NORWEGIAN MINISTRY
OF HEALTH AND CARE SERVICES

Subplan of Care Plan 2015

Dementia Plan 2015

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Preface

From the start this Government has focused on the situation of those with dementia disorders and their families. Already at Soria Moria we agreed to formulate an overall plan to improve dementia care and make more resources available to dementia research. For that reason I am pleased to present the Government's Dementia Plan, which is a subplan of Care Plan 2015 and a follow-up of Report No. 25 (2005-2006) to the Storting, *Long-term care – future challenges.*

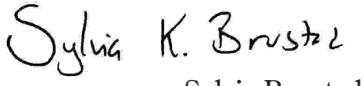
Report No. 25 (2005-2006) to the Storting describes the long-term future challenges for the municipal care services and contains strategies as well as specific initiatives for the period until 2015. Care Plan 2015 summarises the initiatives in the Report and places its main focus on new investment grants for nursing homes and assisted living facilities, increases in man-years, new expertise and recruitment plans: Competence Lift 2015 and Dementia Plan 2015. The Dementia Plan is to help to focus the Care Plan's general instruments, and for that reason initiatives to improve dementia care must be viewed in the context of the care plans' other main focus areas.

Dementia disorders involve the fates of individuals as well as the experiences and feelings of family members of those affected. Dementia disorders are still the subject of ignorance, guilt and taboos. There is a lack of knowledge about dementia among professionals and in society as a whole. At the same time we see that services offered to this group are inadequate and that in many places there are links missing in the chain of services.

If we include immediate family members, at least 250,000 people are affected by dementia disorders in Norway. It is often the families who observe the first symptoms and are confronted with the individual's fear and uncertainty. Being a family caregiver for a person with dementia can be very burdensome. Working together with family caregivers is fundamental, to create good quality services for the individual as well as to provide relief for families.

Care services that are well-adapted to persons with dementia tend also to be good for other users of nursing and care services. For that reason it is to be as integral a part as possible of overall health and social service offerings at local level and in the specialist health service. Day programmes, well-developed home care services and adequate respite schemes are essential to these offerings.

It is my hope that the plan raises the visibility of what it means to have a dementia disorder and clarifies how we can meet the challenges relating to a growing number of persons with dementia. It is also my hope that we not lose sight of the individual and the ethical challenges of meeting the individual with dignity and respect. This is largely a matter of making possible a meaningful day-to-day existence characterised by good moments, despite illness and functional impairment.



Sylvia Brustad

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Small is beautiful

"We need different living arrangements for patients with dementia. In many ways the principle for residential facilities of this type is the same as the one found in sheltered units in nursing homes – 'small is beautiful'. That is, residential units are set up to accommodate six to eight residents, and patients with dementia are offered the chance to participate in ordinary everyday activities.

Institutionalisation can easily lead to passivity precisely because passivity, forgetfulness and a lack of ability to plan are part of the dementia disorder. It is our experience from studies as well as practice that getting the patient with dementia active pays off. Stimulation through everyday activities can have a very beneficial effect on behaviour, and we recommend that all institutional units that provide care to dementia patients emphasise a programme based on just those activities that daily life presents. The degree of difficulty needs to be tailored to the remaining resources the patient possesses."

From the book *Aldring og hjernesykdomer* (Ageing and brain disorders)

Professor Knut Engedal

1 Summary

Dementia Plan 2015, is one of the subplans within Care Plan 2015. The plan has been drawn up against the background of Report IS 1486, *Glemsk, men ikke glemt* (Forgetful but not forgotten), from the Directorate for Health and Social Affairs, which outlined challenges and needs and recommended focus areas.

One of the biggest care challenges we face as a consequence of longer life expectancies and changes in the age composition in the population, is the expectation of twice as many people in the next 35 years with various dementia disorders. The sharpest growth will be in 10 - 15 years. This gives us time to prepare and plan, while even now it is necessary to invest for the long term in knowledge and skills, technology and the building stock. It takes many years to recruit and train adequate health and social services personnel, and it often takes a long time to plan and build nursing homes and other residential facilities.

Most important of all will be to prepare the local community for this situation and provide better facilities for persons with dementia disorders and their families, who over many years often bear the heaviest burdens. In this context well-developed home care services and day programmes play a crucial role.

The Dementia Plan is based on a recognition that current care services are inadequately developed and adapted to persons with dementia. This means that in the coming years changes within the care services are necessary in terms of skills, organisation and physical form. The Dementia Plan will emphasise three main focus areas:

1.1 Day programmes

There are many who refer to day programmes as the missing link in the care chain. Only 4 % of those who live at home with a dementia disorder have a programme to attend during the day. These programmes are meant to occupy and stimulate patients, be enjoyable and provide them with a meaningful daily existence. At the same time they can provide some relief for immediate family from care tasks during the day, helping to enable spouses and other family members to cope with the demands of caring for a loved one with dementia. The development of home care services and day programmes will be crucial for the interaction with families and the local community.

In Circular I- 5/2007, *Aktiv omsorg* (Active care), the Government made clear the local government responsibility for such services in line with the purpose of the Social Services Act, namely "*to help to give individuals the opportunity to live independently and to have an active and meaningful existence in community with others*".

Here it is emphasised that well-developed day programmes, along with home care services, may, in many cases, help to prevent or postpone institutionalisation. The importance of day programmes for persons with dementia disorders and others with long-term, complicated disease progression or impaired functional abilities is noted in particular.

