

Linda GjØra

Aim wide and hit straight

A summary of the measures taken
under Dementia Plan 2015

The background of the lower half of the cover is a solid blue color. Overlaid on this is a faint, white line-art illustration of a hallway or room. In the center of the illustration, two human silhouettes are shown walking away from the viewer. The silhouettes are dark blue, matching the background color. The line-art shows architectural details like walls, windows, and a door.

SHORT VERSION

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Preface

The Norwegian Dementia Plan 2015 was one of the subplans within Care Plan 2015. Dementia Plan 2015 have had five main strategies for meeting the 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 and Partnerships with families and local communities.

This report is a short version of the Norwegian summary that describes the measures taken within these strategies under Dementia Plan 2015.

Quality development, research and planning

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.*

There has been a marked increase in several of the services available for persons with dementia and their families during the plan period. Three national surveys of the municipalities' planned services for persons with dementia were carried out during the plan period. Supplementary information was obtained concerning the priority areas in Dementia Plan 2015 and there was particular focus on the areas of *diagnosis and assessment of dementia, schools and support groups for families of persons with dementia and day care services for persons with dementia*. The surveys have provided an overview of both how far efforts to facilitate services have progressed in the municipalities, and where there is a need for further efforts.

Altogether, 80 percent of the municipalities in Norway have described services for persons with dementia in their plans. A local sub-plan for the health care sector can be a useful means of putting the future health care challenges on the agenda of municipal planning. In order that the plan can help set guidelines for practical policy, it must be rooted with local politicians who allocate resources

and provide guidance for the total range of health services. The municipalities that have described services for persons with dementia in their plans offer some additional services to this group, than those municipalities that do not have these services featured in their plans. This is most applicable to the small municipalities.

Research into dementia has increased considerably during the plan period. There is ongoing research activity related to several of the focus areas from the Dementia Plan, both through the Dementia Plan and through several other initiatives. Throughout the plan period, NOK 5 million of the Dementia Plan funds has been allocated annually for research. Norwegian Health Association has also launched a major dementia research programme, with funds from a Norwegian TV fundraising event. The research into dementia ranges from epidemiological research aimed at finding the causes of the diseases, to what may have a preventive effect on the development of dementia, and the treatment and care research in services for persons with dementia and their families. Many of the research projects in this area are carried out in cooperation with several of the research environments nationally and several in international cooperation.

The dementia diseases have serious consequences for the person with dementia and their families. The services for persons with dementia include both municipal and specialist health care services and involve large financial and human resources, with significant socio-economic consequences. The services provided are often fundamentally important to maintain life, health and quality of life. Persons with dementia belong to a vulnerable group that can have difficulty to safeguard their own interests. Services for persons with dementia are an area with a high risk of failure and the consequences of deficiencies in the provision of services can be serious. On this basis, *National guidelines on the assessment of dementia and follow-up of persons with dementia and their families* are being developed. These guidelines will be completed in 2016-2017. The work is organized into two sub-projects that respectively deal with assessment, diagnosis and medical treatment, and care for persons with dementia and their families.

Capacity growth and raising skills and knowledge

When the Dementia Plan has been implemented in 2015:

- *New nursing homes and assisted living facilities built or modernized with grants from the Norwegian State Housing Bank during the plan period, will be adapted to persons with dementia and physical and cognitive impairments.*
- *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.*

It is a major challenge to ensure access to sufficient, competent and qualified personnel in the health care services for persons with dementia. *The ABC of care for people with dementia* is a training model developed to convey updated knowledge of dementia diseases and about good practice for personnel working in the community health service. During the plan period, a total of 95 percent of all the municipalities in Norway were involved in ABC training and a total of 22,000 employees were registered for training. Staff at almost three out of four day care services for persons with dementia and staff from about 80 percent of the assisted living facilities for persons with dementia have completed the ABC training. About 11 percent of those participating in the ABC training have no prior health care education. A separate training programme provides ABC participants who have no health care education, the opportunity to obtain authorization as health workers. The training programme had participants from across the country and at the end of 2015, over 200 participants had passed the written exam in the Health Worker subject and over 100 participants had taken

a certificate of apprenticeship. The ABC initiative has contributed to increasing knowledge and professional awareness about providing healthcare services tailored to the individual patient's needs for treatment and care. In order to utilize the potential of the increased levels of competency, organisation adaptations are required and major demands are made on the management.

