

National Memory Programme 2012-2020

CREATING A "MEMORY-FRIENDLY" FINLAND

DOCUMENTATION PAGE

| | |
|---|---|
| Publisher | Date |
| Finnish Ministry of Social Affairs and Health | 22 March 2013 |
| Authors | Commissioned by |
| | Finnish Ministry of Social Affairs and Health |
| | Project number and date when body appointed |

Title of publication

National Memory Programme 2012–2020. Creating a "memory-friendly" Finland

Summary

■ The European Parliament adopted a written declaration in 2008 which highlighted the increasing importance of memory disorders from the perspective of public health and the national economy and the need for national dementia strategies as one means of preparedness. Finland's national programme was produced by a committee set up by the Finnish Ministry of Social Affairs and Health.

More than 13,000 people in Finland are diagnosed with a dementing disease every year. Such memory disorders do not only affect the elderly; estimates of the number of people among the working-age population who suffer from progressive memory disorders vary between 5,000 and 7,000. Individuals with progressive memory disorders need and rely heavily on social welfare and health care services; for example, three out of four patients receiving 24-hour care have a memory disorder. In order for us to be able to meet the increasing demand for services, we need action a) to promote brain health, b) to prevent memory disorders, c) to detect memory problems as early as possible and d) to develop a system that ensures that treatment, rehabilitation and support are provided systematically and at the right time and that allows monitoring and follow-up – in other words, an effective and seamless clinical pathway for people affected.

The objective that the committee chose for the programme was to build solidarity to create a "memory-friendly" Finland on the basis of four pillars:

1. Promoting brain health
2. Fostering a more open attitude towards brain health, treatment of dementing disease and rehabilitation
3. Ensuring a good quality of life for people with dementia and their families through timely support, treatment, rehabilitation and services
4. Increasing research and education

The programme ties in with the objectives of Finland's social welfare and health care policies and existing care guidelines and quality control recommendations, and its implementation will be coordinated with ongoing legislative initiatives and other programmes such as Finland's National Development Programme for Social Welfare and Health Care (Kaste).

Keywords

clinical pathway, dementia, health promotion, prevention, quality of life

Finnish Ministry of Social Affairs and Health
Reports and Memorandums 2013:9

Further information

www.stm.fi

ISSN-L 2242-0037
ISSN 2242-0037 (online version)

Number of pages

21

Language

English

ISBN 978-952-00-3286-9 (PDF)
URN:ISBN:978-952-00-3286-9



MINISTRY OF
SOCIAL AFFAIRS AND HEALTH
Finland

CONTENTS

| | |
|--|----|
| Preface..... | 5 |
| Why the National Memory Programme is needed now? | 7 |
| What is the objective of the programme? | 8 |
| 1 BRAIN HEALTH IS A LIFELONG CONCERN | 9 |
| 2 MEMORY DISORDERS AFFECT US ALL – TIME FOR AN ATTITUDE CHECK..... | 11 |
| 3 PROPER TREATMENT AND CARE IS A WORTHWHILE INVESTMENT | 13 |
| 4 MORE RESEARCH AND EDUCATION STILL NEEDED | 17 |
| Implementation | 19 |
| More information | 21 |

Preface

The National Memory Programme is designed to help local authorities and joint authorities to prepare for a phenomenon that will have grave implications on public health and the national economy: the growing number of people suffering from memory disorders and the development of an ethically, socially and economically sustainable system for providing care and services. The programme is aimed at the decision-makers and directors of local authorities and joint authorities, who will play key roles in making far-reaching decisions about the promotion of brain health, the treatment of memory disorders and the provision of support and services for patients and their families. Several evidence-based guidelines and recommendations have been prepared for social welfare and health care professionals, which are aimed at making the care given to people with dementia more effective and at providing better support for patients and their families. It is now time for decision-makers to take action. Political choices and decisions can help to promote public health, to improve the quality and effectiveness of care and services and to rein back the rising costs of ageing Finland.

The National Memory Programme was commissioned from a committee set up by the Finnish Ministry of Social Affairs and Health. The committee was tasked with preparing a national dementia strategy for Finland, including objectives for promoting brain health, for ensuring the early detection and treatment of memory disorders, for establishing a system for ensuring the availability of timely support and services for people with dementia and their families and for formulating an action plan for implementing the necessary measures (including details about coordination and timescale).

The committee was instructed to hand the finished programme to the Finnish Ministry of Social Affairs and Health.