The Dementia Plan proposes a programme to try out models that work for day programmes for persons with dementia.

1.2 Living facilities better adapted to patient needs

Despite the fact that nearly 80 % of those who live in nursing homes have a dementia disorder, many nursing homes are not built for or adapted to persons with dementia and cognitive failure. If they are to function as living facilities for this group in the future, renovation and adaptation of a considerable portion of today's nursing homes and assisted living facilities are required. At the same time, everything that is built or modernised with financing through the Norwegian State Housing Bank's grant scheme for nursing homes and assisted living facilities should be adapted to persons with dementia. This means that small-scale communal living arrangements and wards with programmed activities and direct access to adapted outdoor areas are better than old-fashioned multi-storey institutions with large wards and long corridors.

1.3 Increased knowledge and skills

Information

Dementia disorders concern society as a whole and continue to be associated with ignorance and various conceptions of shame and guilt, so that those who have this condition and their families sometimes try to keep it hidden and withdraw from social contexts. That is why education and information are needed, for the patients themselves, their families and the general public. A separate information and educational campaign is planned.

Education

Immediate family members will also be reached by dedicated support groups and schools for family caregivers for persons with dementia in collaboration with volunteer organisations. At the same time the focus will be on giving all employees of the municipal health and social services the necessary knowledge through various educational measures.

New expertise

Medical expertise is to be increased both locally and through closer follow-up from the specialist health service with regard to diagnosis and treatment. Through Report no. 25 (2005-2006) to the Storting, the Government aims to create greater professional breadth in the care services, with more professions and a greater emphasis on an interdisciplinary approach.

Research

Another reason for the lack of knowledge about causes, the development of disease and forms of treatment is the fact that dementia disorders have not enjoyed high status in medical research. For that reason, research is a key focus area in the Government's Dementia Plan.

2 Fundamental principles for improving dementia care

Persons with dementia are not a homogeneous group. Like everyone else they have different needs and different interests. Proper dementia care means meeting the individual where they are and initiating individually adapted services based on insight into the individual's life story and medical history.

Dementia has had low priority in both the specialist health service and the municipal health and social services. In many locales the services offered are not adapted in terms of physical building stock, organisation or profession qualifications for persons with dementia and/or cognitive failure. There is also a lack of capacity, continuity and knowledge in these services. Dementia Plan 2015, *Making the most of the good days*, contains long-term strategies and specific measures, based on important principles and values for improving dementia care.

Proper dementia care is proper care for everyone

The aim of the measures in the Dementia Plan is for the individual to have a good quality of life, feel secure and have a meaningful day-to-day existence despite serious illness and functional impairment. Dementia is the most common reason for admission to and long-term stays in nursing homes. A very large percentage of the users of care services have dementia, often in combination with other illnesses and losses of function. The primary strategy is to conform and adapt current care services to this reality. The Dementia Plan is primarily linked to the instruments in Care Plan 2015, which is intended to provide quality and capacity to all users of care services. Report No. 25 (2005-2006) to the Storting on future challenges to care describes this as follows: *"It is assumed that dementia care will be part of an integrated care services at municipal level and be developed into a special care service."* This is based on the recognition that proper dementia care is often proper care for nearly everyone.

Openness and inclusion

An important principle for the Government's dementia care is openness and inclusion. The Government wishes to counteract stigmatising of and discrimination against persons with dementia and their immediate families. For that reason the Government will ensure greater knowledge and skills among family caregivers, employees and the general public and develop care services characterised by collaboration between the public sector, family caregivers, volunteer organisations and local communities.

Integrated chain of care

The Government wishes to develop dementia care as an integrated, continuous chain of measures. Persons with dementia and their families are to feel a sense of predictability and security when meeting the services sector. Services offered shall be based on a holistic view of the person and characterised by continuity and interaction between various service providers. Dementia disorders develop over time, and services need to be adapted to the individual's functioning level and service needs. The Government will emphasise measures early in the course of the illness, as this may prevent additional afflictions and improve quality of life. For persons with dementia, moving may often exacerbate the symptoms and create confusion and passivity. For that reason one should avoid as much as possible moving between different living arrangements and treatment offerings, and aim for continuity and a sense of belonging.

"Small is beautiful"

The Government's objective is to design service offerings on the basis of users' needs and wishes. Today, nearly 80 % of everyone living in Norwegian nursing homes has a dementia disorder; even so, the institutions were neither built for nor adapted to them. There is a consensus among professionals that the large nursing homes are very poorly adapted to long-term residents with

dementia. With the new investment grant from the Norwegian State Housing Bank, the Government will make it possible for assisted living facilities that are built or modernised to be adapted for persons with dementia and/or cognitive failure. This is primarily a matter of "small is beautiful". This means small units in terms of both building size and organisation. Small shared living facilities and wards with access to pleasant outdoor spaces are better than traditional multi-storey nursing homes with long corridors and large wards.

Dignity and respect

The quality of care services is being tested where the employee meets the individual user. Good quality services are ensured through professionally qualified staff, who meet the individual user with respect and dignity, and who can translate reliable knowledge into proper practice. Employees of the health and care services face difficult situations every day requiring knowledge of proper practice, awareness of their own values and attitudes and venues for guidance, reflection and sharing experiences. The Government has established a collaborative project between the State, the Norwegian Association of Local Authorities (KS) and professional organisations that is to facilitate ethical reflection and guidance in municipal health and social services.

