build linkages and foster exchanges of knowledge and information between the various research settings on the one hand and clinical settings, industry, and users on the other. Such linkages will enable best practices in Alzheimer's care to be implemented so as to meet the needs of people with Alzheimer's more quickly.

2. Obtaining funding for research projects that involve high risk but have high clinical potential is also difficult.

Research funding agencies often hesitate to back research projects that have high clinical potential but involve a certain level of risk. Yet the complexity of the challenge presented by Alzheimer's disease makes it imperative to fund these projects, which have the potential to improve the health and quality of life of people with Alzheimer's and their families.

3. A critical mass of researchers has not yet been achieved.

Research capacity involves both a quantitative dimension (the number of research teams) and a qualitative dimension (quality of research training and interdisciplinarity of research). Notwithstanding the efforts that have already been made, it is urgent to train tomorrow's researchers properly in all areas and approaches related to Alzheimer's disease.

Some research areas are receiving less attention than they should—for example, research into how health care services for people with Alzheimer's should be organized, and, even more so, research into the social dimensions of the disease.

4. **Alzheimer’s research is underfunded.**

In Québec, as elsewhere in Canada and the rest of the world, funding levels for Alzheimer’s research are far lower than those for research on other diseases such as cancer, heart disease, and stroke. The costs associated with Alzheimer’s disease in Canada totalled an estimated \$5.5 billion in 2000,^{18,19} yet funding for Alzheimer’s research represents only 3% of the budget of the Canadian Institutes of Health Research (CIHR). In 2007-2008, CIHR budgeted \$26 million for Alzheimer’s research, compared with \$170 million for cancer research.^{u,60}

5. **Alzheimer’s research is not interdisciplinary enough.**

In Québec, though there are many researchers involved in Alzheimer’s research, there are not enough exchanges among researchers in different disciplines and different settings. Thus there are few mechanisms for maximizing Québec’s research potential and facilitating the necessary interactions among researchers, clinicians, people with Alzheimer’s, their families, community organizations, and the private sector.

6. **Current law is impeding research.**

In the 1990s, the Government of Québec modified the legal framework governing research on human subjects by revising the provisions concerning consent and by adopting a ministerial action plan on research ethics and scientific integrity that applies to all institutions in the public health and social services system. The new provisions concerning consent, set out in Article 21 of the Civil Code of Québec, are designed to protect research subjects. But these provisions have also been found to have a considerable negative impact on research concerning adults who are incapable of giving their consent to serve as research subjects. Article 21 gives the power of such consent to these people’s “mandataries” (persons with powers of attorney), “tutors” (guardians), or “curators” (trustees). But because most adults who are incapable of giving consent have no such legal representatives, Article 21 is considerably impeding research on this segment of the population. In 2006, various individuals and groups in the research community recommended making Article 21 more flexible, so as to facilitate research concerning adults who are incapable of giving consent.^{v,w}

^u Search on CIHR Funding, Grants and Awards, 2007-2008. Keywords: Alzheimer’s, cancer, cardiovascular system. [Online: <http://webapps.cihr-irsc.gc.ca/funding>].

^v *Rapport final du groupe-conseil sur l’encadrement des banques de données et des banques de matériel biologique à des fins de recherche en santé* (FRSQ, 2006).

^w *L’article 21 du Code civil et la recherche auprès des aînés atteints de démence dans les milieux de soins de longue durée au Québec: Une analyse, un constat et une proposition* (Philippe Voyer and Sylvie St-Jacques, 2006).

2. OBJECTIVES

1. Promote planning, organization, and support for:

- research among all disciplines and settings dealing with all dimensions of Alzheimer's disease;
- disseminating knowledge to users and sharing knowledge with them.

2. Enable people with Alzheimer's and their families to express their needs for new knowledge and to influence research efforts to meet these needs.

3. Ensure fast, complete dissemination of best practices.

4. Increase research capacity in all areas and approaches related to Alzheimer's disease.

3. RECOMMENDATIONS

1. We recommend that a research consortium on Alzheimer's disease and related disorders be established in Québec.

The objective of this consortium would be to promote and fund research on all aspects of Alzheimer's disease and related disorders. Like organizations established elsewhere (such as the Pacific Alzheimer Research Foundation in British Columbia), this consortium would make it possible to achieve the objectives listed above. This consortium should have the following characteristics.

- Substantial annual funding, on the order of at least \$10 million, from public sources (provincial and federal granting agencies, departments, and ministries), private sources (pharmaceutical, biotechnology, and information technology companies), and community sources (the Alzheimer Society, foundations, and community organizations). Though the amounts involved are considerable, the investments made in research will leverage economic development and training of a skilled workforce, at a time when such objectives are necessary for the country's economic health.
- Close ties with the Québec Fund for Health Research (*Fonds de la recherche en santé du Québec*, FRSQ) and a governance structure that might consist of a scientific director, supported by a national and international scientific advisory committee.
- An interface with all relevant organizations, including the Québec Consortium for the Discovery of Medications.
- Activities that include:
 - providing resources to support research projects and research infrastructures, with priority given to structural investments that will bring together teams from various institutions, sectors, and disciplines to examine the major issues facing people with Alzheimer's and their families;

- developing strategies to enhance Québec's Alzheimer's research capacity both quantitatively and qualitatively;
- providing participatory mechanisms that let people with Alzheimer's and their families express, directly and indirectly, their needs regarding the development of new knowledge and new practices, and convey these needs to research teams;
- providing mechanisms for disseminating and sharing new knowledge and care practices with users of the health and social services system as quickly as possible.

1.1 Research grants targeting tangible results

The proposed consortium will offer an integrated range of strategic programs to support Québec research teams, giving priority to inter-institutional, inter-sectoral, and interdisciplinary teams. The consortium will do the following, in particular.

- Give priority to supporting interdisciplinary approaches in each of the four research domains, as well as inter-domain approaches that include at least two domains. This support may take the form of:
 - grants designed to accelerate the development of knowledge whose consequences can be foreseen;
 - grants for research projects that involve risk but are innovative and have strong clinical potential.
- Help to establish highly productive research infrastructures. Each of these infrastructures must serve as many teams of researchers as possible and help to accelerate high-level research that leads to major advances.
- Provide graduate scholarships and postdoctoral fellowships to help increase research capacity, with a special strategic component for clinicians who want to acquire training in research.
- Promote projects aimed at sharing knowledge of and disseminating best clinical practices.

1.2 Research priorities for the Alzheimer's research consortium

The proposed consortium's research priorities could include topics such as the following:

- determining underlying mechanisms of and risk factors for Alzheimer's;
- developing approaches and measures for early diagnosis;
- preventing cognitive impairment;
- pharmacological treatments;

- cognitive, psychosocial, and environmental interventions;
- pharmaco-economic dimensions;
- organization of and access to health-care services;
- family/informal caregivers;
- keeping people with Alzheimer's in the community and their social role;
- end-of-life care;
- ethical issues;
- living conditions in residential facilities.

1.3 Advanced infrastructures for advanced research

The complexity and scope of the organizational, scientific and technological challenges posed by Alzheimer's research demand that the following advanced infrastructures be established.

- A **collaborative clinical-research network**: establish a collaborative clinical-research network with standardized clinical tools.
- A **provincial clinical-research registry**: create a provincial registry for clinical research incorporating data of several types (biological, clinical, psychosocial, etc.) obtained from individuals who have no cognitive impairments, from individuals with moderate cognitive impairments (MCIs), and from individuals with Alzheimer's disease or related disorders.
- A **coherent infrastructure for neuroimaging-based research**:
 - implement provincial standards for capturing neuroimaging data;
 - establish centres of expertise that will provide image-analysis services to the Alzheimer's research community.
- **Banks of biological materials for advanced research**:
 - establish a bank of blood materials for genetic studies;
 - establish an immortalized tissue cell line;
 - support one or two brain banks.

2. We recommend that Article 21 of the *Civil Code of Québec* be amended.

When an adult who is incapable of giving consent to be a research subject has no legally designated representative, Article 21 of the *Civil Code of Québec* should allow that person's spouse or close relative or someone who has demonstrated a special interest in him or her to give that consent.

Article 21 should also be amended so that the rules about obtaining consent from adults who are incapable of giving it are more flexible in certain situations, such as when:

- a research project involves no act that might harm such persons' integrity or pose any serious risk to them;
- a research project could benefit the individual concerned (when that individual is the only subject in the experiment) or could benefit other persons of the same age or with the same disease or disability (when the project involves a group of adults who are incapable of giving consent);
- a research ethics committee is satisfied that the adults who are incapable of giving consent and who are the proposed subjects of the research project have not been subjected to undue pressure;
- the persons who are the proposed subjects of the research project would not have refused to take part in it.

Section 5

Strategy for implementing the report of the Committee of Experts

1 THE CHALLENGE: MOVING INTO ACTION

Within Québec's Ministry of Health and Social Services, there is no body that has a clearly defined responsibility for Alzheimer's disease. The most recent update of the Québec government's public health program, for 2008, does not address Alzheimer's disease.⁶¹ Québec's health and social services system still does not even officially recognize Alzheimer's disease as a chronic disease, much less treat it as a top-priority health challenge in the same way as cancer, cardiovascular disease, diabetes, and chronic lung disease. Moreover, the regional health and social service agencies and local health and social service centres (CSSSs) have no programs or resources devoted specifically to Alzheimer's disease.

For effective action to be taken, the following considerable obstacles will have to be overcome.

1. A large number of organizations have to be enlisted in the effort:
 - various Québec government ministries, the main ones being Health and Social Services; Family and Seniors; Education, Recreation and Sports; and Economic Development, Innovation and Exports;
 - Québec's individual health and social service institutions;
 - various agencies that fund research: the Québec Fund for Health Research (FRSQ), the Québec Fund for Research on Society and Culture (FQRSC), the Canadian Institutes of Health Research (CIHR), and others;
 - universities and colleges;
 - associations, foundations, and not-for-profit community organizations;
 - the private sector, including health and social service organizations; educational institutions; private community organizations; the pharmaceutical, biotechnology, and information technology industries; and other private companies and organizations.
2. A wide variety of initiatives (medical, rehabilitative, psychological, environmental, social, and societal) will have to be undertaken by various categories of professionals, institutions, and organizations.
3. There are shortages of certain professionals, such as family physicians, geriatricians, geriatric psychiatrists, and nurses, and these shortages are worse in some parts of Québec than in others.
4. Regions differ in their needs, the characteristics of their populations, and the services and resources that they have available.

5. There is no shared overall vision that would promote efficiency and effectiveness in the various actions taken to deal with Alzheimer's disease. Instead we see many different initiatives that affect people with Alzheimer's and their families directly or indirectly but have no connection with one another.
6. Despite the major efforts that have been made by the Canadian Consensus Conferences on Diagnosis and Treatment of Dementia, there are no recognized clinical guidelines for dealing with Alzheimer's, nor are there any recognized clinical tools. The vast majority of guidelines and tools available, especially to physicians, are fragmentary and come from the pharmaceutical industry.

2. OBJECTIVES

1. Design a strategy based on leadership, free flow of information, support for implementation, development of clinical guidelines and clinical tools, and the establishment of a culture of quality assurance and continuous improvement in the services offered.
2. Define priorities, objectives, timetables, and monitoring mechanisms.
3. Make a co-ordinated effort to share the overall vision proposed in the report of the Committee of Experts, taking into account the priorities assigned to the various actions to be taken and the roles and responsibilities of each of the organizations concerned.
4. Provide co-ordinated leadership to implement the recommendations in the report of the Committee of Experts, enlisting the efforts of the various parties involved in planning, organizing, and delivering services, and representatives of people with Alzheimer's and their families.

3. RECOMMENDATIONS

1. **We recommend that the Ministry of Health and Social Services (MSSS) respond rapidly to the report of the Committee of Experts, define a strategy for implementing its recommendations, and allocate the funding needed to carry this strategy out gradually over the coming six years (through 2015).**
2. **We recommend that the Ministry of Health and Social Services make Alzheimer's disease a priority challenge for the health and social services system and recognize Alzheimer's as a chronic disease.**
 - The Ministry of Health and Social Services should incorporate its future ministerial action plan into:
 - the 2010-2015 strategic action plan;
 - the Québec plan for managing chronic diseases;
 - the Québec public health program;

- management and accountability agreements:
 - regarding the role that the regional health and social service agencies are expected to play;
 - regarding the role that the various entities in the health and social services system are expected to play in developing clinical Alzheimer's projects;
- the guidelines recommended to the integrated university health networks (RUISS) with regard to the clinical support that they should provide to health-care institutions.

3. **We recommend that the Ministry of Health and Social Services, in co-operation with university medical teams,^x rapidly establish a group of experts to design clinical guidelines and tools covering the various stages of Alzheimer's disease and the various settings in which people with Alzheimer's may live.** These guidelines and tools should be based on the recommendations of the Canadian Consensus Conferences on Diagnosis and Treatment of Dementia, and on other research dealing with long-term care and end-of-life care.