Päivi Sillanaukee
Director General, Chair of the
Committee
Finnish Ministry of Social Affairs and
Health

Päivi Voutilainen
Ministerial Councillor, Deputy Chair of
the Committee
Finnish Ministry of Social Affairs and
Health

Members of the committee

Ulla Eloniemi-Sulkava, Adjunct
Professor
Memory Experts of Finland

Timo Erkinjuntti, Professor
University of Helsinki

Minna Huhtamäki-Kuoppala,
Development Manager
Alzheimer Society of Finland

Juha Jolkkonen, Medical Director
City of Vantaa

Jaakko Kontturi, Director of Home Care
City of Seinäjoki

Taina Lupsakko, Deputy Medical
Director for Welfare for the Aged
Public Health Coordination Network

Antti Malmivaara, Senior Medical
Officer
National Institute for Health and Welfare

Anu Olkkonen-Nikula, Director of Home
Care and Assisted Living
Päijät-Häme Social and Health Care
Group, Primary Care Centre

Heikki Palomäki, Medical Adviser for
the Health Department
Social Insurance Institution of Finland

Sirpa Sarlio-Lähteenkorva, Ministerial
Adviser
Finnish Ministry of Social Affairs and
Health

Hilkka Soininen, Professor
University of Eastern Finland

Timo Strandberg, Professor
Finnish Gerontological Society

Jaana Suhonen, Adjunct Professor
Finnish Alzheimer's Disease Research
Society

Eevaliisa Virnes, Senior Adviser
Association of Finnish Local and
Regional Authorities

Secretaries

Sirkkaliisa Heimonen, Line Manager
Age Institute

Päivi Topo, Research Manager/General
Secretary
National Institute for Health and
Welfare/Finnish Ministry of Social
Affairs and Health/National Advisory
Board on Social Welfare and Health
Care Ethics

WHY THE NATIONAL MEMORY PROGRAMME IS NEEDED NOW?

Progressive memory disorders, such as Alzheimer's disease and other progressive memory disorders, are a major strain on public health and the national economy, and more could be done to prepare for this challenge. The number of people suffering from progressive memory disorders will increase in the future as the population ages, but memory disorders also occur among the working-age population.

The considerable costs associated with memory disorders are due to the high number of people with dementia and especially their need for 24-hour care. It has been estimated that half of all sufferers have not been diagnosed and only a quarter of Alzheimer's patients have been prescribed appropriate medication. Early diagnosis, treatment and rehabilitation of memory disorders can help to improve patients' ability to function and their quality of life as well as to curb the rising costs. The incidence of memory disorders can be decelerated, and that is why it is worthwhile to invest in the promotion of brain health and preventive action.

- Thirty-six people in Finland are diagnosed with a memory disorder every day; the annual figure is approximately 13,000.
- Progressive memory disorders do not only affect the elderly; estimates of the number of people among the working-age population who suffer from memory disorders vary between 5,000 and 7,000.
- Among the adult population, eight percent of men and two percent of women are alcohol-dependent, and of these as many as 10 percent suffer from alcohol dementia.
- The number of people diagnosed with progressive memory disorders is growing rapidly. Just over 95,000 people had been diagnosed with at least a moderate dementia and approximately 30,000–35,000 people with a mild memory disorder in 2010. Approximately 130,000 people are estimated to be suffering from at least a moderate dementia in 2020 (Table 1).
- As many as 120,000 people suffer from mild cognitive impairment, which is a prodromal stage of memory disorders and requires diagnostic attention.
- The majority of costs result from the need for 24-hour care. Approximately 80 percent of patients in 24-hour care have cognitive decline or a diagnosed progressive memory disorder.
- In 2010, the average cost of 24-hour care was EUR 46,000 per person per year. The average cost of home care was EUR 19,000 per person per year. Delaying a patient's admission to 24-hour care saves money, but systematic action is needed to enable prevention and early diagnosis and to support patients living in their own homes.
- According to a Finnish study, the cost of providing the social welfare and health care services that one individual with dementia and his or her family need in one year is EUR 23,600 (control group). When services are tailored to patients on the basis of a comprehensive assessment of their personal circumstances and a service coordinator appointed to the case, the annual costs drops to EUR 15,600. Improving home care services is therefore a highly cost-effective solution, in addition to which it increases patients' quality of life and delays their need for 24-hour care.
- The incidence of progressive memory disorders and dementia can be decelerated. By treating the prodromal stages of Alzheimer's disease, for example, the onset of the disease can be delayed by as much as five years. This could reduce the incidence of Alzheimer's disease by 50 percent in a single generation.

No new drug treatments that could cure memory disorders can be expected in the next few years. A lot can nevertheless be done. Our own actions play a big role in keeping our brains healthy. The incidence of memory disorders can be controlled from childhood by preventing known risk factors such as obesity, high blood pressure, high cholesterol and diabetes; all of these conditions can be prevented and treated effectively. Exercising, eating a healthy diet, cutting down and avoiding psychoactive substances and maintaining mental agility are all effective shields against memory disorders.

Finland is well prepared for preventing and treating progressive memory disorders and dementia. Early diagnosis is crucial. The risk of memory disorders can be lowered, the worsening of symptoms decelerated, patients' ability to function maintained and the quality of life of patients and their families therefore improved. A number of recommendations on good diagnostic practice and effective treatment have been issued in Finland. These can be used as a basis for introducing more effective practices in the future.

Rising costs can be reined back by making decisions today – that is why the National Memory Programme is needed now.