3 The challenges

3.1 What is dementia?

Around 60-70 % of all persons with dementia have Alzheimer's disease. The next most common form is vascular dementia following a stroke. This form occurs in around 15-20 % of all persons with a dementia condition. Beyond this, dementia can arise with a number of more or less frequently occurring brain diseases.

The most important symptom or characteristic of dementia is impaired memory. Dementia also results in impairments in thinking, communication and orientation. Persons affected by dementia have difficulty performing habitual tasks or coping with everyday problems. Some develop personality changes featuring a lack of insight and poor judgement, lack of inhibitions, aggressiveness and a lack of empathy. Other symptoms are anxiety, depression, suspiciousness, delusions and compulsive behaviours.

Dementia is a degenerative condition. Those affected will function increasingly poorly and will eventually be dependent on help. Persons with dementia often have a very complex clinical situation with functional impairments in several areas. For the health service in general and municipal care services in particular, this means great challenges in planning, determining the size of the service, and facilitating an integrated and continuous care chain for persons with dementia.

3.2 Missing links in the care chain

Diagnosis and clinical coordination

Before appropriate treatment and care can be provided, the patient needs to be adequately evaluated. A diagnosis gives the patient, his or her family and the assistance services a realistic chance to plan and implement necessary measures. Studies show that up to 50 % of all users in nursing homes with sure signs of dementia have not been diagnosed.

The Norwegian model for diagnosis and evaluation requires collaboration between the specialist health service and municipal health and care services. It is a challenge to ensure proper routines for collaboration between service levels for evaluating and diagnosing dementia. At the same time there is a considerable lack of expertise at both levels.

The proportion of elderly who use hospital services is rising. The patients are discharged from hospital with the assumption of follow-up and aftercare by the municipal health service. This requires professional expertise at local level that is sufficiently qualified for proper follow-up care and for local authorities to be ensured access to advice and guidance from the specialist health service. It is a big challenge to ensure that the specialist health service is dimensioned and organised to provide adequate follow-up care with geriatric, psychiatric and general medical care.

Day programmes – the missing link in the care chain

Most studies indicate that it is in the social and cultural areas that current municipal care services come up short. This is reflected in services offered to persons with dementia. Approx. 50 % of all persons with dementia live outside of an institution. A national survey of services offered to persons with dementia at the local level from 2004-2005 shows that fewer than 4 % of them are in day programmes adapted to their needs. The percentage receiving such services declined somewhat from 2000-2001.

National and international studies show that specially adapted day programmes can be cost-effective and provide appropriate respite to family caregivers. It will be a big challenge to attain coverage that will ensure such programmes to everyone who needs them. It will require proper models for day programmes adapted to patient needs and greater professional breadth with room for more professions in line with the strategy "Active care" in Care Plan 2015. At the same time there is reason to emphasise that day programmes can represent a key element in the interaction with family caregivers and help to prevent or postpone institutionalisation.

Support and guidance for family caregivers and staff

Many people experience difficulty in finding out what is offered by the health and care services, and what their rights as individuals are. It is a big challenge to ensure that information and knowledge is disseminated to users, family members, employees and society as a whole. This requires various instruments and close collaboration with volunteer organisations and communities of specialists.

Being a family caregiver for a person with dementia increases the risk of harm to their health. Families need information about dementia disorders, relevant treatment and available support mechanisms and they need to be included in the evaluation. Experience shows that families of persons with dementia have a higher quality of life when they are educated about and given guidance in, dealing with the dementia disorder.

The municipal health and social services provide services and information to a large number of persons affected by dementia disorders. It is a challenge to ensure that all employees are knowledgeable about and qualified to deal with dementia. There is a need for training and skills development in professional training programmes for careers in the health and social services.

Research and development

In the past ten years there have been several initiatives in the area of dementia, particularly in research and development. This has provided a deeper insight into dementia disorders and helped to improve dementia care. The mystery of Alzheimer's disease and other dementias has not been solved by any means, and a continued focus on research and development efforts is needed.

The challenge is to obtain new knowledge that can improve the services offered to persons with dementia and their families and implement good knowledge-based services. In many areas we know too little about the causes, disease progression, forms of treatment and how best to organise and adapt services for persons with dementia.

3.3 Adapting residences

We estimate that around half of those with a dementia disorder live in one or another form of institution and that around 3/4 of those with a permanent place in a nursing home have developed a dementia disorder. This means that around 30,000 places in nursing homes are occupied by persons with dementia, while only a tiny fraction of these places have been adapted to this user group. The Directorate for Health and Social Affairs has estimated the need for rebuilding nursing homes and new construction of adapted housing at 37,000 dwelling units from now until 2030.

Tabell 3.1 Estimated need for adapted living facilities for persons with dementia 2006-2030

Years	Conversion and renovation needs	Need for new construction	Total housing needs
2006-2020	20,000	4,000	24,000
2020-2030		13,000	13,000
By 2030			37,000

Source: The Directorate for Health and Social Affairs

A dementia disorder means impairments in memory, attention, orientation in time and place and understanding of space and direction. The optimal framework for such patients is small living groups in an easily navigated physical environment with only a few residents (four to eight persons) and a stable staff with the necessary knowledge and skills. There are not many studies in Norway and the Nordic region that have evaluated such adapted living environments. In professional circles, however, there is agreement that new institutions and assisted living facilities should in principle be constructed as small living groups with stable staffing. Shared social activities and direct access to adapted outdoor areas should also be provided for. Persons with dementia who have behavioural problems need specially adapted services in small and reinforced units. In this area skills development and collaboration between professions and municipalities are necessary.

