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Addressing Alzheimer's and Other Types of Dementia: Israeli National Strategy

Summary Document of the Interdisciplinary, Inter-organizational Group of Experts

Coordination and Writing:

Jenny Brodsky, Netta Bentur,
Michal Laron, Shoni Ben-Israel

We would like to thank the Helen Bader Foundation for its support for the development of the Strategic Plan

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Foreword

The aging population creates multiple challenges for Israeli society, one of the most significant being the need to cope with the steadily increasing number of elderly with dementia. This illness has a dramatic impact on the lives of those with dementia and on family members who care for them. It necessitates special efforts on the part of the service system in order to address the needs.

We welcome the formulation of the National Strategic Plan to Address Alzheimer's and Other Types of Dementia. The recommendations offer a holistic perspective and emphasize collaboration among all relevant agencies: government ministries, the health plans and other organizations in both the volunteer and private sectors.

The Strategic Plan aspires to cope with key issues that make it difficult for the current service system to provide an appropriate response to the unique needs of dementia patients:

- ❖ The need to raise public awareness of the illness and dispel related stigmas.
- ❖ The prevailing sense that "nothing can be done" among the public and the need to make them aware of the ways in which patients and their families can be helped.
- ❖ The need for diagnosis at the earliest possible stage, so as to prepare for the illness and provide the patients with appropriate care through to the end of life.
- ❖ The need to develop a range of services for dementia patients and ensure support for their families.
- ❖ The need to develop and expand training for professionals working with dementia patients, not only to ensure quality care, but also to prevent burnout.
- ❖ The need for research to support policy planning and service development.

The National Strategic Plan lays down the basic principles for the development of the most appropriate services and interventions for dementia patients. The Ministry of Health has already set up an implementation committee and is working intensively to implement the plan. The Strategic Plan will be announced to the public at a national conference in October 2013.

We wish to thank the team of experts who rose to the challenge, for their commitment, dedication and highly professional effort. We thank the members of the Center for Research on Aging at the Myers-JDC-Brookdale Institute, headed by Jenny Brodsky, and the National Council on Geriatrics, led by Shoni Ben-Israel, for their professional leadership.

We are grateful to the Helen Bader Foundation for the support that made it possible to develop the Strategic Plan. This is an excellent example of productive and meaningful cooperation between government, a public research institute, and a philanthropic foundation, in order to promote social change in Israel.

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Executive Summary

Introduction

As populations age, the prevalence of chronic diseases and related disabilities rises significantly. Thus, caring for the elderly, which entails coping with chronic diseases and disabilities, promoting prevention, and helping with end-of-life decisions, is a major challenge for the health and social services today. Dementia is one of the “geriatric giants” – a term coined by the late Prof. Bernard Isaacs to highlight the major illnesses associated with aging (Isaacs, 1976).



Alzheimer’s and other forms of dementia are degenerative diseases affecting the brain and causing irreversible, progressive cognitive and functional deterioration. The early symptoms are loss of memory, impaired thinking ability, and impaired orientation. Gradually, there is also a loss of ability to perform daily activities and communicate with the surroundings. As the disease progresses, cognitive deficiencies are accompanied by functional, behavioral and psychological symptoms. Dementia is one of the main causes of disability among the elderly (OECD, 2012), and is viewed as one of the most distressing and devastating of conditions that has a great impact on those who suffer from it, and on the family members who care for them. Dementia also has a significant financial impact on society and poses a challenge for the health and social service systems. As a result, there is a broad worldwide consensus that there is a need for a systemic response to the implications of the aging of the population, in general, and to the rise in dementia, in particular. According to a report by WHO and Alzheimer’s Disease International (WHO, 2012), “Population aging is having a profound impact on the **emergence of the global dementia epidemic**, influencing awareness and driving demand for services”.

Many countries, including the UK, France, Scotland, Norway, Ireland, Switzerland, Australia, Japan, Canada and the US have developed national strategic plans and other countries are in the process of doing so. Recently, Israel has joined these countries by developing a national strategic plan for dealing with the challenges posed by the disease, as presented in this document. The plan was formulated by an interdisciplinary group composed of experts from government ministries (health, social affairs and services, national insurance, and senior citizens), health plans, hospitals, JDC-Eshel, non-profit organizations (Emda and Melabev), and leading academics. The process was headed by the Center for Research on Aging at the Myers-JDC Brookdale Institute (MJB) and the National Geriatric Council, with the support of the Helen Bader Foundation.