The National Memory Programme is Finland's way of joining many other countries that are responding to the European Parliament's written declaration on preventing memory disorders, especially Alzheimer's disease, and on improving patients' quality of life.

Table 1. Number of people suffering from at least a moderate memory disorder in 2010, 2015 and 2020 as estimated on the basis of population statistics and incidence figures. Columns 2010M, 2015M and 2020M represent the number of people suffering from memory disorders.

| Age group (incidence %) | 2010 | 2010M | 2015 | 2015M | 2020 | 2020M |
|----------------------------|---------|--------|-----------|---------|-----------|---------|
| 65–74 (4.2) | 505,492 | 20,220 | 647,907 | 25,916 | 719,024 | 28,761 |
| 75–84 (10.7) | 321,389 | 35,353 | 346,015 | 38,062 | 406,582 | 44,724 |
| 85+ (35.0) | 114,160 | 39,956 | 144,186 | 50,465 | 164,537 | 57,588 |
| Total | 941,041 | 95,528 | 1,138,108 | 114,443 | 1,290,143 | 131,073 |

What is the objective of the programme?

The objective of the National Memory Programme is to build solidarity to create a “memory-friendly” Finland on the basis of four pillars:

1. Promoting brain health
2. Fostering a more open attitude towards brain health, treatment of dementing disease and rehabilitation
3. Ensuring a good quality of life for people with mild, moderate or severe dementia and their families through timely support, treatment, rehabilitation and services
4. Increasing research and education.

A “MEMORY-FRIENDLY” FINLAND IS A SOCIETY THAT TAKES THE PROMOTION OF BRAIN HEALTH AND THE EARLY DETECTION OF COGNITIVE SYMPTOMS SERIOUSLY. ANYONE DIAGNOSED WITH A COGNITIVE PROBLEMS OR DEMENTIA HAS ACCESS TO APPROPRIATE TREATMENT, CARE AND REHABILITATION. PATIENTS CAN LEAD THEIR LIVES WITH DIGNITY, AND THEY WILL NOT BE LEFT WITHOUT SUPPORT.

1 BRAIN HEALTH IS A LIFELONG CONCERN

Brain health is an important human asset. Memory and other cognitive skills affect an individual's well-being from childhood until old age. They are a prerequisite for learning, for being able to work and have a long career and for living independently. Brain health must be promoted in all stages of life in order to support people's ability to work and cope with daily life and to ensure that fewer people fall victim to memory disorders and only later in life.

We can all actively promote our own brain health throughout our lives. Promoting brain health is only one aspect of general health promotion. Brain health can be promoted by maintaining mental agility, by being physically and socially active, by eating a healthy diet and maintaining a healthy weight, by effectively controlling high blood pressure and cholesterol and by avoiding psychoactive substances and tobacco products. There are many different ways to promote brain health, including activities that increase society's well-being on the whole, such as supporting young people and adults who are at risk of becoming socially excluded and enabling lifelong learning. Brain health can also be managed by reducing work-related stress, as prolonged stress and a hectic lifestyle can cause cognitive symptoms and concentration problems.

Brain health promotion is a worthwhile investment in ageing Finland.

Brain health can be promoted in all sectors of society: In addition to social welfare and health care, decisions made with regard to housing, culture, transport, education, spatial planning, non-governmental organisations and economy are also important. Brain health promotion challenges social welfare and health care professionals to increase their know-how about advising and supporting all citizens to make choices that promote brain health.

TARGET 2020

Brain health promotion has been factored into all sectors of society. Health promotion, including the promotion of brain health, is an integral part of the strategies of local authorities and joint authorities and consequently reflected in local and joint authority action plans and budgets. The effectiveness of the strategies is measured systematically. Public awareness about brain health has increased, and people are supported in their efforts to keep their brain healthy. Social welfare and health care professionals are more knowledgeable about brain health and better able to promote their customers' mental well-being. Problems resulting from work-related stress are identified earlier and proactive intervention is provided.

COMMITTEE'S PROPOSALS FOR ACTIONS AND COORDINATORS

- The Finnish Ministry of Social Affairs and Health will be responsible for the national coordination of brain health promotion as part of the National Development Programme for Social Welfare and Health Care and for coordinating and involving other ministries in the implementation of the programme.
- The National Institute for Health and Welfare, universities and other research organisations will be responsible for developing indicators and for producing more information about brain health and the prevention of memory disorders.
- The National Institute for Health and Welfare, the Finnish Institute of Occupational Health and the Association of Finnish Local and Regional Authorities will support local authorities in their efforts to promote brain health and to prevent memory disorders.
- Joint municipal authorities in charge of hospital districts will be responsible for updating their health care provision plans and local authorities and joint authorities their

strategies (Finnish Health Care Act (1326/2010), Section 34) to cover brain health promotion and issues relating to the health and well-being of people living with dementia.