This group of experts must consider the ethical issues surrounding such matters as the right to know the diagnosis, the choice of treatment, being allowed to drive, the choice of living arrangements, giving consent to research, and end-of-life care decisions.

This group can be made permanent so that it can oversee ongoing updates of these guidelines and tools and work in close co-operation with the future Québec Institute for Excellence in Health and Social Services (INESSS).

4. **We recommend that the Ministry of Health and Social Services create a strategic ministerial team to implement, monitor, and follow up on the future ministerial action plan.** This team should be led by a credible, recognized professional expert, whose mandate will be as follows.
- Formulate an overall strategy for gradually implementing the recommendations in the report of the Committee of Experts by 2015, and define the priority directions for this strategy, all with the support of appropriate operational planning.
 - Provide concerted leadership, with the participation of the key players in the planning, organization, and delivery of services, Alzheimer's disease experts, and representatives of people with Alzheimer's and their families. More specifically:
 - define the mandate that each of these parties is to be given and the results that are expected of them;
 - provide support and do monitoring and follow-up;

^x Integrated university health network (RUIS) cognition clinics, RUIS geriatric psychiatry teams, the Geriatrics Institutes at the University of Montreal and the University of Sherbrooke, the Centre of Excellence on Aging at Laval University, and the Division of Geriatric Medicine at McGill University.

- designate and support non-government partners with Québec-wide mandates, such as the Federation of Quebec Alzheimer Societies;
 - develop a plan for service quality assurance and continuous service improvement and ensure that it this plan is carried out.
- Carry out the recommendations in the report of the Committee of Experts with regard to Québec-wide bodies. More specifically:
 - establish groups of experts to develop clinical guidelines and tools in co-operation with the future Québec Institute for Excellence in Health and Social Services;
 - establish committees or other groups to examine and implement the recommendations of Priority Action 6: Develop and support training programs;
 - create a web site and portal for the public, for caregivers, and for professionals;
 - develop the awareness and information strategy for the general public;
 - in co-operation with the Québec Institute of Statistics (ISQ), establish a watch to gather information on matters related to Alzheimer's disease, such as risk factors, the number of people who have Alzheimer's, its effects on caregivers, the path followed through the health-care system, and so on; establish a Québec-wide registry of people with Alzheimer's disease, based on the records of family medicine groups.
 - In addition to existing measures and policies to overcome the shortage of general practitioners and nurses, carefully consider the following:
 - steps to increase the number of physicians specializing in geriatrics, geriatric psychiatry, and neurology, as well as the number of general practitioners with recognized expertise in caring for the elderly;
 - the possibility of recognizing a geriatric nursing speciality and creating the role of specialized geriatrics nurse practitioner, who would assume clinical and teaching responsibilities and participate in research. This professional could play a key role, for example, in local and regional BPSD teams and in alternative living facilities, including residential and long-term care centres (CHSLDs).
5. **We recommend that the regional health and social service agencies and local health and social service centres (CSSSs), with the support of the strategic ministerial team for implementing, monitoring, and following up on the future ministerial action plan:**
- develop and implement regional and local Alzheimer's plans for the populations in their service areas, in accordance with the characteristics of these populations and with available resources;

- deploy services and resources in co-operation with community organizations (particularly the regional Alzheimer societies) and the private sector. While the specific characteristics of these organizations and their status as community or private entities must be respected, accountability mechanisms must also be established in co-operation with them in order to ensure that resources are deployed in a way that meets the needs of people with Alzheimer's and their families and that is consistent with the priorities defined by the CSSSs and the regional health and social service agencies.

Conclusion

Alzheimer's disease and related disorders present a major challenge for Québec society in general and for Québec's health and social services system in particular. Alzheimer's is poorly understood and its extent is underestimated, but this disease has major consequences, particularly for the people who have it and for the family members who take care of them.

In Québec, as elsewhere in the world, the urgent need to act now has been recognized, and that is all to the good. We must start today to meet the needs of people with Alzheimer's, whose numbers are growing constantly, and to provide them with the best possible quality of care and quality of life.

On the strength of our own experience and commitment, the members of the Committee of Experts are convinced that implementing the recommendations in this report will make a difference in the lives of the people who must deal with Alzheimer's—not only those who have the disease, but their family members as well. The committee members are also firmly convinced that Québec's health and social services system, whose activities and structures continue to evolve, is up to this challenge. But for this challenge to be met, one condition is vital: this effort must involve all parties concerned—in the public health and social services system, in associations such as the Federation of Quebec Alzheimer Societies, in community organizations, in the private sector, and in academia.

To be sure, implementing this report's recommendations successfully will demand conviction, leadership and tenacity—vital traits not only for implementing the priority actions identified in this report, but also for doing the necessary monitoring and follow-up, at all levels of the health and social services system.

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APPENDICES

Appendix 1: Recommendations

Priority Action 1

Raise awareness, inform, mobilize

RECOMMENDATIONS

- 1. We recommend that Québec’s Ministry of Health and Social Services, together with its Ministry of the Family and Seniors and in partnership with the Federation of Quebec Alzheimer Societies, the academic community, and the private sector, develop and implement a strategy for raising awareness, disseminating information, and mobilizing resources to meet the challenges posed by Alzheimer’s disease.**

This strategy must:

- address all aspects of the disease, including promotion of protective factors, mitigation of risk factors, identification of early signs of the disease, treatment, support resources, services for people with Alzheimer’s and their family/informal caregivers, alternative living arrangements, behavioural and psychological symptoms of the disease, later stages of the disease, way of dealing with end of life, and research and assessment;
 - include efforts to fight ageism and discrimination against people with Alzheimer’s and to raise awareness of the roles, contributions, and efforts of family/informal caregivers;
 - be based on validated knowledge and on the systematic application of best practices;
 - be implemented by means of a variety of information-dissemination initiatives, such as an annual Québec-wide Alzheimer’s information and awareness campaign, information brochures, and support for organizations that assist in and support the promotion of this information;
 - provide mechanisms for the public to access information, such as a specific website containing a section for family/informal caregivers.
- 2. We recommend that the Québec Public Health Service (Direction de la santé publique du Québec) develop a strategy for raising awareness, disseminating information, and mobilizing resources regarding the major protective factors and risk factors associated with Alzheimer’s disease.**

This strategy must:

- be one of the priorities of Québec’s Director of Public Health and be incorporated into Québec’s provincial public health program and regional public health action plans, as well as into health promotion and disease prevention campaigns;

- be designed to stimulate the interest and involvement of the public and of community organizations;
- have the official backing of the regional health and social service agencies (ASSSs), local health and social service centres (CSSSs), Family medicine groups (FMGs) and all primary medical practitioners;
- be grounded in evidence-based knowledge and research findings, and on the systematic implementation of what experts consider best practices, a few examples of which are as follows:³⁷
 - prevention, detection and early management of hypertension, hyperlipidemia, and diabetes to help reduce the risks of developing Alzheimer's disease or of aggravating its symptoms';
 - steps to improve children's educational attainment and prevent head injuries, to reduce the risk of their developing Alzheimer's disease or related disorders later in life;
 - encouragement of healthy lifestyles, including physical, intellectual, and social activity, good eating habits, not smoking, and consuming alcohol in moderation, all of which can help to reduce the risks of developing Alzheimer's disease or of aggravating its symptoms.

Priority Action 2

Provide access to personalized, coordinated evaluation and treatment services for sufferers and caregivers

RECOMMENDATIONS

1. **We recommend the implementation of a service structure based on the chronic-care model⁴⁵ and the collaborative-practice model.⁴⁶ This new structure should be introduced gradually, starting in Family medicine groups (FMGs) and network clinics (NCs).**

Here are the key elements of this new service structure.

1.1 A physician-and-nurse partnership with patients and their families

In FMGs and NCs, the primary-care physician and the nurse responsible for continuity of patient services establish a partnership with each patient and his or her family to ensure access to the process of assessment, diagnosis, treatment, monitoring, and follow-up, as well as the quality and continuity of this process. The patient and his or her family are regarded as members of the team and participate actively in its decisions.

1.2 An Alzheimer's nurse care navigator^a

In practice, the FMG nurse in charge of continuity of patient services plays the role of Alzheimer's nurse care navigator. This role is entirely consistent with the definition of the role of the FMG nurse, as defined by the Ministry and the regional health and social service agencies.^{47,48} The Alzheimer's nurse care navigator acts as care co-ordinator and advisor for patients and their families, liaises with the FMG's other professionals, and interacts with specialized services such as cognition clinics, BPSD teams, Alzheimer's support centres, and age-related loss of autonomy (PALV) programs. The Alzheimer's nurse care navigator, in co-operation with the physician and in accordance with established protocols, takes part in:

- identifying individuals who require cognitive assessments;
- conducting cognitive assessments (taking histories, administering cognitive tests);
- discussions leading to determination of the diagnosis;
- explaining the diagnosis and treatment to patients and their families;
- evaluating and developing plans for providing services to patients and their family/informal caregivers, including personalized recommendations on the diagnosis, treatment, support measures, legal issues, driving a car, and so on;
- referring patients to community and specialized services, as required;

^a In some English-language documents from Québec, this role is referred to as the "Alzheimer's pivot nurse".

- referring patients to age-related loss of autonomy (PALV) programs when they need more complex home-support or case-management services, because the services of such programs must be available. It should be stressed that FMG nurses acting as Alzheimer's nurse care navigators do not replace PALV program case managers and do not play their role.

In short, the Alzheimer's nurse care navigator becomes the primary contact for people with Alzheimer's and their families and ensures that the required care and services are delivered by the right person at the right place and the right time.

1.3 Vital support elements to facilitate the physician-and-nurse partnership with patients and their families

- Intensive, specialized training about the disease, for physicians, nurses, and other members of the team;
- Use of clinical guidelines and other standardized tools:
 - to assess, diagnosis, and treat persons with Alzheimer's;
 - to assess and provide services to their family/informal caregivers.
- Additional human resources as required, such as nurses for patient monitoring and follow-up, and psychosocial professionals, depending on the characteristics of the FMG's clientele, the number of clients with Alzheimer's, and the number of physicians;^b
- A revised and specific medical remuneration structure well suited to the work of identifying cases of this chronic disease and assessing, diagnosing, treating, and managing it;
- Elimination of the requirement to go through the exception drug status process to obtain coverage for Alzheimer's medications;
- Creation of a computerized registry of Alzheimer's patients and their family/inform caregivers at the FMGs;
- Fast access to the required technical platforms.

2. We recommend that specialized resources be put in place to ensure that physician-nurse partnerships, as well as patients and their families, have fast, easy, flexible access to a varied range of resources.

The accessibility of these resources must be in keeping with the changing needs of patients and their families and the progression of the disease. For example, after the diagnosis, it must be possible to quickly refer patients and families to an Alzheimer's support centre (ASC), where they will receive information and education about the disease and about strategies for dealing with the difficulties associated with it. If the

^b It is estimated that one physician can handle a caseload of 10 to 12 people with Alzheimer's disease, so one FMG with 10 physicians can handle an estimated 100 to 120 such patients. According to the Ministry and its agencies, an FMG with 10 physicians may have two to four nurses and possibly other health and psychosocial professionals, depending on the characteristics of its clientele (number of patients registered, number of elderly patients, difficulty of cases, and so on).

diagnosis or required treatment proves hard to establish, then there must be quick access to a cognition clinic. If behavioural and psychological symptoms of dementia are persistent or present problems that the FMG team cannot solve, then there must be reliable access to a specialized team that can intervene rapidly. If an individual's functional abilities deteriorate and he or she needs more complex home-assistance or case-management services, an age-related loss of autonomy (PALV) program must be available.

2.1 Psychosocial resources

- **We recommend encouraging the creation of Alzheimer's support centres (ASCs)** in the service areas of individual CSSSs or groups of CSSSs, by establishing partnerships of community groups under the leadership of regional Alzheimer societies (see Priority Action 5: Treat family/informal caregivers as partners who need support).
- **Ensure fast, flexible access to other psychosocial resources for patients and their families.**
 - For patients:
 - socialization and stimulation activities, in accordance with the stage of the disease;
 - on an individual basis, at home, in groups, in day centres, and in community agencies.
 - For caregivers (see Priority Action 5: Treat family/informal caregivers as partners who need support).

2.2 Cognition clinics

1. **We recommend that individual CSSSs or groups of CSSSs, with the support of the regional health and social service agencies, set up local or regional cognition clinics.** We must ensure that there is at least one cognition clinic in the service area of every regional hospital. Every FMG will be linked with a designated cognition clinic. The CSSS (or group of CSSSs with the support of the regional agency) will be able to choose whether to create a new cognition clinic or enhance an existing one.

These cognition clinics can be located in hospital centres or in other clinical settings, such as neurologists' offices or associated medical clinics. The regional agency or the CSSS will be responsible for ensuring that the FMGs have access to the cognition clinics. Where distances or limited staff availability pose problems, a cognition clinic should be designated to provide telehealth consultations.