3.4 A growing number of persons with dementia

Today there are around 66,000 persons with dementia in Norway. The prevalence rises with increasing age. If we assume that each person who develops dementia affects four close family members, we can estimate approx. 250,000 close family members affected by dementia disorders.

The prevalence of dementia in the age group 65-69 is 0.9 %, rising to 17.6 % in the age group 80-

Tabell 3.2 Prevalence (estimated number of cases) of dementia in the population

Age group	Prevalence (in %)	2006	2010	2020	2030	2040	2050
65-69	0.9	1594	1895	2402	2646	2865	2662
70-74	2.1	3142	3285	5286	5550	6385	5858
75-79	6.1	8496	8021	10407	13577	15406	17108
80-84	17.6	20410	18878	18944	31926	35232	42342
85-89	31.7	21535	23134	20638	29390	40921	49870
90 +	40.7	12407	13832	16000	17768	32054	41829
TOTAL		67584	69045	73677	100857	132863	159669

Source: Directorate for Health and Social Affairs

84 and from age 90 and above, 40.7 % have developed a dementia disorder. From around 2020 we will have to expect the number of inhabitants over age 80 to explode. The group aged 90 and over will grow sharply already in the coming years. If the prevalence of dementia disorders stays at current levels, the number of persons with dementia will double to around 135,000 by 2040.

The costs to society of dementia disorders are high and will rise even higher. Annual costs in Norway in 1995 were around NOK 14 billion. By comparison, gross expenditure on the entire health and social services at municipal level was just over NOK 45 billion. The Directorate for Health and Social Affairs will perform a more detailed analysis of these costs. The objective of such an analysis is to shed light on the care burden of affected families.

A breakthrough in research on dementia would be of great significance for care needs and employment in the sector in the future. Report no. 25 (2005-2006) to the Storting illustrates the effect of such a breakthrough by suggesting that it would result in a reduction in staffing needs by over 50,000 man-years or around 25 % in 2050. However, there are no grounds to expect a breakthrough in this research. All care service planning needs to be based on the fact that dementia is a quickly growing reason for the need for services.

Recruiting health and social services personnel to the care services and geriatrics will be one of the biggest challenges. The demand for personnel will be especially acute beginning in 2020 on account of the increase in the number of over-80s. Many of them will have developed a dementia disorder.

An important strategy will be to retain staff who already work in the care services. This can be done by schooling those who are without professional training, offering in-service training, proper management and a good working environment. Furthermore, nursing homes need to be improved in terms of expertise. Good professional environments are among the most important ways to attract qualified professionals.

4 Strategies and actions

The Dementia Plan is one of the subplans under Care Plan 2015, which was presented in Report no. 25 (2005-2006) to the Storting, *Long-term care – future challenges*. Dementia Plan 2015 has five main strategies for meeting future care challenges.

- Quality development, research and planning
- Capacity growth and raising skills and knowledge
- Improving collaboration among professions and medical follow-up
- Active care
- Partnerships with families and local communities

Care Plan 2015 assumes that the Dementia Plan will emphasise measures that can be deployed before round-the-clock services are necessary and ease the burden of family caregivers. Persons with dementia and their families are to receive the information and assistance they need as well as individually adapted services from the municipal government and specialist health service.

The Dementia Plan is intended to help to target the Care Plan's more general instruments. For that reason the actions necessary to improve dementia care need to be viewed in connection with the Government's commitment to 10,000 new man-years in the care services. The plan will employ instruments from Competence Lift 2015 and the new investment grants for nursing homes and assisted living facilities.

To follow up Care Plan 2015 the Government has set outcome targets for 2015 and devised specific measures in a four-year action plan based on the five long-term strategies for dementia care.

Box 4.1 Care Plan 2015

Care Plan 2015 comprises subplans and measures that follow from Report no. 25 (2005-2006) to the Storting, *Long-term care – future challenges*. The report was presented by the Stoltenberg II government in the autumn of 2006 and debated by the Storing during spring 2007. In addition to the Dementia Plan, Care Plan 2015 consists of:

- Competence Lift 2015
- 10,000 new man-years
- Investment grants for nursing homes and assisted living facilities
- Care research and regional R&D centres for care research
- A national standard for medical services in nursing homes
- "The Cultural Walking Stick"

Competence Lift 2015 is a plan for improving skills and recruitment for the care services. Its objective is to ensure proper recruitment, high levels of skills, more man-years and a stable staffing-situation in the nursing and care sector.

Investment grants for nursing homes and assisted living facilities with round-the-clock care will be in place starting in 2008. The target group for these grants are the elderly as well as persons with long-term somatic illnesses, developmental disabilities and psychiatric and social disorders. These grants are intended to increase capacity and to help to replace old and unsuitable buildings. It is a requirement for both new construction and modernisation that what is built must be adapted to residents with dementia and cognitive impairments.

4.1 Quality development, research and planning

4.1.1 Long-term strategy and outcome targets for 2015

The most important actions in any long-term improvement in the quality of services offered to persons with dementia and their families will be investing in expertise, research and development, adapting residences and the building stock, and developing day programmes. Together with home care services and other respite measures, this will

serve to foster the interaction with family caregivers and others affected.