- Joint municipal authorities in charge of hospital districts will be responsible for advising and supporting local authorities by providing training, by compiling statistics about health and well-being and by disseminating best practices, for example. Local authorities will be responsible for cooperating across administrative boundaries to promote brain health and to train professionals in different sectors (e.g. sports, culture and education) to become more knowledgeable about brain health promotion. (Finnish Health Care Act (1326/2010), Sections 35 and 36; Finnish Social Welfare Act (710/1982), Section 13)
- Local authorities/joint authorities and hospital districts will be responsible for ensuring that social welfare and health care professionals have the skills required for effectively promoting brain health (Finnish Health Care Act (1326/2010), Section 5; Finnish Social Welfare Act (710/1982), Section 53).
- Educational institutions responsible for social welfare and health care training as well as primary health care units of joint municipal authorities in charge of hospital districts will be responsible for including brain health promotion in their basic, further and supplementary training programmes (Finnish Health Care Act (1326/2010), Section 35).
- Local authorities and joint authorities will be responsible for cooperating with the third sector to provide their residents with opportunities to take part in activities that promote brain health and for taking the needs of different kinds of people into account when planning such activities. Special attention must be given to the needs of vulnerable groups, such as people undergoing rehabilitation for mental health issues and people who are alone and at risk of becoming socially excluded.
- Maternity and child health clinics, clinics for children with developmental disabilities, school and student health care providers, occupational health care providers, providers of health care for the unemployed and advisory centres for elderly people will be responsible for including brain health promotion in their advice and support services.
- Education authorities will be responsible for ensuring that information about brain health promotion is included in the public health education provided in preschools, primary and secondary schools, sixth form colleges and vocational and other educational institutions and that the teaching is tailored to people of different ages as well as for training teachers in these issues.
- State aid paid towards Finland's National Development Programme for Social Welfare and Health Care and funding from Finland's Slot Machine Association will be channelled into activities that promote brain health. Finland's Slot Machine Association will be responsible for providing non-governmental organisations with resources for publishing information about brain health promotion.
- Local authorities and joint authorities, occupational health care providers, sports associations and cultural organisations as well as social welfare and health care organisations will be responsible for providing support and information about brain health promotion to the general public.
- Citizens will be aware about how to actively promote their own brain health.

2 DEMENTIA AFFECT US ALL – TIME FOR AN ATTITUDE CHECK

At the moment, there is still a stigma attached to memory disorders and dementia and prejudiced attitudes have a negative impact on the well-being of people with such conditions. Although knowledge and understanding of cognitive problems and dementia and the available treatments have increased rapidly, negative attitudes have been slower to change. What is needed is an attitude check to allow people with cognitive problems and dementia to be included in society on equal terms with others, to lead a full and active life and to have timely access to the support, treatment and care that they need to enable rehabilitation.

The number of people with mild, moderate or severe dementia currently stands at approximately 130,000. Many of us also have a family member, a neighbour or a colleague who has cognitive problems or dementia. Social welfare and health care professionals, but also professionals in other sectors, encounter people with dementia and their families in their work. A more encouraging and accepting society is needed to allow people with dementia to be able to lead their lives on equal terms with others. Society has a responsibility to ensure people with dementia and their families the right to be treated equally with others and to make decisions about their own lives independently.

Increasing public awareness and fostering a more accepting society are prerequisites for improving prevention, early detection and the effectiveness of treatment and services.

TARGET 2020

Public attitude towards memory disorders, dementia and people with dementia has turned more positive. The basic rights and ¹ of people with dementia and their right to make decisions about their own lives independently are guaranteed.

COMMITTEE'S PROPOSALS FOR ACTIONS AND COORDINATORS

- The Finnish Ministry of Social Affairs and Health will be responsible for coordinating actions in a manner that ensures that the basic rights and liberties and human rights of people with dementia and their families are guaranteed.
- The Finnish Ministry of Social Affairs and Health will be responsible for cooperating with the Association of Finnish Local and Regional Authorities, local authorities and joint authorities, research organisations and educational institutions, Finland's Slot Machine Association and the third sector to organise a campaign aimed at raising awareness and moulding public opinion across the population.
- The National Institute for Health and Welfare will be responsible for cooperating with experts and citizens to develop an online memory portal (www.muisti.fi) containing information about memory loss symptoms, memory disorders, dementia and the opportunities presented by research, treatment and rehabilitation.
- The National Institute for Health and Welfare will be responsible for cooperating with other research organisations to produce information about the way the basic rights of people with dementia are guaranteed.

¹ Of the basic rights and liberties and human rights that public authorities are responsible for upholding according to the Constitution of Finland (731/1999, Section 22), those most pertinent to the position of people suffering from memory disorders are equality (Section 6), freedom of movement (Section 9) and the right to social security (Section 19), such as indispensable care and adequate social, health and medical services.

- Local authorities and hospital districts will be responsible for ensuring that the maximum queuing times laid down in law are observed at all stages of the long clinical pathway of people living with dementia.
- Local authorities, hospital districts and the Social Insurance Institution of Finland will be responsible for cooperating with the third sector and the private sector to ensure that people with dementia have access to rehabilitation on equal terms with others.
- The third sector will be responsible for cooperating with local authorities and joint authorities to provide people with dementia and their families with opportunities to engage in social activities, access to peer support and information to help them cope with daily routines and enjoy a richer life.