Conditions for the success of cognition clinics:

- well-trained staff with the necessary expertise;
- access to the appropriate technology;

- a suitable method of remuneration, specific to Alzheimer’s disease, for physicians in family medicine and other specialties who work as consultants to the clinic;
- a recognized process and approaches, based on proven facts, along with quality standards and indicators that allow a comparative analysis of cognition clinics;
- mechanisms and criteria for referral to the clinic that are explicit, harmonized, and well known to health professionals.

The cognition clinic’s **mandate**:

- support the established partnership and meet the needs of team members in complex detection, diagnosis and treatment situations; access to the cognition clinic, including access for advice by telephone, must be fast and easy;
- provide training and education to FMG and other health professionals who are involved in treating patients in the clinic’s service area.

The cognition clinic **team**:^c

- one specialist physician (geriatrician, neurologist, geriatric psychiatrist, family physician, etc.) who has been trained to diagnose and treat Alzheimer’s disease;
- one nurse clinician;
- one neuropsychologist;
- one co-ordinator.

2. We recommend that every integrated university health network (RUIS) establish a more specialized cognition clinic, with the following mandate:

- provide support to local and regional cognition clinics in very complex cases;
- offer continuing-education activities to the professionals at local and regional cognition clinics;
- ensure that the process and approaches used by all the local and regional cognition clinics in that university health network’s service area are compatible and of high quality;
- help regional health and social service agencies to ensure that the local and regional cognition clinics’ professional services provide sufficient coverage of needs in their service areas, including setting up telehealth services in the university health network’s service area;
- assume leadership in developing research within the university health network’s service area;

^c In determining the number of professionals (physician, nurse, neuropsychologist, etc.) required on the clinic team, needs and numbers of professionals available in the service area will be taken into account.

- develop clinical guidelines, clinical tools, and a web site with a portal for clinicians;
- take part in creating training programs (see Priority Action 6: Develop and support training programs);
- take part in assessing clinical methods and technologies in the field of Alzheimer’s disease and related disorders.

2.3 Teams to manage behavioural and psychological symptoms of dementia (BPSD)

1. **We recommend that individual CSSSs or groups of CSSSs, with the support of their regional health and social service agencies, set up outreach teams to deal with moderate to severe BPSD.** These teams’ services should be available to FMGs, to Alzheimer’s support centres, to age-related loss of autonomy (PALV) programs, and to all residential facilities, including private facilities and residential and long-term care centres (CHSLDs).

Depending on the resources in the area served, the CSSS or group of CSSSs may either create a new outreach team or designate an existing team, specializing in geriatric medicine, geriatric psychiatry, or another appropriate discipline, to play this role. If management of common BPSD is handled by primary-care teams (FMGs, ASCs, PALV programs), then the professionals and other care providers on these teams will need to receive appropriate training. The BPSD outreach team must then be available to help primary-care teams deal with persistent, moderate, and severe BPSD.

Conditions for the success of BPSD outreach teams:

- well-trained staff with the necessary expertise;
- a suitable method of remuneration for physicians working on the team;
- availability and flexibility of the required resources, plus a flexible method of operation that allows needs to be met in a rapid, timely fashion;
- a recognized process and approaches, based on proven facts, along with quality standards and indicators that allow a comparative analysis of BPSD outreach teams;
- mechanisms and criteria for referral to the team that are explicit, harmonized, and well known to health professionals.

The BPSD outreach team’s **mandate**:

- assess and diagnose people presenting with behavioural and psychological symptoms of dementia, in their own living environment;
- working with the attending team, develop an individualized pharmacological, psychosocial, and environmental treatment plan;
- contribute to the implementation of the intervention plan by providing either clinical support or training and education to local primary-care teams;

- provide short- and medium-term monitoring and follow-up until the problem has stabilized.

The BPSD outreach **team members**:^d

- one physician (geriatric psychiatrist, geriatrician, or general practitioner) who is an expert in the diagnosis and treatment of BPSD;
- one nurse;
- one psychosocial clinician;
- one co-ordinator.

2. We recommend that every integrated university health network (RUIS) assemble a specialized geriatric psychiatry team with the following mandate:

- provide support to local BPSD outreach teams in very complex cases;
- offer continuing-education activities to local BPSD outreach teams;
- ensure that the process and approaches used by all local BPSD outreach teams in that university health network’s service area are compatible and of high quality;
- help regional health and social service agencies to ensure that the local and regional BPSD teams’ professional services provide sufficient coverage of needs in their service areas, including setting up telehealth services in the university health network’s service area;
- assume leadership in developing research within the university health network’s service area;
- develop clinical guidelines, clinical tools, and a web site with a portal for clinicians;
- take part in creating training programs (see Priority Action 6: Develop and support training programs);
- take part in assessing clinical methods and technologies in the field of BPSD.

2.4 Alzheimer’s-specific age-related loss of autonomy (PALV) programs

We recommend that the CSSSs ensure that their PALV programs are better adapted to the management of Alzheimer’s disease and have well-trained staff and the necessary resources. (See Priority Action 3: In the advanced stages of Alzheimer’s, promote quality of life, provide access to home-support services, and provide the choice of high-quality alternative living facilities.)

^d In determining the number of professionals (physician, nurse, neuropsychologist, etc.) required on the BPSD team, needs and numbers of professionals available in the service area region will be taken into account.

2.5 An easier hospital stay and optimal transitions when Alzheimer's patients are hospitalized for acute care^e

We recommend that, when Alzheimer's patients are hospitalized for acute care, the CSSS (and, in the case of a university hospital, the integrated university health network), take the necessary steps to facilitate their hospital stays and ensure optimal transitions when they are admitted and when they are discharged.

The **conditions for success** will be as follows:

- Ensure that hospitals quickly recognize patients with cognitive impairments and Alzheimer's disease, by ensuring that at the time of admission, information is transmitted quickly from the FMG (and from the PALV program, if the patient is involved in one);
- Prevent, detect, and treat delirium;
- Involve family members and the FMG's Alzheimer's nurse care navigator right away:
 - keep them informed and involve them in treatment decisions and discharge planning;
- Make sure that the services of a qualified team are available for consults at the hospital, especially with regard to BPSD;
- Provide an appropriate care structure for safely assessing and treating patients who have Alzheimer's, especially when they present with BPSD;
- Provide professionals and other staff with continuing education regarding Alzheimer's disease, delirium, BPSD, and end-of-life care, to deal with the growing numbers of people admitted to hospital who have Alzheimer's and the complex nature of co-morbidity.

3. Service structure adapted to local and regional circumstances

We make the following recommendations.

3.1 The CSSSs, in co-operation with their regional health and social service agencies, should be responsible for implementing the recommendations and, most important, for adapting them to the characteristics and needs of the populations they serve, the configuration of their service areas, the availability and organization of their health and social services, the availability and expertise of their primary professional resources (including FMG teams), their specialized resources, and their community resources.

Here are some examples.

^e These recommendations will have to be harmonized with those of the Committee of Experts on appropriate approaches to care and services for the elderly in hospital settings.

- In areas where there are few or no FMGs, existing groups of physicians will have to be relied on to implement the recommendations.
- A nurse from a CSSS's chronic-disease program might be assigned the role of Alzheimer's nurse care navigator, working with a group of physicians who practice in one or more offices or at a local community service centre (CLSC).
- The functions of the cognition clinic and the BPSD team could be combined into a single team.
- Certain programs could be delivered jointly by more than one CSSS.
- Certain programs could rely on telehealth technology.

3.2 Every regional health and social services agency, in co-operation with its CSSSs, should set up an advisory committee whose mandate would be, first, to analyze the strengths and weaknesses of the region's service structure and available resources, and second, to co-ordinate, monitor and follow up on the implementation of the recommendations.

Priority Action 3

In the advanced stages of the disease: promote quality of life and provide access to home support and the choice of a quality living environment

RECOMMENDATIONS

1. To support families who want to care for loved ones in the advanced stages of Alzheimer's in their homes, we make the following recommendations.

1.1 Every CSSS should ensure that its age-related loss of autonomy (PALV) program is better suited to the management of Alzheimer's disease and has well trained staff and the resources required to do the following.

- Give people who have Alzheimer's fast, flexible access to the PALV program once they have been referred to it by the FMG/patient-and-caregiver partnership. Once the disease has reached such an advanced stage that the individual and his or her caregivers need a complex combination of services from the PALV program, case-management becomes appropriate. Each such case must be managed in cooperation with the FMG and psychosocial resources, in particular the Alzheimer's Support Centre, as well as with any respite and alternative living resources that may be involved.
- Co-ordinate access to all psychosocial services and respite resources, for the sake of continuity.
- Respond rapidly to crises, for example, by having the BPSD team intervene.
- Help families to co-ordinate private services in accordance with their choices and particular needs.

1.2 The Ministry of Health and Social Services should support the use of home automation—a combination of electronic, computer and telecommunications technologies—to equip residences so as to promote autonomy and prevent accidents.

- The Ministry, in partnership with universities and the private sector, must define the role of home automation, evaluate its consequences, and encourage its incorporation into treatment plans.
- The technologies used for home automation are varied and can be helpful in many different situations that are common among people with Alzheimer's, in particular those involving isolation, falls, running away, wandering, and anxiety. Examples of these technologies include fall detectors, videotelephones, remote monitoring of biological parameters, behaviour measurement devices (sensors), audible reminder devices (for taking medication, for example), memory function stimulation, anti-runaway devices (such as door contacts, bracelets, tracking devices, and geolocators), and devices for countering anxiety (ranging from light-sensitive automatic lighting to robot pets).
- Many aspects of these technologies require government action, whether to further their development, enhance their usefulness and effectiveness, or fund them and

incorporate them into intervention plans. It is also essential to consider the ethical issues that these measures raise, because they involve weighing restrictions on human freedom and dignity against the safety of people with Alzheimer's and those around them.

2. To improve services in alternative living facilities, we recommend as follows.

2.1 The Ministry of Health and Social Services, the regional health and social service agencies, and the local health and social service centres should encourage the creation and maintaining of diversified facilities that are adapted to the realities of Alzheimer's disease.

Alternative living facilities should be designed in accordance with principles that have been proven in recent experiments (see Appendix 6). We recommend as follows.

- Residents in the earlier stages of the disease should be accommodated in groups of six to 14, in spaces with an appropriate architectural design, and with staff who are trained in the psychological and physical needs of people with Alzheimer's.
- Promote the development of versatile alternative living facilities that can meet the needs of patients not only when they are in the early stages of Alzheimer's, but also when their needs change. If they begin to have persistent problems with wandering or aggressive behaviour, they will need a more secure environment. When they become more physically dependent or require palliative end-of-life care, they will need an environment with enhanced nursing care.
- Ensure that secure units are available for patients who display major physical aggression or disruptive behaviours that are incompatible with life on other care units. These secure units require a higher staff-to-patient ratio than conventional units, as well as the services of a consulting psychiatrist. Patients could be admitted to such units temporarily or for long-term stays.
- Support the development and maintenance of affordable facilities through not-for-profit organizations (such as co-operatives, municipalities, and local Alzheimer's societies) and public-private partnerships.
- Encourage developers to situate these facilities close to or in the community, so that community members can provide assistance and support services, such as providing day care in their own homes, or assistance in the patient's home, or emergency/respite accommodations.

2.2 We make the following further recommendations.

- The CSSSs and the regional departments of general medicine (DRMGs) should provide the required professional support to the various alternative living facilities, not only regarding common medical and nursing problems, but also regarding the clinical approach to behavioural symptoms and for end-of-life care.
- All alternative living facilities, both public and private and including private residences, should be subjected to regular service quality assessment visits focusing not only on safety issues but most of all on the humanization of care.

3. **To train, motivate, and recognize the staff of alternative living facilities, we recommend as follows.**
 - **Improve training for all staff in alternative living facilities, in particular support staff, and recognize the value of the work they do.**
 - This training should cover the fundamentals of caring for people with Alzheimer's, and particularly non-pharmacological approaches to behavioural and psychological symptoms of dementia, and should be based on a humanistic approach (see Priority Action 6: Develop and support training programs).
 - To recognize the important but frequently unacknowledged work of orderlies, adapt the suggestion in France's national Alzheimer's action plan and give orderlies who receive such training the title of "geriatric care assistants." These workers could then perform a wider variety of tasks, such as leading recreational activities and providing home support. The French plan also suggests a wage premium for these staff members.
 - **Increasing the ratios of caregiving staff** so as to improve the quality of medical care and supportive care, personalize these forms of care, and structure them in a more flexible way. This step will help to reduce staff burnout and frustration, improve patients' co-operation in the care that they receive, and reduce aggressive behaviour.⁴⁹
4. **To provide families with better information and support and better encourage their involvement, we recommend as follows:**
 - in every alternative living facility, designate a resource-person who will be responsible for communicating regularly with families and be available to listen to their comments and answer their questions;
 - provide this resource-person with training on the course of the disease, recommended clinical approaches, important aspects of communicating with families, and approaches to conflict mediation.
5. **To encourage and help alternative living facilities to develop an orientation and programming that reflect the realities of Alzheimer's disease, we recommend that those facilities that have a significant proportion of residents with Alzheimer's disease do the following.**
 - Alternative living facilities in residential and long-term care centres (CHSLDs)
 - Regularly update the profiles of their residents who have Alzheimer's disease, specifying their characteristics and the length of their stay, according to their diagnosis.
 - Adjust the orientation, organization, and programming of their institutions to better reflect residents' actual clinical condition.
 - Set up interdisciplinary committees to improve the quality of care provided to residents with Alzheimer's.