In 2006 the Government and the Norwegian Association of Local Authorities signed an agreement for quality development in the municipal health and care services. The parties agree on main strategies and instruments for meeting future care challenges. The quality agreement gives local authorities predictability through various action programmes in the Ministry of Health and Care Services' areas, including an action plan for dementia care.

The Government will give priority to care service research with a specific emphasis on dementia. This will improve the basis for planning, developing and improving the quality of the services for persons with dementia and their families. Better data and increased knowledge will also ensure better local-level planning and help to raise the status of dementia care in the health and social services, as well as boost professional interest in this group of users.

Box 4.2 When the Dementia Plan has been implemented in 2015:

- The data and knowledge base for developing proper measures and services for persons with dementia will be substantially improved by research and development efforts
- Future care challenges will be on the agenda of ordinary municipal planning and funding efforts, with a particular focus on health and social services that are adapted to a growing number of persons with dementia and their family caregivers.

4.1.2 Four-year action programme

Research

A dedicated research programme is in place for health and care services for 2006-2010 under the direction of the Research Council of Norway. The programme will give priority to research dealing with municipal health and care services and have a particular focus on dementia. Furthermore, the establishment of regional R&D centres will strengthen the care research. Research funding for the Research Council's programme for health and care services is to be gradually stepped up. Initially, financial support will be given to the Centre for Care Research in Gjøvik. By the end of 2010, all five centres for care research will be in operation.

Research and development measures

During the programme period 2006-2010 the Directorate for Health and Social Affairs will implement R&D projects concerning various user groups, including:

- Younger persons with dementia
- Persons with minority language backgrounds who develop dementia
- Persons with dementia with a Saami background
- Treating and handling persons with dementia and a challenging behaviour

R&D projects will be started to learn more about adapting services and the effect of various forms of treatment, among other topics:

- The usefulness of milieu therapy and milieu treatment
- Use of individual plans for persons with dementia
- How sheltered units in nursing homes work
- How adapted communal living arrangements function as alternatives to institutions.
- How home care services should be designed and staffed
- How the specialist health service can best follow up the municipal services and users with dementia.
- How IPLOS (Individual-based Nursing and Care Statistics) can be improved, so that it can be a tool that gives us more knowledge about the need to adapt and dimension services offered to persons with cognitive impairments.
- Use and benefits of assistive equipment for persons with cognitive impairments.
- Economic calculations of annual costs relating to dementia disorders.

The projects are to be designed and implemented in close collaboration between the Directorate for Health and Social Affairs, the professions, educational institutions, R&D centres, teaching nursing homes and volunteer organisations. Users and their families are to be involved.

Local-level planning

The quality agreement between the Government and the Norwegian Association of Local Authori-

ties is constructed to help put dementia challenges on the agenda as part of local governments' ordinary planning efforts. Further measures to strengthen local government planning competence must be viewed in connection with the general measures in Care Plan 2015.

4.1.3 Initiatives 2008

Research

Research efforts into dementia will be increased by NOK 5 million in 2008, which will primarily be channelled through the Research Council of Norway's programme for health and care services. The amount is part of the Government's overall increase of funding for care research totalling NOK 15 million in 2008.

Milieu therapy and milieu treatment

In 2008 a three-year development programme on milieu treatment and milieu therapy will be launched. This development programme is to spotlight physical and psychosocial frameworks, relationships, interaction, communication and milieu therapy methods. Furthermore, the programme is to develop usable models for milieu therapy, and assess the effectiveness and benefits of various social and environmental measures.

Younger persons with dementia

In 2008 a three-year Nordic development programme is to be initiated for younger persons with dementia. The objective of the programme is to learn more about the stress experienced by children and spouses of younger persons who develop dementia, survey and implement measures that give spouses and children more accurate information about dementia disorders and develop appropriate models for evaluating and following up younger persons with dementia.

The programme is to contain a survey and evaluation of experience in Nordic countries with various forms of group-based services, day programmes and round-the-clock services specially adapted to younger persons with dementia, compile data on children and adolescents with a parent with dementia and find out which measures improves the quality of life of the family. Furthermore, the programme is to contain a test of assistive devices for younger persons with dementia.

Persons with minority language backgrounds who develop dementia

In 2008 a three-year Nordic development programme is to be initiated for persons with minority-language backgrounds who develop dementia. A Nordic collaboration in this area requires that the other Nordic countries, primarily Denmark and Sweden, participate with know-how and funding. Questions relating to information, diagnosis, treatment and the need for assistance should be key topics.

For both of the Nordic collaborative programmes, the Directorate for Health and Social Affairs will draw up draft programmes and the Nordic countries will be asked to contribute professional expertise and funding.

Individual plans

A large number of persons with dementia need several coordinated services and thus are entitled to an individual plan. In 2008 the Directorate for Health and Social Affairs will step up the effort to implement individual plans for persons with dementia.