3 PROPER TREATMENT AND CARE IS A WORTHWHILE INVESTMENT

Even though we know that an undiagnosed person with dementia is the most expensive kind of patient for society, a significant number of cases still go undiagnosed. Undiagnosed memory disorders lead to uncontrolled use of social welfare and health care resources. By taking timely and preventive action, we can ensure that our operating models are both humane and economically sustainable. Even small evidence-based changes in operating models can help to cut costs.

The objective of primary health care – and in the case of the working population occupational health care – is to detect cognitive disorders and to refer those affected to have the appropriate tests done. In order for us to be able to control the increasing demand for services and the rising costs, we need to detect cognitive disorders as early as possible and ensure the provision of timely treatment, rehabilitation and support as well as follow-up. In the case of people with dementia, primary health care providers are responsible for both treatment and follow-up.

Case management and coordination are vital for ensuring that the services provided to people with dementia make up a seamless and comprehensive bundle. Case management involves carrying out a comprehensive and careful assessment of each patient's personal circumstances and his or her need for assistance, support and care and using this information as a basis for producing a personalised care and service plan. Case management is a means of ensuring that patients and their families have access to as much information as possible about the services available from the public sector, the private sector and the third sector. This creates conditions for making choices and pooling the support services available to build a personalised package that meets the needs of the individual as well as possible. Case management also involves an assessment of the opportunities of the patient's family and friends to form a support network to help the patient cope with daily life. Case management is an important tool for guaranteeing patients' equality.

The performance of clinical pathways is an important quality parameter that needs to be factored in when developing care and support services for people with dementia and their families. The grey areas where different services interface and where patients transition from one service provider to another are the points where clinical pathways are often the weakest. An efficient clinical pathway combines social welfare, primary health care, specialist medical care and rehabilitation services into a seamless bundle that ensures that people with dementia and their families have access to the support and services that they need as the dementia progresses. Ultimately, the aim is to ensure that the right services are provided in the right place and at the right time. Managing clinical pathways requires commonly agreed and efficiently communicated targets and a clear and documented division of responsibilities and work.

A wider range of rehabilitation services is needed for patients to be able to continue living in their own homes. Rehabilitation includes services aimed at improving or maintaining patients' ability to function as well as services designed to decelerate the rate of decline; whatever the circumstances, the goal is always to optimise functional capacity and the quality of life. Rehabilitation needs to be seen as a goal-orientated form of care and a specialist branch of medicine in its own right, and rehabilitation services need to be made more readily available to people with dementia in their own homes and/or at rehabilitation centres and accepted as a viable treatment alternative: Day centres, home care providers and 24-hour care providers all need to adopt an approach that emphasises the importance of restoring patients' ability to function. Substantial savings could be achieved by introducing coordinated home care and rehabilitation services, but these options have not yet been fully explored.

Cognitive problems and dementia are the single most common reason for patients requiring 24-hour care. Timely drug treatment effectively delays the point when people with dementia begin to need 24-hour care. The need for long-term care can also be delayed by maintaining patients' ability to function and by looking after the well-being of patients' families. Goal-orientated 24-hour care gives people with dementia an opportunity to lead a contented life until the end. Activities that promote rehabilitation are also a sign of the quality of treatment in units offering 24-hour care. Mental agility exercises and different kinds of regular activities are fundamental to any treatment aimed at promoting rehabilitation and patients' ability to function.

Local authorities lay down the foundations for effective 24-hour care in their care and service plans. The strategic choices made when deciding on care and service priorities have major implications on the lives of residents. Local authorities can choose to provide the 24-hour care services for which they are responsible either internally or in cooperation with other local authorities. Alternatively, they can outsource the services to private or public service providers or furnish their patients with service vouchers that can be exchanged for services available in the private sector. Local authorities often use competitive tendering to procure 24-hour care services for their patients. This has led to some problems, for example when people with dementia have had to relocate from one housing unit to another because the assisted living unit where they were residing lost the contract for 24-hour care.

Many local authorities have also adopted a practice whereby patients are transferred to new units whenever their condition deteriorates, sometimes several times. One of the most important tasks is to widen the range of services available at units offering 24-hour care so that residents there have access to any health care and rehabilitation services that they require as well as end-of-life care. Ideally, people with dementia should be able to stay in the same place and services be brought to them. This is due to the fact that transitions are especially challenging for them. Adjusting to new surroundings and to new people is about more than just learning places, faces and names; it is a gradual process the length of which varies from one individual to the next. Among the fundamentals of ensuring a high standard of care are that patients and their families are consulted at all stages of the process and that residents are not moved from one place to another unnecessarily.