- Each institution's committee should be composed of clinicians and at least one representative of residents with Alzheimer's and their families.
 - Its mission should be to improve the quality of care, particularly by communicating the recommendations on best clinical practices within the institution.
 - This committee could include members of management, but should focus mainly on clinical issues.
 - Quality of care should be monitored through evaluations based on explicit criteria (such as rates of use of certain medications, rates of restraint, stimulation and maintenance of functional capacities, and pain relief), as well as through surveys of caregiving staff and surveys of families' satisfaction with the care given to their relatives.
- Other alternative living facilities
 - Provide these facilities with the consulting services and expertise that they need to apply clinical guidelines and other clinical tools that will help them to implement a care and management approach compatible with the changing needs of people with Alzheimer's (see Priority Action 8: Strategy for implementing the ministerial action plan).
 - Provide training on Alzheimer's disease to their staff and managers.

Priority Action 4

Promote high-quality, therapeutically pertinent end-of-life care, with respect for people's wishes, dignity and comfort

RECOMMENDATIONS

1. **We recommend that the Ministry of Health and Social Services, drawing on the work that has already been done in Québec, develop an integrated approach to end-of-life care.**
 - The group to be set up to create clinical guidelines and other tools (see Priority Action 8: Strategy for implementing the ministerial action plan) must address the following end-of-life issues without fail, though it may address other such issues as well:
 - definition of end of life (factors indicating that death is imminent);
 - concept of comfort care;
 - roles of the physician and the patient's representative in medical decision-making;
 - appropriateness of cardiopulmonary resuscitation;
 - appropriateness of using technology to prolong life (artificial nutrition and hydration, repeated doses of antibiotics for recurrent infections, and so on);
 - prescribing medication when the treatment objective is comfort care;
 - the most effective ways of relieving pain and breathing problems in the terminal phase of Alzheimer's;
 - communicating with families;
 - cultural and religious differences regarding end-of-life care.
 - The strategy for raising public awareness about Alzheimer's (see Priority Action 1: Raise awareness, inform, and mobilize) should stress the issues mentioned in the preceding recommendation, together with the following ones:
 - the natural progression of Alzheimer's disease;
 - the inevitable end-of-life complications;
 - the palliative-care choices available;
 - the usefulness of written advance end-of-life instructions and the choice of a representative legally empowered to ensure that the patient's wishes are respected.
2. **We recommend that all health and social service centres (CSSSs), Family medicine groups (FMGs), network clinics (NCs), primary-care physicians, hospitals, and residential and long-term care centres (CHSLDs) provide families with education and educational materials about the end of life in cases of Alzheimer's disease, drawing on tools that have already been developed in Québec.**

3. **We recommend that universities and colleges, on-the-job training programs for new and current employees, and continuing professional development programs incorporate the following topics into the Alzheimer’s training that they provide to physicians, other professionals, and support staff at hospitals and CHSLDs (see Priority Action 6: Develop and support training programs): appropriate knowledge of end-of-life medical complications in Alzheimer’s patients and the various treatment choices, including palliative care. This training should also provide professionals with the tools they need to discuss treatment objectives and levels of care with patients and their representatives.**
4. **We recommend that all health-care institutions concerned, and at a minimum all age-related loss of autonomy (PALV) programs, all CHSLDs, and all hospitals, take the following steps.**
 - Carry out a process to evaluate the quality of the end-of-life care that they provide. More specifically, by using a sample of cases to conduct a study of families’ satisfaction with this care, these institutions can verify their performance regarding various aspects of care, such as controlling symptoms, respecting patients’ and families’ wishes, maintaining personal dignity, and communicating with and providing support to families (a number of easy-to-use evaluation tools are available for this purpose). The institutions could then take corrective action on the basis of the weaknesses that their studies revealed.
 - Use appropriate tools to detect the pain and discomfort that people at the end of life cannot always express orally, and make sure to properly treat any pain or discomfort thus detected.
5. **We recommend that every CHSLD create a pharmacological care committee, one of whose tasks would be to review the appropriateness of the prescriptions issued for residents of that institution, in light of the consensus of experts and the aforementioned clinical guidelines (see recommendation 1 above).**

Priority Action 5

Caregivers: partners who deserve support

RECOMMENDATIONS

- 1. We recommend that as soon as someone is diagnosed with Alzheimer's at a Family Medicine Group or health and social services centre, a family/informal caregiver file be created, based on a partnership between the family/informal caregiver and the professional caregivers and including a tool for assessing the caregiver's needs and jointly developing a service plan.**
 - The family/informal caregiver file will make it possible to ensure the continuity, co-ordination, safety, and overall quality of the interdisciplinary measures to be taken until the person with Alzheimer's dies; this file should be reassessed and followed up on regularly (see Priority Action 2: Provide access to personalized, co-ordinated assessment and treatment services for people with Alzheimer's and their family/informal caregivers).
 - Introducing the family/informal caregiver file will require a change in professional caregivers' current practice, in which assessments and service plans are based on standardized criteria related mainly to the patient's state of health.
 - Professional caregivers will have to be given training on the partnership approach and on the problems experienced by family/informal caregivers. This training will enable these professionals to take family/informal caregivers' special needs into account so as to facilitate the partnership.

- 2. In order to implement a range of services designed specifically for family/informal caregivers and suited to their needs, we recommend that the following steps be taken.**
 - 2.1 Support the creation of an Alzheimer's support centre (ASC) in the service area of each CSSS or group of CSSSs, by creating a partnership of community groups under the leadership of the regional Alzheimer's society and with the co-operation of the CSSS.**
 - Under the leadership of the regional Alzheimer's society, the ASC enables the community to mobilize and facilitates the following tasks:
 - determining families' needs;
 - referring families to resources in the health and social services system and in the community;

- delivering direct services to individuals and groups;
- supporting society campaigns;
- combining initiatives to provide support for families.
- The ASC is a community facility that provides information, training, and access to services primarily for family/informal caregivers, but also for people in the early stages of Alzheimer's.
- Though volunteers play a central role in any ASC, certain professional resources from the CSSS are essential for establishing one. The ASC must be able to count on co-operation from the CSSS to do the following:
 - ensure that the ASC's projects mesh properly with the CSSS's services (for example, the professional team dealing with chronic diseases, the age-related loss of autonomy (PALV) program, the day centre, and temporary accommodation programs);
 - make use of the CSSS's professional resources;
 - enable the ASC to train human resources, including volunteers, in co-operation with colleges and universities.
- The ASC is a neighbourhood facility that is easily accessible to family/informal caregivers and that offers the following:
 - information and advice to individuals and groups, about Alzheimer's disease and the resources available (brochures, web sites, and so on);
 - information on how to access the psychosocial and psychosocial follow-up resources offered by the CSSS;
 - information on access to respite services;
 - emotional support, individually and in groups (support groups, relaxation courses, information on health promotion, social activities, and so on);
 - individual and group psycho-educational support (in person or on line):
 - programs for learning various skills related to psychosocial issues;
 - stress-management programs for family/informal caregivers;
 - programs regarding tools to use as they begin their role as caregivers, to learn how to navigate through the health-care system, share caregiving responsibilities within the family, communicate with the person with Alzheimer's, deal with behavioural problems, and so on;

- programs to teach various strategies for dealing with the residence where a family member with Alzheimer’s is living—for example, how to deal with caregiving staff, how to make visits enjoyable, and how to communicate with family members who are in the advanced stages of Alzheimer’s;
- community consultation and advocacy to promote the needs of people with Alzheimer’s and their family/informal caregivers in the community and to develop skills within the health-care system, the legal system, and so on;
- information on financial assistance available to caregivers.

2.2 Provide flexible respite and supportive-care services

- Caregivers must be able to rely on flexible respite and supportive-care services, day and night, for shorter and longer periods, whether planned and agreed to in advance or in emergencies.

2.3 Support the use of information and communication technologies

- The use of information and communication technologies will allow wider access to the various psycho-educational programs that will be offered, particularly in remote regions.

3. We recommend that the Government of Québec make social and financial support programs for family/informal caregivers stronger and more flexible, and inform caregivers about these programs:

- explore various mechanisms besides tax credits, which are available mainly to people with higher incomes, so as to expand the range of social and financial programs provided to family/informal caregivers;
- take the necessary steps to ensure that all family/informal caregivers are systematically informed of the social and financial programs available to them;
- ensure that these programs are clear and flexible enough to make them easy to understand and to access;
- for greater flexibility, where appropriate, provide direct allowances (also known as “service employment paycheques”);
- ensure that the various Québec ministries (Finance, Health and Social Services, Labour) work together to better co-ordinate all of the support programs offered to family/informal caregivers.

Priority Action 6

Developing and supporting practice

RECOMMENDATIONS

1. **We recommend that the Québec Ministry of Education, Leisure, and Sport (MELS), in co-operation with the Québec Ministry of Health and Social Services (MSSS), develop a strategy to provide education on aging, and more specifically on Alzheimer’s disease, at all colleges and universities in Québec.** The curriculum and programs that these institutions implement to provide academic training at the bachelor’s, master’s and doctoral levels, as well as continuing professional development, will enable professionals^f and other people working in this field to gradually upgrade their skills and keep them up to date thereafter.
 - The MSSS should put the appropriate incentives in place to attract and recruit health professionals to careers working with the elderly.

2. **We recommend that the MSSS mobilize universities,¹¹ professional associations and colleges, the pharmaceutical industry, and the Alzheimer Society to pool their expertise and resources in a coherent, collective effort to establish an extensive continuing professional development operation aimed at the main health professionals who provide care to Alzheimer’s patients.**
 - This initiative should produce a “uniprofessional”, interprofessional training plan based on the stages of the disease, adapted to the various clinical settings, and including end-of-life medical interventions and the various treatment options, including end-of-life care (see Priority Action 4: Promote high-quality, therapeutically appropriate end-of-life care that respects people’s wishes, dignity, and comfort).
 - This training plan should be designed to reach as many professionals as possible, especially those who generally show no interest in continuing professional development.
 - This training plan should define strategies and methods for maintaining previously acquired knowledge and skills and transmitting new knowledge and skills, drawing mainly on the work of the Canadian Consensus Conferences.
 - These strategies should innovate by using a variety of methodologies, such as a web portal, e-learning, contributions from regional and national experts, train-the-trainer programs to train local expert coaches, visits to teaching institutions (academic detailing), on-the-job training by local coaches, use of telehealth, etc.
 - In the very short term, priority should be given to providing the following groups of professionals with training in the following topics:
 - Family Medicine Group physicians and nurses, in detection, diagnosis, treatment and follow-up;

^f Particularly physicians, nurses, physiotherapists, occupational therapists, social workers, nutritionists, and psychologists

- BPSD team physicians, nurses and psychosocial clinicians, in detection, diagnosis, treatment, follow-up, and support in the community;
 - physicians, nurses, and psychosocial clinicians from residential settings, chiefly in BPSDs and end-of-life care.
- The MSSS, regional health and social service agencies, and health-care institutions should provide innovative organizational, professional, and financial incentives to promote active participation in this training.
3. **We recommend that the MSSS, in co-operation with universities,⁸ regional health and social service agencies, and local health and social service centres (CSSSs), develop an Alzheimer’s disease training program for support staff in community agencies, in public and private alternative living facilities, and in residential and long-term care centres (CHSLDs).**
- This program should emphasize the fundamental aspects of caring for people with Alzheimer’s. It should focus especially on humanistic, non-pharmacological approaches to dealing with behavioural and psychological symptoms of dementia and providing end-of-life care.
 - To reach as many people as possible, this program should use a variety of innovative methods, such as e-learning and training in the workplace.
4. **We recommend that the MSSS develop a plan for raising awareness and providing training about Alzheimer’s disease to decisionmakers, including members of boards of directors, planners, and managers at the MSSS, regional health and social service agencies, CSSSs, and community organizations.**

⁸ More specifically, integrated university health network (RUIS) cognition clinics, RUIS geriatric psychiatry teams, the Geriatrics Institutes at the University of Montreal and the University of Sherbrooke, the Centre of Excellence on Aging at Laval University, and the Division of Geriatric Medicine at McGill University.