Continued initiatives from 2007:

- Development of evaluation tools for diagnosing persons with developmental disabilities who develop dementia
- Refinement of IPLOS for persons with cognitive impairments
- Gathering data on dementia and driving skills
- Developing quality indicators for services offered to persons with dementia

4.2 Boosting capacity and improving skills

4.2.1 Long-term strategy and outcome targets for 2015

One of the big challenges for dementia care is ensuring an adequate number of residences and nursing homes adapted to persons with dementia. To provide financial predictability and encourage the needed expansion of nursing homes and assisted living facilities, the Ministry of Health and Care Services proposes for 2008 a new investment grant (cf. Proposition no.1 to the Storting for 2007-2008). Designing the grant needs to begin with the fact that a very large percentage of residents have

dementia and serious mental disorders. For that reason the housing grant needs to be adapted to persons with physical and cognitive impairments. Small-scale collective-style residential units should be the main principle rather than traditional institutions with long corridors and a large number of residents in each unit. The new grant scheme is to be administered by the Norwegian State Housing Bank and is also intended to guarantee common spaces for activities and day programmes in both nursing homes and assisted living facilities.

Another big challenge for dementia care is to ensure access to adequate, competent and qualified health and social services personnel. This is to be ensured primarily by education and recruitment measures and by strengthening professional expertise in the areas of mental health, geriatrics and dementia disorders. Knowledge about and interest in age-related illnesses are scant, and there is little professional status in working in services for the elderly. It is necessary for all healthcare and social service educational programmes at university, college and upper secondary level adapts their instruction to the challenges posed by a growing number of persons with dementia.

The implementation of new rules that deals with medical assistance for persons incompetent to give their consent has been announced. The purpose is to limit and control the use of coercion. Persons with dementia will be the largest group the rules will apply to, and training health personnel will be crucial for ensuring legal due process for the individual user.

In Report no. 25 (2005) to the Storting the Government presented a new competence and recruitment plan, Competence Lift 2015. The initiative is designed to ensure ample recruitment, high levels of skills and a stable workforce in the care sector. The instruments in the Competence Lift 2015 are to be enhanced with a particular view to the manpower challenges relating to dementia.

In recent years the Government has improved local government finances substantially, making it possible for municipal care services to be strengthened by 10,000 new man-years with professional competence in health and social service subjects by the end of 2009. On the basis of local needs and priorities, these man-years are to be used to enlarge capacity and improve the qualifications of the care services. In Report no. 25 (2005-2006) to the Storting the Government particularly emphasised the opportunities made possible by improved local government finances to strengthen the entire chain of measures for persons with dementia, expand day programmes and give care services a more proactive profile.

Box 4.3 When the Dementia Plan has been implemented in 2015:

- New nursing homes and assisted living facilities built or modernised with grants from the Norwegian State Housing Bank during the plan period, will be adapted to persons with dementia and physical and cognitive impairments
- The capacity of respite measures will be of greater importance and day programmes will have become a key link in the chain of measures for persons with dementia and their families
- Employees without professional training who provide services to persons with dementia should have been offered elementary training in dementia
- Further education in geriatrics and dementia for college-trained personnel and personnel with upper secondary school educations will be expanded in line with the Competence Lift 2015

4.2.2 Four-year action programme

Capacity growth

To ensure expansion and renovation of nursing homes and assisted living facilities, the Ministry of Health and Care Services' budget proposes to create a new investment grant. The purpose of these grants is to bolster local authorities' offerings of rooms on short-term basis in nursing homes and housing for the elderly and others with disabilities who need extensive care services. The aim of the grant is for new nursing homes and assisted living facilities that are built or modernised during the plan period to be adapted to people with dementia or other physical and/or cognitive impairments. New construction and renovation with a view to such adaptation will be given priority in awarding grants by the Norwegian State Housing Bank.

The Government's commitment to 10,000 new man-years in the care sector by the end of 2009 and further staffing increases in the run-up to 2015 is intended to help to ensure more professionally trained personnel for persons with

dementia in nursing homes, assisted living facilities and home care services, particularly in day programmes and respite measures.

Boosting expertise

During the first plan period several initiatives will be implemented to increase knowledge and improve skills relating to dementia, geriatrics and mental health. First, various training programmes will be developed for internal use by municipal health and care services, including training packages in basic knowledge about dementia and training programmes in dementia and mental health. Continuing education and in-service training in geriatrics and dementia in college and trade school programmes are to be further developed as part of the Competence Lift 2015. In Care Plan 2015, initiatives have been implemented to enhance the ethical competence of the care services.

The competence development measures in the Dementia Plan must also be viewed in connection with the care plan's initiatives to strengthen the clinical services in nursing homes and improve medical follow-up from the specialist health service. As part of Competence Lift 2015, during the plan period continuing education will be given to 3,000 employees with college-level training in the areas of ageing, geriatrics, dementia disorders and counselling. The aim is to offer professional school programmes in the areas of elder care and mental health to 6,000 persons.

During the plan period an experience bank will be set up at which the health and care services can exchange ideas and learn from one another and where family caregivers can find useful information. A subject library on dementia will also be developed under the Helsebiblioteket (Health Library) web portal. The subject library will contain up-to-date professional knowledge in the area.

4.2.3 Initiatives 2008

Investment grants for nursing homes and assisted living facilities

The new grant scheme for nursing homes and assisted living facilities is proposed for implementation starting in 2008. Assessing construction needs, determination of grant levels and the design of the grant has been submitted in the budget for 2008.

Training programme for volunteers, employees and family caregivers

To ensure that all players in the care chain have basic competence and knowledge about dementia and dementia disorders, training programmes for volunteers, employees and family caregivers are to be developed.

Bolstering continuing education and in-service training in geriatrics and dementia

The Government will bolster expertise in the areas of geriatrics and dementia for college-trained staff and staff with upper-secondary qualifications who work in the care services. This will be done by further enhancements of continuing education offerings within the framework of Competence Lift 2015.