Palliative care becomes relevant for people with dementia when prolonging life is no longer meaningful. Palliative care focuses on alleviating pain and other symptoms while also being considerate of patients' psychosocial and spiritual views and beliefs. The objective is to make patients nearing the end of their lives as comfortable as possible. When correctly planned and administered, palliative care helps people with dementia to lead the remainder of their lives as fully as possible and supports their families during the process and after their loved one's death. Personalised palliative care plans and clear documentation help to coordinate the work of the professionals involved, alleviate the anguish of patients' families and improve patients' quality of life even as they near death.

TARGET 2020

Cognitive symptoms are detected and people affected referred to have examinations done, conditions are diagnosed and appropriate drug and other treatments started early. Finland has consistent and efficient clinical pathways for treating, rehabilitating and providing services for people with progressive memory disorders and dementia in a manner that ensures patients' equality. The provision of timely support, care and services is based on a) comprehensive assessments of patients' health and resources and their ability to function; b) maintaining and promoting patients' rehabilitation and coping, controlling behavioural and psychological

symptoms and treating illnesses efficiently; and c) good palliative and end-of-life care when prolonging life is no longer meaningful.

COMMITTEE'S PROPOSALS FOR ACTIONS AND COORDINATORS

- Local authorities and joint authorities will be responsible for providing people with mild, moderate or severe dementia and their families with efficient and coordinated support, care and services from the detection of symptoms to support and end-of-life care.
 - Local authorities and joint authorities will be responsible for setting up regional outpatient clinics offering primary health care services to people with memory disorders and dementia so as to ensure that patients have access to doctors, nurses and social workers as well as rehabilitation and psychiatric services.
 - Hospital districts and catchment areas for highly specialised medical care will be responsible for setting up outpatient clinics offering specialist medical care to people with memory disorders and dementia in order to deal with specific memory loss issues and to provide primary health care consultation and training.
 - Occupational health care providers will be responsible for detecting cognitive symptoms among the working population and for referring sufferers to have the appropriate examinations done.
 - Local authorities and joint authorities will be responsible for setting up and introducing clinical pathways for treating people with memory disorders and dementia and for providing services for them according to national recommendations and for determining clear responsibilities for different parties and for documenting them. Special attention will be given to rehabilitation. Clinical pathways will be designed so as to take into account the changing circumstances of the patients and the possibility of them requiring urgent attention as well as their need for good end-of-life care. The effectiveness and quality of the pathways will be assessed on a regular basis.
 - Local authorities and joint authorities will be responsible for providing 24-hour care for people with dementia according to national guidelines: The objective is to reduce the amount of residential care and to increase the availability of treatment alternatives based on housing and personalised services. The Finnish Ministry of Social Affairs and Health, the Finnish Ministry of the Environment and the Housing Finance and Development Centre of Finland will be responsible for coordinating local authorities and joint authorities in their efforts to ensure the quality of the living environments of patients requiring 24-hour care and for promoting the development of alternatives based on housing and personalised services.
 - Local authorities and joint authorities will be responsible for procuring 24-hour care for their patients in a manner that ensures that the rights of people with mild, moderate and severe dementia are guaranteed and that the chosen service providers have sufficient know-how of treating individuals with dementia.
 - Local authorities and joint authorities will be responsible for providing access to high-quality daily living aids and for ensuring that the opportunities presented by the aids and information technology are made use of to promote ability of people with dementia to function and to lead full and active lives safely.
 - Local authorities and joint authorities will be responsible for cooperating with the third sector at the different stages of the clinical pathways developed for individuals with memory disorders and dementia: Once a diagnosis has been confirmed, patients will be guaranteed access to key facts about their condition, support for adjusting to the situation and information about rehabilitation possibilities (public health care, Social Insurance Institution of Finland). As the disease progresses, use will be made of research and existing best practices to ensure access to cost-effective support. The most essential elements of cost-

effective support include a case worker who will coordinate the provision of support, care and services for the affected family in partnership with a physician as well as goal-orientated peer groups for kinship carers.

- Non-governmental organisations will be responsible for providing people with dementia and their families with information, guidance and advice, help with adjusting to the situation and peer support. Funding from Finland's Slot Machine Association will be used systematically to provide information and peer support.
- The National Institute for Health and Welfare, universities and other research organisations will be responsible for producing information about services used by individuals with dementia, the quality of those services, the effectiveness and quality of clinical pathways as well as costs. The Palveluvaaka online portal created by the National Institute for Health and Welfare will be developed further and used to monitor and assess the quality of care and services.
- Research organisations, universities, other institutes of higher education as well as the third sector and businesses will be responsible for producing information and best practices for local authorities and joint authorities to use as a basis for developing services to support and care for people with dementia and their families in a manner that improves their quality of life and coping on a daily basis. Finland's Slot Machine Association, the Finnish Funding Agency for Technology and Innovation and other parties that grant funding for research and development will be responsible for systematically granting funds to the aforementioned purposes. The Innokylä innovation community will be responsible for disseminating best practices.