Priority Action 7

An unprecedented research drive: mobilization of all actors in the public, university and private sectors

RECOMMENDATIONS

1. **We recommend that a research consortium on Alzheimer’s disease and related disorders be established in Québec.**

The objective of this consortium would be to promote and fund research on all aspects of Alzheimer’s disease and related disorders. Like organizations established elsewhere (such as the Pacific Alzheimer Research Foundation in British Columbia), this consortium would make it possible to achieve the objectives listed above. This consortium should have the following characteristics.

- Substantial annual funding, on the order of at least \$10 million, from public sources (provincial and federal granting agencies, departments, and ministries), private sources (pharmaceutical, biotechnology, and information technology companies), and community sources (the Alzheimer Society, foundations, and community organizations). Though the amounts involved are considerable, the investments made in research will leverage economic development and training of a skilled workforce, at a time when such objectives are necessary for the country’s economic health.
- Close ties with the Québec Fund for Health Research (*Fonds de la recherche en santé du Québec*, FRSQ) and a governance structure that might consist of a scientific director, supported by a national and international scientific advisory committee.
- An interface with all relevant organizations, including the Québec Consortium for the Discovery of Medications.
- Activities that include:
 - providing resources to support research projects and research infrastructures, with priority given to structural investments that will bring together teams from various institutions, sectors, and disciplines to examine the major issues facing people with Alzheimer’s and their families;
 - developing strategies to enhance Québec’s Alzheimer’s research capacity both quantitatively and qualitatively;
 - providing participatory mechanisms that let people with Alzheimer’s and their families express, directly and indirectly, their needs regarding the development of new knowledge and new practices, and convey these needs to research teams;
 - providing mechanisms for disseminating and sharing new knowledge and care practices with users of the health and social services system as quickly as possible.

1.1 Research grants targeting tangible results

The proposed consortium will offer an integrated range of strategic programs to support Québec research teams, giving priority to inter-institutional, inter-sectoral, and interdisciplinary teams. The consortium will do the following, in particular.

- Give priority to supporting interdisciplinary approaches in each of the four research domains, as well as inter-domain approaches that include at least two domains. This support may take the form of:
 - grants designed to accelerate the development of knowledge whose consequences can be foreseen;
 - grants for research projects that involve risk but are innovative and have strong clinical potential.
- Help to establish highly productive research infrastructures. Each of these infrastructures must serve as many teams of researchers as possible and help to accelerate high-level research that leads to major advances.
- Provide graduate scholarships and postdoctoral fellowships to help increase research capacity, with a special strategic component for clinicians who want to acquire training in research.
- Promote projects aimed at sharing knowledge of and disseminating best clinical practices.

1.2 Research priorities for the Alzheimer's research consortium

The proposed consortium's research priorities could include topics such as the following:

- determining underlying mechanisms of and risk factors for Alzheimer's;
- developing approaches and measures for early diagnosis;
- preventing cognitive impairment;
- pharmacological treatments;
- cognitive, psychosocial, and environmental interventions;
- pharmaco-economic dimensions;
- organization of and access to health-care services;
- family/informal caregivers;
- keeping people with Alzheimer's in the community and their social role;
- end-of-life care;
- ethical issues;
- living conditions in residential facilities.

1.3 Advanced infrastructures for advanced research

The complexity and scope of the organizational, scientific and technological challenges posed by Alzheimer's research demand that the following advanced infrastructures be established.

- A **collaborative clinical-research network**: establish a collaborative clinical-research network with standardized clinical tools.
- A **provincial clinical-research registry**: create a provincial registry for clinical research incorporating data of several types (biological, clinical, psychosocial, etc.) obtained from individuals who have no cognitive impairments, from individuals with moderate cognitive impairments (MCIs), and from individuals with Alzheimer's disease or related disorders.
- A **coherent infrastructure for neuroimaging-based research**:
 - implement provincial standards for capturing neuroimaging data;
 - establish centres of expertise that will provide image-analysis services to the Alzheimer's research community.
- **Banks of biological materials for advanced research**:
 - establish a bank of blood materials for genetic studies;
 - establish an immortalized tissue cell line;
 - support one or two brain banks.

2. We recommend that Article 21 of the *Civil Code of Québec* be amended.

When an adult who is incapable of giving consent to be a research subject has no legally designated representative, Article 21 of the *Civil Code of Québec* should allow that person's spouse or close relative or someone who has demonstrated a special interest in him or her to give that consent.

Article 21 should also be amended so that the rules about obtaining consent from adults who are incapable of giving it are more flexible in certain situations, such as when:

- a research project involves no act that might harm such persons' integrity or pose any serious risk to them;
- a research project could benefit the individual concerned (when that individual is the only subject in the experiment) or could benefit other persons of the same age or with the same disease or disability (when the project involves a group of adults who are incapable of giving consent);
- a research ethics committee is satisfied that the adults who are incapable of giving consent and who are the proposed subjects of the research project have not been subjected to undue pressure;
- the persons who are the proposed subjects of the research project would not have refused to take part in it.

Proposed implementation strategy

RECOMMENDATIONS

1. **We recommend that the Ministry of Health and Social Services (MSSS) respond rapidly to the report of the Committee of Experts, define a strategy for implementing its recommendations, and allocate the funding needed to carry this strategy out gradually over the coming six years (through 2015).**
2. **We recommend that the Ministry of Health and Social Services make Alzheimer's disease a priority challenge for the health and social services system and recognize Alzheimer's as a chronic disease.**
 - The Ministry of Health and Social Services should incorporate its future ministerial action plan into:
 - the 2010-2015 strategic action plan;
 - the Québec plan for managing chronic diseases;
 - the Québec public health program;
 - management and accountability agreements:
 - regarding the role that the regional health and social service agencies are expected to play;
 - regarding the role that the various entities in the health and social services system are expected to play in developing clinical Alzheimer's projects;
 - the guidelines recommended to the integrated university health networks (RUIs) with regard to the clinical support that they should provide to health-care institutions.
3. **We recommend that the Ministry of Health and Social Services, in co-operation with university medical teams,^h rapidly establish a group of experts to design clinical guidelines and tools covering the various stages of Alzheimer's disease and the various settings in which people with Alzheimer's may live.** These guidelines and tools should be based on the recommendations of the Canadian Consensus Conferences on Diagnosis and Treatment of Dementia, and on other research dealing with long-term care and end-of-life care.

This group of experts must consider the ethical issues surrounding such matters as the right to know the diagnosis, the choice of treatment, being allowed to drive, the choice of living arrangements, giving consent to research, and end-of-life care decisions.

^h Integrated university health network (RUIS) cognition clinics, RUIS geriatric psychiatry teams, the Geriatrics Institutes at the University of Montreal and the University of Sherbrooke, the Centre of Excellence on Aging at Laval University, and the Division of Geriatric Medicine at McGill University.

This group can be made permanent so that it can oversee ongoing updates of these guidelines and tools and work in close co-operation with the future Québec Institute for Excellence in Health and Social Services (INESSS).

4. **We recommend that the Ministry of Health and Social Services create a strategic ministerial team to implement, monitor, and follow up on the future ministerial action plan.** This team should be led by a credible, recognized professional expert, whose mandate will be as follows.

- Formulate an overall strategy for gradually implementing the recommendations in the report of the Committee of Experts by 2015, and define the priority directions for this strategy, all with the support of appropriate operational planning.
- Provide concerted leadership, with the participation of the key players in the planning, organization, and delivery of services, Alzheimer's disease experts, and representatives of people with Alzheimer's and their families. More specifically:
 - define the mandate that each of these parties is to be given and the results that are expected of them;
 - provide support and do monitoring and follow-up;
 - designate and support non-government partners with Québec-wide mandates, such as the Federation of Quebec Alzheimer Societies;
 - develop a plan for service quality assurance and continuous service improvement and ensure that it this plan is carried out.
- Carry out the recommendations in the report of the Committee of Experts with regard to Québec-wide bodies. More specifically:
 - establish groups of experts to develop clinical guidelines and tools in co-operation with the future Québec Institute for Excellence in Health and Social Services;
 - establish committees or other groups to examine and implement the recommendations of Priority Action 6: Develop and support training programs;
 - create a web site and portal for the public, for caregivers, and for professionals;
 - develop the awareness and information strategy for the general public;
 - in co-operation with the Québec Institute of Statistics (ISQ), establish a watch to gather information on matters related to Alzheimer's disease, such as risk factors, the number of people who have Alzheimer's, its effects on caregivers, the path followed through the health-care system, and so on; establish a Québec-wide registry of people with Alzheimer's disease, based on the records of family medicine groups.
- In addition to existing measures and policies to overcome the shortage of general practitioners and nurses, carefully consider the following:

- steps to increase the number of physicians specializing in geriatrics, geriatric psychiatry, and neurology, as well as the number of general practitioners with recognized expertise in caring for the elderly;
- the possibility of recognizing a geriatric nursing speciality and creating the role of specialized geriatrics nurse practitioner, who would assume clinical and teaching responsibilities and participate in research. This professional could play a key role, for example, in local and regional BPSD teams and in alternative living facilities, including residential and long-term care centres (CHSLDs).

5. We recommend that the regional health and social service agencies and local health and social service centres (CSSSs), with the support of the strategic ministerial team for implementing, monitoring, and following up on the future ministerial action plan:

- develop and implement regional and local Alzheimer’s plans for the populations in their service areas, in accordance with the characteristics of these populations and with available resources;
- deploy services and resources in co-operation with community organizations (particularly the regional Alzheimer societies) and the private sector. While the specific characteristics of these organizations and their status as community or private entities must be respected, accountability mechanisms must also be established in co-operation with them in order to ensure that resources are deployed in a way that meets the needs of people with Alzheimer’s and their families and that is consistent with the priorities defined by the CSSSs and the regional health and social service agencies.

Appendix 2: Members of the Committee and Sub-Committees

Comittee members

Howard Bergman, M.D.

Professor and holder of Dr. Joseph Kaufmann Chair
Geriatrics Division, McGill University and the Jewish General Hospital
Vice-President and Scientific Director, Fonds de la recherche en santé du Québec (FRSQ)

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Céline Bureau, M. Sc. Inf.

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Martine Lecoœur

First Vice-President
Québec Federation of Alzheimer Societies

Claire Pagé

Présidente-directrice générale
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Nicole Poirier

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Lucie Tremblay, inf.

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Appendix 3: Alzheimer's and related diseases: definitions

Alzheimer's disease

Alzheimer's disease is a progressive, irreversible degenerative brain disease. It was discovered in 1906 by Dr. Alois Alzheimer, who identified two manifestations of the disease that now bears his name: "plaques" and "tangles." The plaques are small dense deposits spread over the entire brain that are toxic for brain cells at high concentrations. The tangles interfere with vital processes by "stifling" healthy brain cells. The degeneration and death of brain cells causes shrinkage of certain regions of the brain. These changes in the brain cause cognitive disturbance and behavioural and psychological symptoms in the sufferer.

There are two forms of Alzheimer's disease: the sporadic form, which accounts for over 90% of all cases and which usually develops in people aged 65 and over, and the autosomal-dominant familial form, which is the cause of less than 10% of all cases and which usually appears before the age of 65.

The first cognitive symptom to appear is often memory loss (amnesia). Memory problems initially manifest themselves by the loss of memory of recent events, whereas older memories remain relatively well preserved. Mnesic impairment progressively worsens as the disease progresses. Subsequently, cognitive impairment extends to the fields of language (aphasia), ordering of movement (apraxia), visual recognition (agnosia) and executive functions such as decision taking and planning.

Behavioural and psychological symptoms (BPSD) are important manifestations of the disease. BPSD pose a major problem for patients, their families and caregivers. Behavioural symptoms include physical aggression, shouting, inability to rest, agitation, wandering, culturally inappropriate behaviours, sexual disinhibition, hoarding, swearing and stalking. Psychological symptoms include anxiety, depressive mood, hallucinations, and delusional ideas.

The manifestations of the disease affect activities of daily living, along with work, habitual social activities and relations with others. The progress of the disease may extend over a period varying from 3 to 20 years and is often divided into stages: early, moderate, advanced, and end-of-life. The length of time a stage lasts varies greatly from one person to another.

Currently there is no single test to determine whether a person is suffering from Alzheimer's disease. In a systematic assessment, a diagnosis is established by eliminating other possible causes and by attempting to establish whether the cause of symptoms is reversible. Some people may present problems that resemble those observed in Alzheimer's disease but which are attributable to a treatable or reversible cause. So-called reversible difficulties are very rare and may be associated with the use of certain drugs, with depression or with a metabolic cause. Other, still rarer, causes include subdural hematoma and normal-pressure hydrocephalus. Once other causes have been ruled out, the diagnosis of Alzheimer's disease is made.

The stages of Alzheimer's disease

The mild stage

The “mild” stage (also called early stage) applies to people of all ages who show slight deficits attributable to the symptoms of Alzheimer's disease. Among the most common symptoms are memory loss, communication difficulties and changes in mood and behaviour. At this stage, people retain most of their capacities and require only minimal assistance. Since they are generally aware of the changes in their capacities, they are able to inform those around them about what they are experiencing and help to prepare and orient future care. Note that the term “early stage” applies to people of all ages who show mild deficits attributable to Alzheimer's disease. This is not to be confused with “early-onset” Alzheimer's disease, a term used to designate Alzheimer's disease diagnosed in people at an earlier age than is usual.