The vision of the strategic plan is to enable people with dementia and their families - through a broad array of easily accessible, high-standard supports and services - to live

as full, independent and dignified lives as possible. The plan recognizes the need to address dementia from the stages of prevention of risk factors and early detection, to diagnosis and patient care, and through assurance of quality of end of life. It proposes to do so by implementing interdisciplinary work principles and care, and boosting the coordination and cooperation of all the parties involved.

The strategic plan relates to a number of areas that the interdisciplinary group of experts identified as central:

1. Raising public awareness of dementia and dispelling the associated stigma
2. Improving the array of community health services offered to provide comprehensive care at every stage of the illness
3. Improving the array of community social services (such as the Long-Term Care Insurance Law and daycare centers)
4. Developing responses to support family caregivers directly
5. Adapting the array of long-term institutional services in view of the changing needs
6. Developing and expanding resources to train manpower in the community and in hospitals
7. Promoting critical research to support policy planning and service development.

In preparing the plan, a review was conducted of the current situation in each area and an effort was made to identify the major gaps that need to be addressed and the major challenges of addressing them. Based on this assessment, the group of experts formulated a set of directions to address the gaps and challenges.

The development of the strategic plan built upon other processes taking place in Israel that are relevant to the improved care of people with dementia. The most important was the formulation of Clinical Guidelines by the Clinical Consensus Conference held in November 2011, which were adopted by the Israeli Medical Association and the Ministry of Health. In addition, in-depth discussions are underway in an attempt to create a more integrated system of care for elderly with disabilities, in general. Integrative care constitutes a key element in improving care for people with dementia, and it is expected that the strategic plan presented in this document will be incorporated in all national programs for the provision of integrative care.

Below, we briefly elaborate upon the main recommended programmatic directions in each of these areas.

1. Raising Public Awareness of Alzheimer's and other Forms of Dementia

Today there is a low level of awareness of dementia among both the public and the health care and social services systems. This leads to: non-identification of the problem,

the absence of early intervention, ineffective care management, stigmatization of patients, and a lack of suitable family support. Therefore, the following steps are recommended:

- a. Having the government and health and social systems recognize dementia as an issue of national priority
- b. Organizing campaigns to raise public awareness in collaboration with civil society organizations and major public stakeholders
- c. Developing a national program to disseminate information on dementia that is culturally adapted to Israeli society and to different cultural groups
- d. Raising awareness of the importance of improving the quality of care and quality of life at end of life, making available the means to respect the desires of the patient such as advanced health care directives, and appointing a power of attorney or custodian
- e. Raising awareness of the rights of patients and their families, and the services available to them.



2. Developing an Array of Health Services

Health services are a major element in the prevention of risk factors, diagnosis, treatment, and support for people with dementia. Therefore, the following steps are recommended:

- a. Providing greater attention to risk factors by implementing a prevention program according to the recommendations of the Clinical Consensus Conference held in 2011, and enhancing the dissemination of the recommendations
- b. Improving diagnosis by broadening the knowledge base on dementia among community professionals and increasing access to early diagnostic services (memory clinics, cognitive assessment clinics, geriatric assessment clinics)
- c. Improving care at various stages of the disease by:
 - Formulating a comprehensive care plan together with the patient and his or her family immediately after diagnosis
 - Developing a “care package” for patients with dementia, to be included in the basket of services provided by the national health insurance law
 - Developing training programs for family doctors, specialists, nurses and health professionals (including urgent care medicine) and implementing them widely
 - Expanding use of drug therapy to delay disease progression and addressing the accompanying symptoms as needed
 - Increasing referrals to non-medical treatment, such as psychosocial intervention and the treatment of behavioral and psychological symptoms
- d. Informing the family of the progress of the disease, medical complications, and the types of treatment available

- e. Improving coordination and continuity of care, and ensuring a patient's full use of services and full exercise of rights by:
 - Developing models to ensure continuity of care including the creation of the new role of "nurse coordinator"
 - Strengthening the communication and cooperation between health and social systems so that patients can be referred from one to the other according to need
- f. Improving the treatment of advanced dementia at end of life:
 - Recognizing advanced dementia as a condition requiring palliative care
 - Provision of home care or home hospice from a multidisciplinary staff
 - Informing the family of the progress of the disease
- g. Paying special attention to informing and involving the family about issues that arise at the end of life and to providing the support they need.