4 MORE RESEARCH AND EDUCATION STILL NEEDED

Diverse and nationally representative high-quality research has already unearthed new opportunities for promoting brain health, for diagnosing cognitive problems and memory disorders and for improving the effectiveness of services. Fields representing the cutting edge of research worldwide must be taken care of, as these are where innovations are born. More research is still required with regard to how psychosocial support and technology can be used to help individuals with memory disorders and dementia and how operating models derived from latest know-how can be disseminated across basic services in particular. Allocating resources to coordinated multidisciplinary research is essential for Finland to be able to respond to the challenge that memory disorders and dementia present in terms of public health and the national economy.

TARGET 2020 (research)

Finland has a well-established culture of high-quality multidisciplinary research in the sphere of memory disorders and dementia that benefits public health and the national economy, people affected and their families as well as social welfare and health care professionals. Advances have been made in the most important fields such as epidemiology and research into genetics, imaging and services. New fields that have previously been overlooked or that have developed sluggishly have been identified and resources allocated to their development. The role of basic research in the innovative process is recognised. An evidence-based approach has been adopted with regard to services. Quality indicators measuring the success of brain health promotion and the performance of clinical pathways relating to memory disorders and dementia have been developed and introduced across the country. Research findings have been made available to decision-makers and this information is used as a basis for decision-making as well as planning and providing services and care.

The committee proposes that

- the Finnish Ministry of Social Affairs and Health investigate potential to establish a national network of centres of expertise;
- the National Institute for Health and Welfare engage in cooperation with other research organisations as well as universities, the Social Insurance Institution of Finland, primary health care units of joint municipal authorities in charge of hospital districts, centres of expertise in the social welfare sector and supervisory authorities to develop national criteria and indicators for the quality control and supervision of care and services and to disseminate information about quality control via the Palveluvaaka online portal;
- the National Institute for Health and Welfare engage in cooperation with other research organisations as well as universities to provide information about the progress of efforts to promote brain health and the development of and costs associated with the provision of care and services for individuals with memory disorders and dementia;
- universities engage in cooperation with research funding agencies to ensure the continuity of basic research in the sphere of memory disorders and dementia; and
- the Finnish Institute of Occupational Health engage in cooperation with universities to coordinate research into the promotion of brain health among the working population.

An adequate supply of skilled professionals is essential for the promotion of brain health, to enable memory disorders to be detected and for patients to be treated and rehabilitated successfully. Special attention must be given to promoting patients' ability to function and to providing them with a range of services to help them to continue living in their own homes as well as to fostering multidisciplinary cooperation between primary health care providers, specialist medical care providers and social services. The know-how, skills and attitudes of professionals play vital roles in ensuring ethical sustainability in all areas of care and services. In order to guarantee the quality of care and services, more attention must be given to the training of professionals and rehabilitation must be incorporated into the basic and supplementary training of care workers as well as into induction programmes.

TARGET 2020 (education)

Social welfare and health care professionals at all levels of the service system promote the brain health of citizens and are able to detect cognitive problems and refer sufferers to have the appropriate examinations done as recommended by experts. They treat people with memory disorders and dementia and their families with respect in all service areas, take the characteristics of different memory disorders and types of dementia into consideration when deciding on the appropriate treatment, are able to control the onset of behavioural symptoms and situations arising from them by means of preventive action and support patient's ability to function. Treatment is provided according to evidence-based practices. Professionals have the skills required for treating individuals with memory disorders and dementia in a manner that supports their identity and quality of life until the end. Professionals are able to support patients' families and are familiar with the most essential legal rights of people with dementia.

The committee proposes that

- education authorities and organisations give particular attention to ensuring that basic, further and supplementary social welfare and health care training include enough elements aimed at promoting brain health, detecting memory disorders in their early stages, treating and rehabilitating patients, providing palliative and end-of-life care and supporting people with dementia and their families;
- national targets be agreed for the skills that professionals (such as nurses and coordinators) working with individuals with memory disorders and dementia must have; and
- the most essential elements relating to the promotion of a "memory-friendly" Finland, such as the importance of brain health and treating individuals with dementia with respect, be included in the curricula taught in preschools, primary and secondary schools and sixth form colleges in order to bring about a change in people's attitudes.

Implementation

The implementation of the programme will be tied in with the implementation of the National Development Programme for Social Welfare and Health Care, and the action plan associated with the programme will be incorporated into the action plan produced for the National Development Programme for Social Welfare and Health Care. The action plan will be based on the recommended actions discussed in the programme.

The action plan will be produced in cooperation with the National Institute for Health and Welfare. The action plan will specify which of the programme's objectives will be prioritised between 2012 and 2020. Assessments will be carried out to measure how successfully tangible objectives have been achieved, including

- human impact assessments (HuIA: http://www.thl.fi/en_US/web/en/research/tools/human_impact_assessment),
- analyses of the effects of local authority decision-making (see <http://www.kunnat.net/fi/Kuntaliitto/yleiskirjeet-lausunnot/yleiskirjeet/2011/Sivut/y08802011-suositus-kunnallisessa-paatoksenteossa.aspx>) and
- costs.