The moderate stage

At this stage of the disease, further decline of sufferers' cognitive and functional faculties are observed. Although they may still be aware of their condition at this stage, their memory and other cognitive faculties continue to deteriorate. They also need assistance to perform many daily tasks.

The advanced stage

At this stage, sufferers become incapable of communicating verbally and of taking care of themselves. They need around-the-clock care. The objective of care at this stage is to continue supporting sufferers in order to provide them with the best possible quality of life.

The end-of-life stage

As sufferers approach death, care is aimed primarily at providing comfort. As in the case of anyone with a fatal disease, it is important to take into account not only the person's physical needs, but also their emotional and spiritual needs and to ensure that these are met. Support provided at this stage is aimed at quality of life and comfort. This final phase ends in death, resulting from secondary complications of the disease.

Related diseases

Alzheimer's disease accounts for close to two thirds of cases designated by the term "Alzheimer's and related diseases." Although Alzheimer's disease is by far the most common, there are a number of others, called "related diseases." Among related diseases are vascular dementiaⁱ, Lewy body dementia, Parkinson's disease and Creutzfeldt-Jakob disease, which are described briefly below.

Vascular (multi-infarct) dementia

Vascular dementia develops following disturbances in blood flow to the brain (vascular system). These have the effect of damaging brain cells, leading to symptoms similar to those observed in Alzheimer's disease. Vascular dementia accounts for 20% of cases. Typically, it evolves in stages, but it can also progress insidiously. Typical cognitive symptoms of this disease are disturbances in executive functions. In most patients, apathy is observed, meaning that sufferers no longer show any interest in those around them or in activities that they used to enjoy.

Frontotemporal dementia

Frontotemporal dementia is a generic term designating a group of rare conditions that primarily affect the brain's frontal and temporal lobes. It appears at a younger age than does Alzheimer's disease. The first signs are changes in personality and behaviour (e.g. disruption of social behaviour, disinhibition and sudden mood swings) and major changes in language (e.g. aphasia, with confusion as to the meanings of words and knowledge). In contrast with Alzheimer's disease, amnesia appears only at the second stage. In most patients, apathy is observed. Pick's disease is a type of frontotemporal dementia characterized by particular lesions known as Pick bodies.

Lewy body dementia or dementia associated with Parkinson's disease

Lewy body dementia is characterized by abnormal deposits of a protein called alpha-synuclein inside the brain cells. These deposits are called Lewy bodies after the researcher who first described them. The mechanism by which these Lewy bodies originate is poorly understood. The disease manifests as cognitive impairment and visual hallucinations which may be accompanied by symptoms of parkinsonism. The disease progresses much more quickly than Alzheimer's disease and is characterized by fluctuation in its progress. The disease may also begin with Parkinson's disease and the associated manifestations considerably overlap those observed in Lewy body dementia.

ⁱ In recent years, use of the term "dementia" has been challenged by various groups, in particular the Federation of Québec Alzheimer Societies. This term, historically associated with madness, is deemed likely to lead to the exclusion of and discrimination against people suffering from this type of disease. In the present document, particular attention has been paid to ensure that the term "dementia" is used only when no other acceptable term will do. Wherever the state of health of persons suffering from impaired cognition associated with a neurodegenerative disease is involved, the terms "Alzheimer's disease" and "related diseases" have been used. However, in order to lighten the text, the term "Alzheimer's disease" here should be taken to mean diseases designated by the terms "Alzheimer's disease" and "related diseases."

Creutzfeldt-Jakob disease

Creutzfeldt-Jakob disease is a rare, fatal, rapidly progressing disease caused by infectious agents known as “prions.” Prions are proteins that naturally occur in the brain and are normally harmless. However, deformed prions may cause a devastating disease by attacking the brain, destroying brain cells and creating spaces in brain tissue. The frequency of Creutzfeldt-Jakob disease is approximately one in 1 million persons worldwide each year.

References

Alzheimer Society of Canada (www.alzheimer.ca)

Voyer, P. (2006). *Soins infirmiers aux aînés en perte d'autonomie. Une approche adaptée au CHSLD. Saint-Laurent (QC), ERPI. p.355-374.*

Appendix 4: Criteria for orienting sufferers to second-line specialists and the use of neuroimaging technologies

Criteria for referring patients to a specialist

- Continuing uncertainty regarding the diagnosis after an initial assessment and follow-up;
- Request for a second opinion from the patient or his or her family;
- Presence of significant depression, in particular in the absence of response to treatment;
- Failure or therapeutic problems associated with drugs prescribed to treat Alzheimer's disease;
- The need to obtain assistance with management of the patient (e.g. in cases of behaviour problems or functional incapacity) or support for a caregiver;
- Genetic screening where indicated;
- An expression of interest from the patient or his or her family in participating in diagnostic or therapeutic research conducted by the person to whom the referral is being made;
- Young patients, or patients presenting an atypical picture.

Criteria for the use of neuroimaging using computer tomography (CT scans) and magnetic resonance imaging

- Cranial CT scans are recommended if the patient meets one or more of the following criteria:
 - Age < 60 ;
 - Rapid (e.g. over one or two months), unexplained decline in cognition or functioning;
 - Recent appearance (< 2 years);
 - Significant recent cranial trauma;
 - Unexplained neurological symptoms (e.g. new appearance of severe headaches or crises);
 - History of cancer, particularly those that produce metastases in the brain;
 - The taking of anticoagulants or a history of haemostatic problems;
 - A history of urinary incontinence or gait disturbances occurring at the onset of the disease (as may be manifested in the presence of normal-pressure hydrocephalus);
 - Any new localized sign (e.g. hemiparesis or Babinski's sign);
 - Unusual or atypical cognitive symptoms or presentation (e.g. progressive aphasia);
 - Gait disturbance.
- Current data tend to support the use of the structural neuroimaging using CT scans or magnetic resonance imaging to establish the presence of a concomitant cerebrovascular disease that could influence the management of the patient.

References: Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia. *Alzheimer's & Dementia*, 2007. Hogan DB, Bailey P, Black S, Carswell A, Chertkow H, Clarke B, Cohen C, Fisk JD, Forbes D, Man-Son-Hing M, Lanctôt K, Morgan D, Thorpe L. Diagnosis and treatment of dementia: 4. Approach to management of mild to moderate dementia. *CMAJ*. 2008 Oct 7;179(8):787-93. Review. Erratum in: *CMAJ*. 2008 Oct 21;179(9):932.

Appendix 5: Risk factors and protective factors, the prevention and treatment of Alzheimer’s disease: recommendations of the Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia

The cognitive skills of elderly people vary greatly from one person to another.¹ About 5% of elderly individuals have a level of cognitive functioning that is superior to that of young people. Generally, however, elderly people show a slight decline in comparison with younger people. This decline particularly involves memory and may manifest, for example, as difficulty recalling the name of an acquaintance, and in the speed of processing information, which may result in taking longer to perform a task. Although these changes may cause some people to worry, they are not generally associated with a disease, and are considered part of normal aging. Others may show slight cognitive impairment that measurable during a properly conducted assessment. Such people, or members of their family, generally report a gradual decline which, however, has no major consequences on their activities of daily living. In most cases, this will be described as “mild cognitive impairment.” Each year, approximately 15% of people in this group will progress to Alzheimer’s disease. Some people may also present problems similar to those observed in Alzheimer’s disease but which are attributable to a treatable or reversible cause. So-called reversible impairment, which is quite rare, may be associated with the use of certain drugs, with depression, or with a metabolic cause. Other, still rarer, causes include subdural hematomas.

Many people wonder about the risk of one day contracting Alzheimer’s disease or a related disease¹. There are risk factors which may predispose to the development of some form or other of these diseases. The risk factors may be defined as characteristics related to the person and to his or her history, as well as to his or her lifestyle and environment, which contribute to the probability of developing Alzheimer’s disease. It should be understood that in general these factors are elements that can increase the risk of occurrence, but will not systematically lead to occurrence. There are also a certain number of factors, known as protection factors, which may protect people against the development of the disease. Although most risk factors are well established, some are still the subject of controversy. In addition, many risk factors for Alzheimer’s disease, such as hypertension, are also risk factors for many other diseases. Some of these factors, particularly hypertension, are modifiable, while others, such as a person’s age or sex, are not.

Evidence regarding the main risk and protection factors identified and the recommendations regarding primary prevention of Alzheimer’s disease reviewed here are based on the Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD3).^{2,3,4,5,6,7}

CCCDTD3 also formulated a number of recommendations concerning the management of Alzheimer’s disease sufferers. The recommendations regarding pharmacological, psychosocial and environmental interventions in response to the disease will also be discussed.

^j The term “Alzheimer’s disease” is used here to include all diseases designated by the “Alzheimer’s disease” and “related diseases.”

RISK FACTORS AND PROTECTIVE FACTORS AGAINST ALZHEIMER'S DISEASE AND PRIMARY PREVENTION

Personal characteristics

Age and sex

The greatest risk factor for Alzheimer's disease is advanced age: the chances of the disease's occurring increases exponentially with age after 65. Even in the presence of other risk factors, including those related to heredity (discussed in the next point), Alzheimer's disease only appears when a person has attained a minimum adult age.

Twice as many women as men suffer from Alzheimer's disease. This difference becomes especially marked after the age of 75. This can be explained in part by the fact that on average women live longer than men. It is also suspected that this heightened prevalence may be associated with lower estrogen levels in postmenopausal women. Moreover, women may be more liable than men to develop certain diseases that are also risk factors for Alzheimer's disease, such as diabetes.

Genetic factors and heredity

There are two forms of Alzheimer's disease: a familial (genetic) form and a sporadic form. The sporadic form of the disease accounts for over 90% of cases while the genetic form is relatively rare. Although Alzheimer's disease is more commonly found in people aged over 65, it can develop in younger people, particularly in cases of the familial form.

To date, three known causal genetic mutations have been identified in the familial form. These mutations almost invariably result in Alzheimer's disease if the patient lives long enough. The first gene to be discovered was the amyloid precursor protein located on chromosome 21. The two other genes responsible for genetic Alzheimer's disease are presenilin-1, located on chromosome 14, and presenilin-2, located on chromosome 1. In this small group of patients, only 13% clearly present autosomal-dominant transmission over more than one generation, which means that a sibling, parent or grandparent will also have Alzheimer's disease.

Other than the mutant genes that are responsible for the familial form, the most important genetic risk factor, both for the familial form and the sporadic form of Alzheimer's disease, is the apolipoprotein E (apo E) gene located on chromosome 19. Every individual has two copies of this gene, one from each parent. The apo E gene has three common alleles^k: ε2 (present in 8% of white populations) ε4 (in 15%) and ε3 (in about 75%). The risk of developing Alzheimer's disease is determined by the type of combination of the alleles (or the genotype) of apolipoprotein E. Somebody who has two apoε4 alleles is at greater risk of developing the disease than somebody who has only one, or who has a combination of other alleles. None of these genetic particularities inevitably results in the development of the disease. They are simply predispositions that increase the risk of developing it. Nor does their absence provide immunity against the disease. The precise mechanism by which they favour Alzheimer's disease is not yet fully understood.

^k Allele: one of the various forms that a given gene may take.

Researchers have identified and are actively studying other genes that could predispose to Alzheimer's disease. Most cases of Alzheimer's disease are considered complex and are probably the result of a set of genetic (e.g. the apo E gene) and acquired (e.g. lifestyle-related) factors.

Significant family history should call for in-depth analysis from a specialist. The discovery of a causal gene for familial Alzheimer's disease can undoubtedly cause great distress. Thus, before undertaking screening, it is essential that all possible risks and benefits be clearly explained and understood by the person concerned, and that the process be accompanied by genetic counselling. Screening for the apo E gene is not recommended in people who have no symptoms, since the results obtained do not allow us to conclude whether or not there is a real risk of developing the disease.

Vascular factors

Vascular pathology risk factors are known to increase of the related vascular dementia, but they are also suspected of contributing to the development of Alzheimer's disease. These factors include hypertension, strokes (cerebrovascular accidents, or CVA), excessive cholesterol and homocysteine levels, and diabetes.

Hypertension

The relationship between arterial hypertension (blood pressure) and strokes is well-known. There are conclusive data suggesting that systolic hypertension (> 160 mmHg) is associated with a high risk of developing Alzheimer's disease.

Thus, CCCDTD3 recommended the treatment of systolic hypertension (> 160 mmHg) in older people (> 60 years). In addition to reducing the risk of strokes, heart failure and myocardial infarction, this measure could also reduce the incidence of Alzheimer's disease. The target systolic arterial tension should be ≤ 140 mmHg. In addition, some data indicate that the management of hypertension contributes to preventing the cognitive decline associated with cerebrovascular diseases.