3. Developing an Array of Social Services

The functional deterioration of persons with dementia and the emergence of a range of social difficulties pose a significant challenge to the family and to community services. Patients require supervision or actual assistance to perform activities of daily living. As the disease progresses, round-the-clock care and supervision are required. Moreover, at these stages, behavioral and psychological symptoms multiply, demanding that caregivers (relatives or professionals) constantly cope with difficult and draining situations. Therefore, the following steps are recommended:



a. Improving non-professional home care within the National Community Long-Term Care Insurance law

- ❖ Providing more hours of care to patients requiring constant supervision
- ❖ Re-examining the instrument to assess dependency and assigning greater weight to cognitive deterioration, especially when accompanied by behavioral manifestations
- ❖ Developing a special training track for homecare workers that provides them with knowledge, skills and tools to cope with behavioral problems as well as tools to activate and occupy elders
- ❖ Considering the possibility of setting higher wages for caregivers of dementia patients to attract them to this type of work.

b. Increasing the availability of daycare centers

- ❖ Developing additional daycare centers for elderly with dementia
- ❖ Expanding operating hours to 6 days a week and 8-9 hours a day, and examining the possibility of operating on Saturdays for elderly with dementia

- ❖ Preparing the centers to serve as respite venues, both to give families a break from care for a few days and to respond to crisis situations.

4. Directly Supporting Family Members

There is a need to recognize the family members of patients with dementia as a target population in itself, and therefore it is important to develop services that will address their concerns and ensure their physical and mental health. Consequently, there is a need to:

- Develop information and consultation centers accessible by telephone, around the clock, for families to receive help in navigating the service system, and to provide a response in crisis situations
- Expand the development of responses to support families socially and emotionally, such as support groups, family therapy, and individual support, as needed. These services should provide information on the disease and existing services, impart skills and competencies required to care for the patient and provide emotional support.
- Develop respite care within daycare facilities or other settings for elderly patients not attending day care or in locations that have no daycare center
- Raise family awareness of their legal rights - especially their right to be absent from work for 6 days annually in order to care for a spouse or elderly parent - and increase the recognized number of sick leave days to care for a family member
- Develop auxiliary technologies designed to enable caregivers, particularly those employed to provide remote supervision of a patient with dementia. These technologies include sensors, various robots, GPS, telehomecare etc.

5. Long-term Care Institutional Services

In general, there is broad consensus that elderly patients with dementia should be able to continue to live at home as long as possible. Indeed, with the care of the family and the service system, most do live in the community. Some, however, do not have this option and others may prefer institutional care. These frameworks are an important component in the continuity of care and it is necessary to ensure their availability and quality of service. Therefore, the following steps are recommended:

- Adapting the availability of beds in different regions of the country in relation to the needs
- Projecting future needs and monitoring the increases in supply so as to meet these needs
- Developing innovative models for long-term institutional care, such as small and intimate frameworks for dementia patients.

6. Training

Training and broad professional knowledge in the field of geriatrics and dementia are a basic condition of providing high-quality care to people with dementia and their families. Therefore, the following steps are recommended:

- a. Expanding the scope of studies and clinical experience in geriatrics, in general, and dementia, in particular, included in the curricula of physicians, nurses, other health professions, and social workers
- b. Expanding the scope of post-basic and advanced courses for nurses, health professionals, other professionals and social workers
- c. Developing focused training for family physicians on such topics as diagnosis of dementia and management of care, and examining the feasibility of making it mandatory for physicians to take part in such training
- d. Earmarking budgets and resources for in-service training for physicians, nurses and social workers in the community.

7. Research

A research base is a critical resource for decisionmakers and service providers in developing appropriate and effective responses to people with dementia and their families. Therefore, the following steps are recommended:

- a. Defining relevant outcome measures for diagnosis and care of people with dementia, creating broad consensus, and developing necessary procedures and means of measurement
- b. Formulating an agenda for research that will focus on critical areas in which information is lacking with respect to the epidemiology of dementia, organization of services and the socio-economic implications of the disease
- c. Ensuring the inclusion of minority groups and other sub-groups in the research agenda
- d. Considering establishing a national register on the incidence and prevalence of dementia and the degrees of its severity, to be maintained on an ongoing basis
- e. Providing funds for research on issues related to the disease of dementia from the funds designated for research, within the National Health Insurance Law.



Steps to Implement the Strategic Plan

Members of the working group believe that to promote the implementation of the strategic plan, the following steps are recommended:

- a. Creating the recognition by government, health plans and health institutions that dementia is an issue of high national priority

- b.** Allocating resources to implement the national plan and promoting legislative changes as needed
- c.** Setting priorities and goals in every ministry, and formulating a multi-year plan to achieve the goals
- d.** Following-up the program's implementation and the achievement of its goals
- e.** Implementing innovative demonstration programs accompanied by evaluation to examine their effectiveness.

The National Strategic Plan lays down the basic principles for the development of the most appropriate services and interventions for dementia patients. The Ministry of Health has already set up an implementation committee and is working intensively to implement the plan. The Strategic Plan will be announced to the public at a national conference in October 2013.