The action plan will be produced taking into consideration existing laws and new legislative initiatives introduced by the Finnish Ministry of Social Affairs and Health as well as other guidelines, the following in particular:

- Implementation of the Finnish Health Care Act (1326/2010)
- Comprehensive reform of Finland's social welfare legislation (for more information, see http://www.stm.fi/vireilla/tyoryhmat/sosiaalihuollon_lainsaadanto)
- Legislative initiatives relating to the organisation, development and supervision of social welfare and health care services
- Legislative initiatives relating to the elderly population, their ability to function and the social welfare and health care services available to them (for more information, see http://www.stm.fi/vireilla/lainsaadantohankkeet/sosiaali_ja_terveydenhuolto/ikaantyyneet)
- Finnish Alcohol Programme (for more information, see http://www.thl.fi/fi_FI/web/fi/tutkimus/ohjelmat/alkoholiohjelma)
- Care and attention on a 24-hour basis. Working Group (Ikähoiva) Memorandum (available at http://www.stm.fi/julkaisut/nayta/_julkaisu/1554171#fi)
- National Framework for High-quality Services for Older People (revision) (available at http://www.stm.fi/sosiaali_ja_terveyspalvelut/ikaihmiset/palvelujen_laatu/laatusuositus)
- Measuring elderly people's ability to function as part of service need assessments – expert recommendations (for more information, see www.toimia.fi)
- National Plan for Mental Health and Substance Abuse Work (for more information, see http://www.stm.fi/c/document_library/get_file?folderId=39503&name=DLFE-7175.pdf)
- Proposal for a National Programme for the Development of Kinship Care (for more information, see <http://www.stm.fi/vireilla/tyoryhmat/omaishoito>)
- Finnish Leadership Development Network (for more information, see <http://www.ttl.fi/partner/johtamisverkosto/Sivut/default.aspx>)

The programme is also linked to the National Programme for the Development of Housing Services for the Elderly coordinated by the Finnish Ministry of the Environment (for more information, see <http://www.ymparisto.fi/default.asp?contentid=402589&lan=fi>) and to the Active Life Programme sponsored by Finland's Slot Machine Association (<http://www.vtkl.fi/fin/ajankohtaista/?nid=241>).

The Finnish Ministry of Social Affairs and Health will set up a committee to oversee the implementation of the proposals.

The progress of the programme will be monitored by means of various follow-up systems developed by the National Institute for Health and Welfare, such as the regional health and welfare study, the TEAviisari health promotion activeness indicator and the www.terveytemme.fi online health statistics service, and by conducting surveys and by compiling reports (e.g. statistics compiled by the National Institute for Health and Welfare on social welfare and health care customers with memory disorders and dementia) to continuously improve the effectiveness of the efforts. Local authorities and joint authorities will incorporate the monitoring of memory disorders and the coordination of actions into their multidisciplinary welfare policy programmes.

More information

Eloniemi-Sulkava U, Saarenheimo M, Laakkonen M-L, Pietilä M, Savikko N, Pitkälä K 2006. Working together in kinship care. Effectiveness of the support available to families of elderly dementia sufferers. Research and development project for geriatric rehabilitation. Research report 14. Central Union for the Welfare of the Aged.

Eloniemi-Sulkava U, Rahkonen T, Erkinjuntti T, et al. 2010. Multi-professional know-how is a prerequisite for effective treatment of memory disorders. Finnish Medical Journal 65: 3144–3146.

Finnish Alzheimer's Disease Research Society 2008. Best care practices for all stages of progressive memory disorders – expert recommendations. Finnish Medical Journal, memory disorders supplement. 63: 9–22.

Finnish Ministry of Social Affairs and Health 2010. Good end-of-life care in Finland. Publication 2010:6 of the Finnish Ministry of Social Affairs and Health; see http://www.stm.fi/julkaisut/nayta/_julkaisu/1528097.

Finnish Ministry of Social Affairs and Health and Association of Finnish Local and Regional Authorities 2008. Quality recommendations for services for the elderly; see http://www.stm.fi/sosiaali_ja_terveyspalvelut/ikaihmiset/palvelujen_laatu/laatusuositus.

Memory Disorders – Current Care Guideline; see <http://www.kaypahoito.fi/web/kh/suosituksset/naytaartikkeli/.../hoi50044>.

Sormunen S & Topo P (edit.) 2008. High-quality dementia services – guide for local authorities. National Institute for Health and Welfare.

Suhonen J, Rahkonen T, Juva K, Pitkälä K, Voutilainen P & Erkinjuntti T 2011. Clinical pathway for memory loss patients. Duodecim Medical Journal 127: 1107–1116.

Online sources:

Innokylä innovation community; see <https://www.innokyla.fi/>

National Institute for Health and Welfare/Palveluvaaka quality control portal; see <http://www.palveluvaaka.fi/web/guest/>

National Institute for Health and Welfare/TEAvisari health promotion activeness indicator; see www.thl.fi/teaviisari

National Institute for Health and Welfare/www.terveytemme.fi health statistics service; see www.terveytemme.fi

For laws and regulations, see www.finlex.fi.