Strokes (cerebrovascular accidents, or CVA)

Strokes are associated with an increased risk of developing Alzheimer's disease. Implementing the various interventions recommended for treating and preventing strokes in practice guides is therefore justified.

Particularly, the administration of acetylsalicylic acid and statins after a myocardial infarction, antithrombotic treatment for non-valvular atrial fibrillation and the correction of carotid stenosis $> 60\%$ reduce the risk of strokes, but the data for or against these measures are insufficient for a recommendation to be made by CCCDTD3 for the specific purposes of primary prevention of Alzheimer's disease.

High cholesterol levels

According to epidemiological studies¹, there is a link between high blood cholesterol (hypercholesterolemia) and the subsequent appearance of Alzheimer's disease. Studies have shown that a rise in total serum cholesterol in the living environment is associated with an increased risk of eventually developing Alzheimer's disease (serum cholesterol > 6.5 mmol/L).

Although there are many reasons for treating hypercholesterolemia, the evidence was not sufficiently conclusive for CCCDTD3 to recommend or advise against treating this condition for the specific purpose of reducing the risk of Alzheimer's disease. Large-scale studies conducted to date have not succeeded in proving that taking statins reduces the incidence of Alzheimer's disease.

High homocysteine levels

A number of factors can contribute to high levels of homocysteine in the elderly, particularly vitamin B12 and folic acid deficiency, kidney dysfunction, smoking and dehydration. Studies have shown a link between excessive homocysteine levels (hyperhomocysteinemia) and an increased risk of developing Alzheimer's disease.

Although there are many reasons for treating hyperhomocysteinemia, CCCDTD3 does not recommend or advise against treating this condition for the specific purpose of reducing the risk of Alzheimer's disease.

Diabetes

It has been known for a number of years that type 2 (adult) diabetes is a risk factor for Alzheimer's disease: the number of studies have shown a link between the presence of type 2 diabetes and the subsequent development of Alzheimer's disease.

Although there are numerous reasons for treating type 2 diabetes, CCCDTD3 considered that the evidence is not sufficiently conclusive to recommend or advise against treating this condition for the specific purpose of reducing the risk of Alzheimer's disease.

Lifestyle habits

Lifestyle habits discussed in this context are those that have been linked with Alzheimer's disease: they include physical and mental activities, nutrition, alcohol consumption and smoking.

Physical activity

Some epidemiological studies have suggested that regular physical activity, as compared with a low level of or no physical activity, is associated with a reduced risk of subsequently developing Alzheimer's disease.

¹ Epidemiological studies are studies involving a large number of people generally conducted over a longer period for the purpose of ascertaining whether people who suffer from a particular disease presented certain prior conditions, or whether certain conditions present are associated with the subsequent development of a particular disease.

However, the evidence is not sufficiently conclusive for CCCDTD3 to recommend or advise against stepping up physical activity for the specific purpose of reducing the risk of Alzheimer's disease. Nevertheless, CCCDTD3 considers that there are acceptable data for encouraging the elderly, whether or not they have memory loss, to engage in physical activities as part of an overall healthy living program. Stimulation of physical activity is addressed later, in the section on psychosocial and environmental interventions.

Intellectual activity

A link has been established between regularly engaging in stimulating intellectual activities (e.g. reading, crosswords) and leisure activities (e.g. knitting, visiting friends) and a lower risk of Alzheimer's disease. It is therefore plausible that the fact of being mentally active could be associated with a reduced risk of subsequently developing Alzheimer's disease.

According to CCCDTD3, there are acceptable data to suggest that the elderly, whether or not they have memory loss, should engage in intellectual activities as part of an overall program for healthy living. Cognitive interventions – stimulation, rehabilitation and training – are discussed later in the section on psychosocial and environmental interventions.

Healthy diet

Studies have shown an association between a high intake of fats (> 85.5 g/day) and an increased risk of developing Alzheimer's disease. Moreover, regular consumption of fish and seafood is associated with a reduction of this risk.

According to CCCDTD3, although the evidence is insufficient to allow formulation of an official recommendation for the primary prevention of Alzheimer's disease, the public should be informed of the possible benefits of eating more fish and of a lower fat intake.

Wine

Moderate wine consumption (250-500 ml/day), in comparison with consumption of higher or lower amounts, has been linked with a reduced risk of developing Alzheimer's disease.

On the basis of available evidence, CCCDTD3 could not formulate an official recommendation regarding wine consumption for the prevention of Alzheimer's disease, but indicated that informing the public of the possible benefits of moderate wine consumption is justifiable.

Smoking

Some studies have shown a link between smoking and an increased risk of developing Alzheimer's disease. In addition, an analysis of studies on smoking has shown that smokers, unlike ex-smokers, are exposed to a heightened risk of developing Alzheimer's disease.

Although there is no conclusive evidence that giving up smoking reduces the risk of Alzheimer's disease, the possibility alone represents another argument for encouraging people to give up smoking.

Personal history

Personal history is defined here as prior conditions that have been linked with a future risk of developing Alzheimer's disease. They include educational attainment, depression and head injury.

Educational attainment

Educational attainment seems to play an important role in the risk of developing Alzheimer's disease. Those who have not had a long education (less than six years) have a greater risk of being affected. Similarly, a high level of educational attainment seems to have the effect of delaying the appearance of the first symptoms. Studies have highlighted an association between high educational attainment and a reduced risk of developing Alzheimer's disease (education > 15 years compared with < 12 years). The hypothesis is that a high level of education may contribute to increasing reserves of brain cells (neurons) and connections between these cells, which would have the effect of slowing the effect of Alzheimer's disease.

Although CCCDTD3 considers that the evidence is insufficient to formulate an official recommendation regarding the prevention of Alzheimer's disease, it is suggested that measures be taken to encourage the population to acquire an adequate level of education, and that incentives to students to complete a minimum number of years of schooling be fostered.

Depression

A relationship has been established between the presence of the symptoms of depression and the subsequent development of Alzheimer's disease. Thus, a bout of depression during life could increase the risk of developing the disease, particularly if it is accompanied by effects on cognition.

According to CCCDTD3, depression must be treated through psychosocial and environmental interventions and, when needed, using pharmacological treatment. Where antidepressants are prescribed for an elderly person, a drug having a low anticholinergic effect – a selective serotonin reuptake inhibitor for example – is recommended. However, the evidence is not sufficient for CCCDTD3 to recommend or advise against treating this condition for the specific purpose of reducing the risk of Alzheimer's disease. Treatment of depression may improve the quality of life of sufferers and caregivers.

Head injury

Some studies have put forward a relationship between (moderate or severe) head injuries with loss of consciousness and Alzheimer's disease.

Although the evidence is insufficient for CCCDTD3 to make an official recommendation regarding the prevention of Alzheimer's disease, strategies, including legislation, aimed at reducing the risk of serious head injuries are to be recommended. For example, adequately protecting the head when practising contact sports or activities that carry a risk of head injury, particularly cycling, should be encouraged.

Use of drug and vitamin treatments

In the following section we look at the relationship between the taking of certain drugs or vitamin replacements and the risk of developing Alzheimer's disease. The products examined include statins, anti-inflammatories, estrogens for women and vitamin supplements.

Statins

Although there seems to be a link between hyperlipidemia and the subsequent development of Alzheimer's disease, studies conducted for the purpose of evaluating whether taking statins (HMG-CoA reductase enzyme inhibitors) reduces the risk of developing Alzheimer's disease have been inconclusive.

As a result, according to CCCDTD3, the data are insufficient to recommend or advise against prescribing statins for the sole purpose of reducing the risk of developing Alzheimer's disease.

Nonsteroid anti-inflammatories

The most recent analysis of 25 observation studies concluded that the risk of Alzheimer's disease was significantly lower in participants exposed to nonsteroid anti-inflammatories compared with those who had taken none. However, a comparative randomized trial recently published on celecoxib, naproxen and a placebo, conducted with participants in good cognitive health, was suspended prematurely because of worries about the safety of the drugs and the absence of effects, since none of the observations suggested that the development of Alzheimer's disease might be delayed or reduced.

According to CCCDTD3, the data are insufficient to recommend or advise against taking nonsteroid anti-inflammatories for the sole purpose of reducing the risk of Alzheimer's disease.

Estrogens

Low endogenous estrogen levels in postmenopausal women are associated with a higher risk of Alzheimer's disease. Hormone replacement therapy (HRT) is given to women to reduce the undesirable effects of the menopause. Recent data has suggested that the taking of estrogens is associated with a greater risk of developing Alzheimer's disease.

According to CCCDTD3, conclusive data exist against the use of hormone replacement therapy (estrogen and progestogen) or estrogen therapy (estrogens only) for the sole purpose of reducing the risk of Alzheimer's disease.

Vitamins

Studies on the taking of the antioxidant vitamins C and E with the intention of reducing the subsequent risk of developing Alzheimer's disease have produced contradictory results. Moreover, it has been demonstrated that doses of vitamin E higher than 400 units/day have adverse cardiovascular effects.

According to CCCDTD3, the current data are insufficient to recommend or advise against vitamin E or vitamin C supplements to prevent Alzheimer's disease. In addition, high doses of vitamin E (≥ 400 unit/day) are associated with excess mortality and should be discouraged.

Environmental factors/exposure to toxins

According to some studies, environmental factors that may constitute potential risks for Alzheimer's disease include pesticides, fertilizers, fumigants and defoliants. However, additional studies are necessary to confirm the effect of these risk factors on the progression of Alzheimer's disease.

Although this is not an official recommendation by CCCDTD3 for the prevention of Alzheimer's disease, it is recommended that adequate protective garments be worn during the spreading of pesticides, fumigants, fertilizers and defoliants.

Mild cognitive impairment (MCI)

Mild cognitive impairment is a term increasingly being used to designate the condition lying between normal cognitive function and Alzheimer's disease in the elderly. The term designates the condition of elderly people having a short or long-term memory deficits, without significant daily functional incapacity. The first criterion of mild cognitive impairment is a subjective complaint regarding cognitive decline in comparison with former levels, a decline that has appeared gradually and has been present for at least six months. This subjective complaint must be backed up by objective evidence of a decline in memory and learning provided by a cognitive assessment. Other cognitive fields may remain unaffected.

Physicians are seeing increasing numbers of people presenting with mild impairment of their cognitive function; for this reason, according to CCCDTD3, they must familiarize themselves with methods that enable them to recognize mild cognitive impairment. Physicians should know that Alzheimer's disease is preceded by a period of identifiable mild cognitive impairment. They should also be familiar with the notion of MCI as a condition predicting a high risk of decline, Alzheimer's disease and mortality.

CCCDTD3 recommends the treatment of vascular risk factors, particularly arterial hypertension, as a potentially effective means of reducing the progression of mild cognitive impairment to Alzheimer's disease. No particular pharmacological treatment is recommended for the time being, or is even described as having adequately demonstrated its effectiveness for people with MCI. Psychosocial and environmental interventions – for example, interventions directed towards leisure, stimulation of cognition and physical activity – should be encouraged as part of a healthy lifestyle for people suffering from MCI. These interventions are discussed in the following section.

PSYCHOSOCIAL AND ENVIRONMENTAL INTERVENTIONS

In this section, we review psychosocial and environmental interventions as well as associated recommendations made by CCCDTD3 for Alzheimer’s disease sufferers and for elderly people, whether or not they present with MCI.

There are various psychosocial and environmental approaches, also known as *nondrug* or *nonpharmacological interventions*. Different strategies may be employed depending on the desired objective. In elderly people who may or may not have MCI, improving physical or mental performance may be an aim. In the context of Alzheimer’s disease, the aim may be to improve cognitive function and/or functional autonomy, or to act on behavioural and psychological symptoms of dementia (BPSD)^m. Some strategies may be used at home, thereby prolonging the patient’s ability to stay in their own home, and also with people living in an institution. Ultimately, the aim is to improve sufferers’ quality of life and to preserve their social connections and exchanges as long as possible, while at the same time facilitating the role of natural and professional caregivers. A choice of strategy should be guided by the stage of the disease, the nature of its effects, the presence of caregivers and their ability and/or needs, and targeted objectives. Psychosocial and environmental interventions may be employed to complement or replace pharmacological treatment. These various approaches are set out in Table 1.

Intervention type	Approaches
Cognitive	Cognitive stimulation <ul style="list-style-type: none"> • Occupational and recreational activities • Reality orientation • Reminiscence Cognitive rehabilitation Cognitive training
Stimulation of physical activity	Dance, going for walks, movement, gymnastics, aerobic activities
Affective	Validation/empathy therapy Psychotherapy
Environmental	Physical environment Temporal environment Sensory environment

^m Behavioural and psychological symptoms of dementia (BPSD) refer to symptoms of perturbed perception, thinking, mood and behaviour that frequently appear in people suffering from Alzheimer’s disease.

Cognitive interventions

There are three broad categories of cognitive interventions: stimulation, rehabilitation and training.