Initiatives continued from 2007:

- The Government's commitment to local government finances will provide 10,000 new man-years in the care services by the end of 2009, including expansion of day programmes and improving dementia care.
- The Directorate for Health and Social Affairs is in the process of setting up an Internet-based experience bank for local health and social services administrations, staff, users and affected families in the health and care services.
- The Directorate for Health and Social Affairs is in the process of developing a subject library on dementia under the Helsebiblioteket (Health Library) web portal.
- Development of training packages for employees of the care services without professional training.

4.3 Improved coordination and medical follow-up

4.3.1 Long-term strategy and outcome targets for 2015

The Government wishes to strengthen what the specialist health service offers persons with dementia through a national strategy for bolstering the specialist health services for the elderly. Furthermore, general medical services offered to nursing home residents with dementia and recipients of home care services are to be developed further and improved.

The Norwegian model for diagnosis and evaluation assumes a division of tasks between the municipal health service and the specialist health service. When the evaluation is too complicated or when the municipal health service does not have the necessary expertise or resources, the user is to be referred to the specialist health service.

The specialist health service has a key mission related to evaluating, diagnosing, assessing function of and treating persons with dementia. Furthermore, the specialist health service has a statutory obligation to provide guidance to the municipal health service. The Government shall prepare a national strategy for enhancing specialist health services for the elderly. The objective is to meet the challenges posed by the needs of the elderly for specialist health services in an integrated manner. Two of the focus areas will be improving services offered by hospitals and developing collaborative measures with local governments that function well.

Persons with dementia are to feel predictability and a sense of security in the transition between levels in the health services. This requires systematic, ongoing collaboration, which includes sharing of expertise, mobile teams, guidance and the establishment of common procedures. Developing integrated measures and services adapted to individual users requires evaluation and diagnosis at an early stage of the disease, and it must be made clear what services the specialist health service is to provide to this patient group. For that reason the strategies and initiatives in the Dementia Plan need to be viewed in the context of the national strategy for improving the specialist health services for the elderly.

Managing medication is a daunting task for the municipal health and care services. Studies show that nursing home residents with dementia take a large number of various medications and that nearly 3/4 of these patients receive psychopharmaceuticals. It is essential that all links in the care chain that participate in medicating patients have introduced adequate, quality-assured routines to ensure proper treatment and medication management. There is also a need for health personnel to be more knowledgeable about medications for persons with dementia. There are plans to improve skills and quality assurance in this area.

Box 4.4 When the Dementia Plan has been implemented in 2015:

- The individual user will be ensured evaluation and diagnosis in the event dementia is suspected.
- A more systematic and binding collaboration will be developed between the municipal and specialist health services to bring about effective, coherent and predictable courses of treatment for the individual user.
- Health services will be developed in line with the Government's strategy for strengthening the specialist health services for the elderly
- The specialist health service will provide the municipal health and social services with medical and interdisciplinary follow-up and guidance in the area of geriatrics
- Medical services in nursing homes will be substantially improved

4.3.2 Four-year action programme

Evaluation and diagnosis

During the plan period models for evaluating and diagnosing persons with dementia will be developed and tested in a partnership between the specialist and municipal health services. Collaboration routines are to be developed between the local authorities and specialist health service on evaluation and diagnosis, interdisciplinary advising and guidance, sharing of expertise and follow-up of patients with dementia and complex disorders.

Regional action plans to bolster the specialist health services for the elderly

The regional health authorities are to develop regional action plans to improve specialist health services for the elderly and issue annual reports to the Ministry of Health and Care Services. The reports are to provide the basis for status overviews of scope, implementation and effectiveness of the measures in all focus areas in the national strategy for improving specialist health services for the elderly. The Directorate for Health and Social Affairs is to develop indicators and outcome targets in collaboration with the regional health authorities.

Bolstered medical service

A national standard for medical services in nursing homes will enable local governments during the plan period to improve the medical skills and qualifications and quality in nursing homes. The goal is for the number of man-years by doctors in nursing homes to be increased by at least 50 % by the end of 2010. Furthermore, the quality in nursing homes is to be improved by extending Norwegian Quality Improvement of Primary Care Laboratories (NOKLUS) to the municipalities. Participation in NOKLUS will result in more reliable diagnosis and testing, which in turn will reduce the risk of treatment error.

4.3.3 Initiatives 2008

Specialist health services for the elderly

A national strategy and regional action plans to improve the specialist health services for the elderly will be implemented.

Initiatives continued from 2007:

- Development of workable models of collaboration for evaluating and diagnosing dementia
- Training in and implementation of the diagnostic tool among the country's primary care doctors and local authorities
- Development of ICT-based evaluation and diagnostic tools

4.4 Active care

4.4.1 Long-term strategy and outcome targets for 2015

The Government will emphasise day programmes and adapted activities as essential and fundamental elements of integrated care services offered to persons with dementia.

In many locales, day programmes are the missing links in the care chain. Studies show that only 4 % of persons with dementia who receive home care services also receives offers of day programmes. The Government wishes to boost the capacity and quality of day programmes for this group. A stronger focus on culture, activities and well-being measures will require greater interdisciplinary breadth, with a greater emphasis on social education, occupational therapy, physiotherapy and social work.