- ***Cognitive stimulation*** refers to participation in an occupational and recreational activity likely to increase cognitive function in a nonspecific way (e.g. conversation, reading, drawing, games) and in the structured activities such as reality orientation (e.g. use of memo boards, calendars) or reminiscence (e.g. discussion of past events with the help of family photos or personal items)^{8,9};
- ***Cognitive rehabilitation*** is aimed at improving specific skills in connection with individualized objectives determined by the sufferer, relatives or care personnel (e.g. learn the name of the new attendant)^{10,11};
- ***Cognitive training*** is aimed at learning techniques to optimize cognitive functioning (e.g. mnemonics or practice on targeted cognitive tasks).^{12,13}

It has been shown that some cognitive interventions can have an effect on the cognitive and/or functional performance of sufferers and in the elderly with or without MCI. The benefits may be manifested by an improvement in performance or a slowing of the progression of symptoms. It remains to be determined whether this type of effort with healthy people leads to a lower risk of developing Alzheimer's disease. Therefore, in the view of CCCDTD3, further research should be conducted so that these methods' effectiveness can be determined and to allow official recommendations to be made.

Stimulation of physical activity

There is much data to show that personalized physical activity programs, particularly aerobics and muscle training, have an effect on strength and physical fitness, but also on cognitive functioning, functional performance (activities of daily living, activities of home living) and the BPSD of Alzheimer's disease sufferers. Hence a simple physical activity programs such as dance, going for walks, movement and gymnastics (e.g. one hour twice a week) could slow the functional decline of sufferers.¹⁴ Physical activity has also been shown to have benefits for the elderly with or without MCI.

According to CCCDTD3, there is sufficient evidence to show that personalized physical activity programs have a positive effect on the functional performance of mild to moderate Alzheimer's disease sufferers. CCCDTD3 therefore considers that the elderly, whether or not they have memory loss, should be encouraged to practise physical activities as part of a global healthy living program.

Affective interventions

A number of therapeutic approaches focus primarily on working on the emotional life of sufferers. A variety of approaches aimed at the emotions have been used in the context of Alzheimer's disease:

- **Validation/empathy therapy** is a method that helps the therapist to relate to the sufferer through the application of simple verbal and nonverbal communication techniques that are designed to detect, recognize and respond to the emotions expressed by the sufferer¹⁵;
- **Psychotherapy** can be useful with people in the early stages of the disease.¹⁶

Although positive results have been obtained using these therapies with Alzheimer's disease sufferers, CCCDTD3 makes no official recommendations regarding approaches geared towards sufferers' emotions.

Environmental interventions

With a view to maintaining functional autonomy as long as possible and treating, and even preventing, BPSD in Alzheimer's sufferers, certain changes to the environment can prove effective in ensuring the safety and well-being of sufferers.¹⁷ According to CCCDTD3, psychosocial and environmental interventions should be considered first in the presence of BPSD, before embarking on pharmacological treatment.

There are three fields of environmental intervention: those that focus on the physical environment, those that focus on the temporal environment, and those that focus on the sensory environment.

- **Physical environment:** In an institution, this type of intervention is aimed at creating an integrated environment that takes into account the limitations and sensory losses of sufferers (e.g. special care unit). In the home, it involves setting up targeted interventions to improve a particular symptom (e.g. installing bolts on doors to control wandering or removing mirrors to reduce agitation) or providing aids to certain activities (e.g. installing a bath seat, or visual clues);
- **Temporal environment:** This type of intervention arises out of the need to provide a stable routine because changes in routine can cause confusion and distress and exacerbate BPSD. Stability in daily activities and introduction of preparatory elements for activities (e.g. using action preparation techniques) can improve certain symptoms such as sleep disturbances and urinary incontinence;
- **Sensory environment:** This type of intervention is based on techniques designed to enhance sufferers' sensory environment (e.g. music therapy, aromatherapy, luminotherapy, Snoezelen-type multisensory stimulation, massage and therapeutic touch).

Although CCCDTD3 does not officially recommend any of these approaches, lacking studies of their effectiveness, it acknowledges that some Alzheimer’s sufferers may benefit from these types of interventions. CCCDTD3 recommends their use for the management of BPSD in suitable cases prior to embarking on pharmacological treatment.

To summarize, a variety of psychosocial and environmental approaches can benefit elderly persons with or without MCI and Alzheimer’s sufferers. For Alzheimer’s sufferers, drugs are available and may provide a treatment option. The pharmacological interventions recommended by CCCDTD3 are discussed below.

PHARMACOLOGICAL INTERVENTIONS

Currently there are four drugs for the treatment of Alzheimer’s disease on the Québec market: donepezil (Aricept), rivastigmine (Exelon), galatamine (Reminyl), and memantine (Ebixa) (Table 2). The first three are *cholinesterase inhibitors* and the fourth is an *NMDA (N-methyl-D-aspartate) receptor antagonist*. These drugs have symptomatic effects, but do not appear to act on the cause of the disease. Modest benefits in cognitive, functional and behavioural signs can be observed in a number of cases, but not all respond to these triggers. These drugs differ in their mode of action, their mode of administration, and their risk of secondary effects. Although most people experience no secondary effects, the most common reactions are nausea, loss of appetite, vomiting, diarrhoea and muscle pains. A patient who decides to try one of these drugs must be seen again by his or her doctor after approximately three to six months. With the help of the physician, he or she can then decide whether it is worth continuing the treatment. Changes in mini-mental state examination (MMSE) score, functional changes in the person and the general impressions of the caregiver regarding daily and social functioning compared with pretreatment levels can give indications as to the effectiveness of the drug. Although there are no clear indications regarding long-term treatment, in the absence of secondary effects treatment can be maintained if there is improvement, stabilization of symptoms or a slowing in the rate of decline. These medications are refundable by the Régie de l’assurance maladie du Québec (RAMQ) as exception drugs, that is, the physician must request them and must complete forms in order for the patient to have access to them, in accordance with certain criteria.

Table 2
Drugs for treating Alzheimer’s disease and available in Québec

Manufacturer	Generic name	Brand name	Therapeutic class
Pfizer Canada Inc.	Donepezil hydrochloride	Aricept	Cholinesterase inhibitor
Novartis Canada Inc.	Rivastigmine hydrogen tartrate	Exelon	Cholinesterase inhibitor
Janssen-Ortho Canada Inc.	Galantamine bromhydrate	Reminyl	Cholinesterase inhibitor
Lundbeck Canada Inc.	Memantine hydrochloride	Ebixa	NMDA receptor antagonist

It was estimated in 2007 that 87,836 people (8% of those aged 65 and over) suffered from Alzheimer's or a related disease. According to the RAMQ, statistics on drugs used to treat Alzheimer's disease showed that 27,998 distinct patients received a prescription (new or renewed). In 2003-2007, a 65% rise in new prescriptions was recorded. 81% of new prescriptions were made by general practitioners, 14% by specialists and 5% by residents. On the basis of these data, it is estimated that 30% of sufferers received appropriate pharmacological treatment for their condition.

For the treatment of Alzheimer's disease at the mild and moderate stages, CCCDTD3 recommends the use of cholinesterase inhibitors – donepezil, rivastigmine and galantamine. Memantine alone or in combination with cholinesterase inhibitor (the two drugs having a different action) may be considered for patients suffering from Alzheimer's disease at the moderate or advanced stage.

Other products have been evaluated for possible recommendation, including vitamin E (≥ 400 units/day), idebenone, vitamins B1, B6 and B2, as well as folic acid, ginkgo biloba, anti-inflammatories, statins, hormone replacement therapy (estrogen-progestogen combination) or estrogen therapy (estrogens alone) in women and androgens in men. None of these other prescription medications, supplements or psychotherapy products is recommended by CCCDTD3 for the treatment of cognitive or functional manifestations of Alzheimer's sufferers. Other products in different therapeutic classes that could significantly slow the progress of the disease are currently being tested.

PHARMACOLOGICAL INTERVENTIONS FOR THE MANAGEMENT OF BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA (BPSD)

BPSD (behavioural and psychological symptoms of dementia) designates signs of disturbance in perception, thought content, mood and behaviour that frequently appear in people suffering from Alzheimer's disease. Management of BPSD should include the taking of detailed notes on behaviours and a description of targeted symptoms, the search for possible triggering or precipitating elements, documentation of the consequences of the behaviour, evaluation of treatable or concurrent causes with a view to eliminating them, and an assessment of the safety of the patient, the caregiver and family members.

Pharmacological treatment of BPSD should be considered only after psychosocial and environmental approaches have been taken into account and trials made in suitable cases. However, according to CCCDTD3, pharmacological interventions should be introduced at the same time as psychosocial and environmental approaches in cases of severe depression, psychosis or aggressive behaviour endangering the patient and others.¹⁸

The initial dose of drugs to counter BPSD should be low, and possibly increased with caution depending on the patient's response and the appearance of secondary effects. After a period of three months of behavioural stability, attempts should be made, in accordance with current standards, to progressively reduce the dosage of drugs to counter BPSD with a view to complete withdrawal.

In mild to moderate Alzheimer's disease, a cholinesterase inhibitor and/or memantine may be prescribed to patients presenting neuropsychiatric symptoms in order to attenuate these symptoms. At the mild stage, depressive syndromes are common and may take all possible forms, from mild symptoms to depressive disorder requiring pharmacological treatment. Significant clinical depressive symptoms should be treated. Their management consists in psychosocial and environmental measures accompanied by pharmacological treatment where indicated. If an antidepressant is prescribed, an agent having minimal anticholinergic activity should be favoured, for example a selective serotonin reuptake inhibitor. Visual hallucinations at the early stages may suggest Lewy body dementia. Sufferers from Lewy body dementia are abnormally sensitive to antipsychotics. If, however, pharmacotherapy should prove necessary to eliminate visual hallucinations, a cholinesterase inhibitor should be prescribed first, if possible. Should it become necessary to control the symptoms rigorously, or should the cholinesterase inhibitor prove ineffective, an atypical antipsychotic could be tried, but with many precautions.

In the advanced stages of Alzheimer's disease, risperidone and olanzapine may be prescribed to counter severe agitation, aggression and psychosis. The physician must first weigh the expected benefits of these drugs and other antipsychotics against the potentially higher risk of strokes and death. At this stage of the disease, benzodiazepines should be described exclusively for brief periods and taken only in case of need. The use of these drugs is associated with excessive sedation, falls and cognitive impairment. Selective serotonin reuptake inhibitors can be used to treat severe depression.

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Appendix 6: Alternative living environments

Criteria to be considered regarding the creation, improvement and evaluation of alternative living environments

1. Knowledge of needs expressed by Alzheimer's sufferers and their families
 - a. Elderly population in general
 - b. Younger adults
 - c. Cultural communities
2. Values and principles underlying projects
 - a. Respect for residents' rights
 - b. Maintaining dignity
 - c. Right to privacy
 - d. Personalized care
 - e. Detailed knowledge of the resident
 - f. Maintenance and promotion of autonomy
 - g. Recognition of the importance of family and friends
 - h. Management that balances safety and freedom
 - i. Cordial, open human environment
 - j. Calm, serene physical environment
 - k. Possibility of remaining in this facility in the event of behavioural or physical deterioration
3. Management issues
 - a. Attributes of good managers
 - b. Management structures
 - c. Quality assessment
 - d. Personnel management
 - e. Involvement of residents and their families
 - f. Links with outside resources
 - g. Continuing training for managers
4. Care issues
 - a. Care centred on the person's needs
 - b. Admission and discharge criteria
 - c. Pros and cons of mixed clienteles at different stages of AD
 - d. Care planning
 - e. Therapies and activities
 - f. Meal organization and nutrition
 - g. Physical and mental health
 - h. Medication
 - i. End-of-life care
 - j. Involvement of family
 - k. Links with the community
 - l. Management of residents' money
 - m. Risk management
 - n. Maltreatment
 - o. Legal and ethical aspects

5. Personnel management issues
 - a. Number of workers
 - b. Desired skills
 - c. Recruitment policy
 - d. Reception of new personnel
 - e. Personnel retention
 - f. Satisfaction with work
 - g. Salaries
 - h. Continuing training for personnel
6. Architectural design
 - a. Size
 - b. Location
 - c. General concept
 - d. Rooms
 - e. Community areas
 - f. Service areas
 - g. Furnishings
 - h. Technology
 - i. Gardens and outside spaces

Organization and design of alternative living environments

Design principles

- Compensation for incapacities
- Maximization of autonomy
- Promotion of better self-esteem
- Simplicity, facilitating orientation
- Facilitating control of stimuli
- Responsive to the needs of care personnel

Generally appreciated design features

- Small size (6 to 14 residents)
- Family-type environment
- Large kitchen
- Outside environment with garden
- Environment that is safe but does not overly restrict freedom
- Several rooms for various functions
- Furnishings and according to residents' taste
- Single rooms with sufficient space for personal furniture and objects
- Multiple indications (signs, photos, objects rather than colour to facilitate orientation)
- Control of stimuli (especially noise)