The local authorities are obliged to help persons who are completely dependent on practical or personal assistance to be able to live independently and have an active and meaningful existence in community with others. In Circular I 5/2002, *Active care*, the Government places special emphasis on the importance of day programmes for persons with dementia disorders.

Providing proper care requires building on the history of the individual to learn what gives him or her life meaning and content. The government will use milieu therapy and cultural and activity programmes to improve the quality of patient lives.

Food preparation and meals are a key part of integrated dementia care. Poor nutrition may be a sign of early dementia, and weight loss may appear in addition to the emergence of dementia, which may make the situation particularly difficult. For most people, meals are a social event associated with known traditions, identity and culture. Participating in food preparation may enhance memories of familiar, daily activities, helping patients cope and live as normal a life as possible.

Box 4.5 When the Dementia Plan has been implemented in 2015:

- All of the country's local authorities should be able to offer day programmes adapted to persons with dementia, either in their own homes, in a nursing home or at a day centre
- Care services will have a broader professional repertory, with a greater emphasis on keeping patients busy, social education, occupational therapy, physiotherapy and social work
- Greater attention will be paid to culture, measures to promote well-being, meals and the activities of daily life

4.4.2 Four-year action programme

During the plan period the focus will be on developing and implementing models for day programmes and respite schemes for persons with dementia. The Government will also consider the question of enshrining day programmes in law in connection with its efforts towards common local government health and social legislation. In Circular I – 5/2007 the Ministry of Health and Care Services clarified local government responsibility

for day programmes pursuant to current legislation. Together with the Government's commitment to 10,000 new man-years the foundation is being laid for expansion at municipal level of various forms of activity and day programmes.

Competence Lift 2015 emphasises measures to recruit a broader spectrum of educational groups and ensure greater interdisciplinary breadth in the care service sector. The diets and nutritional status of persons with dementia are to be surveyed and models developed for milieu therapy measures.

4.4.3 Initiatives 2008

Investment grants for nursing homes and assisted living facilities

The Government's new investment grants through the Norwegian State Housing Bank will facilitate construction of common spaces to accommodate day programmes at nursing homes and assisted living facilities.

Development programme focusing on environment work

In 2008 a three-year development programme on environmental treatment and environmental therapy will be launched. See section 4.1.3.

Initiatives continued from 2007:

- Follow-up of Circular I – 5/2007, *Active care*
- Three-year development programme for day programmes for persons with dementia

4.5 Partnerships with families and local communities

4.5.1 Long-term strategy and outcome targets for 2015

Voluntary, primarily family-based care is almost as large as municipal care services. The dementia care of the future will be designed where formal and informal care meet, between the home and the institution and between the family and the care services.

The families of persons with dementia often have to perform arduous care tasks over several years. Those who assume strenuous care tasks shall be offered extensive respite services and professional support. Well-set-up day programmes and respite services can also give family caregivers a break from their daily routine. Family members are to receive professional guidance regarding dementia disorders, relevant treatments and available measures.

The Government wishes to do more to enable care efforts towards persons with dementia to be combined with occupational activity and improve the framework conditions for volunteer work.

In Norway we have a strong tradition of volunteer work. The volunteer sector is changing, and it will be crucial to develop new forms of volunteering adapted to the lifestyles of new generations. Volunteer clearinghouses, senior centres, schools for family caregivers and project-based schemes are good examples of this. To meet the growing need for information among family members, employees and the public, the Government wishes to step up its information efforts. The public sector, various volunteer organisations and professional groups need to collaborate on this.

Box 4.6 When the Dementia Plan has been implemented in 2015:

- Schools for family caregivers and support groups should be available nationwide
- Systematic information efforts will be carried out for employees, families, the public and volunteers
- Coordination with volunteer efforts in the area of dementia will be strengthened

4.5.2 Four-year action plan

Schools for family caregivers and support groups

During the first four years of the plan period the Government will ensure the spread of schools for family caregivers and support groups through a three-year development programme. Schools for family caregivers and support groups provide knowledge about dementia disorders and offer support and guidance to families. The programme consists of preparing training materials, training course leaders and implementing measures. The materials are to be used by municipal health and social services in giving professional guidance to users and their family members. Dissemination and training will take place in collaboration with volunteer organisations, including the Dementia Association in the Norwegian National Health Association.

Information and education campaigns

An information and educational campaign will be carried out. The campaign is intended to promote more openness regarding dementia disorders, improve access to information and develop information measures that make local governments' duty to provide information easier.

Volunteer work

The Government will bolster volunteer efforts by preparing a training programme for volunteers. The programme needs to be coordinated with training materials for family caregivers and the planned information campaign.

4.5.3 Initiatives 2008

Training programme for volunteers

See section 4.2.3.

Initiatives continued from 2007:

- Three-year evaluation programme for schools for family caregivers and support groups
- Information and education campaigns
- Grants for the Dementia Association in the Norwegian National Health Association

4.6 Documentation

By the end of 2007 a "Follow Along" system is to be established in the Dementia Plan's focus areas. The system is to present results from the plan's first year of operation up until 2015. The system is to be based on data and registers, including KOSTRA (the municipalities' reports to the central government), IPLOS (Individual-Based Nursing and Care Statistics) and the Norwegian Patient Register, and develop relevant indicators relating to the plan's measures and outcome targets. A national survey of services offered to persons with dementia by local authorities will be conducted every four years. To obtain new documentation and data at the national level, sample surveys are necessary, for both municipal services and the specialist health service.

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