An increasing proportion of elderly people in Norway have a non-Norwegian ethnic background and, consequently there will also be an increasing number of these people who develop dementia in Norway. A survey conducted during the plan period among relatives of persons with various ethnic minority backgrounds, showed that there is a major need for information about both dementia and about the services available. Information about dementia should be provided in different languages and through different channels, both written and oral. The threshold for requesting help can be high and may prevent early diagnosis and treatment. Many families contributed major care efforts before they sought public healthcare for the person with dementia. There is a need for knowledge and competence among health care employees regarding different attitudes to dementia, the role of the family and cooperation between the family and the public services.

Ensuring adequate and equal services for Sami recipients of healthcare depends on where they are in the country and who they are. This is not always clear, and thus there is no simple recipe for how this can be achieved. It is essential that healthcare professionals understand various Sami cultures in order to provide good-quality services. A pamphlet on healthcare services for elderly Sami people has been developed in order to promote awareness and improve the training of personnel who provide this type of service.

In a study conducted under the Dementia Plan 2015, the dementia disease was estimated to cost NOK 2.9 million per person, of which residential care in nursing homes account for 60 percent. According to Alzheimer Europe, there are approximately 78,000 persons with dementia in Norway. If about 40 percent of those with dementia live in nursing homes, this amounts to more than 31,000 persons. Of all the residents in nursing homes, more than 84 percent have a form of dementia and there is a high prevalence of behavioural and psychological symptoms in these patients. The strong growth that will occur in the number of elderly citizens over the coming years means that the municipalities are facing major challenges, related to the development of adequate and appropriate quality in residential care. Over 92 percent of all municipalities have adapted housing for

persons with dementia in residential care. From the perspective of the person with dementia, small residential groups and person-focused care that facilitates autonomy are the most important factors when it comes to good housing. Overall, there has been an increase in places in assisted living facilities of 17.8 percent. The increase was modest in the latter part of the plan period.

Improving collaboration among professions and medical follow-up

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.*

The dementia teams/memory teams are defined as a multidisciplinary group of health professionals in community health services. They assist GPs conducting assessment of persons with suspected dementia, and together with the GP they are responsible for the follow-up of persons with dementia and their caregivers. Throughout the plan period, a great deal of attention was devoted to the organization of dementia assessment in the municipalities. Nearly 80 percent of the municipalities in Norway have an organised service for assessment of dementia, and this is a threefold increase since 2007. This has meant that more people have been assessed for suspected dementia. Norwegian municipalities vary greatly in size and organization, and it is difficult to recommend a single model for the provision of dementia assessment. Experience shows, however, that the establishment of a dementia team is an appropriate way to organize in order to ensure the

assessment and follow-up of persons with dementia. It is possible to establish dementia teams in small, medium sized and large municipalities. An assessment tool has been developed for use in dementia assessment in the municipal healthcare service. The tool is recommended by the Norwegian Directorate of Health and is used by 97 percent of municipalities with organised services for dementia assessment. There are still a considerable number of municipalities that do not have an organised service. Many established teams are in need of more resources and competence. The dementia teams' follow-up after diagnosis varies greatly and relatively little time is spent per patient per year for follow-up.

The dementia assessment of persons with immigrant background is described as a challenge because of factors such as language, culture and level of education. Professional interpreters must be used for the dementia assessment of persons who have a native language other than Norwegian. There are currently few assessment tools for this group, which are adapted for Norwegian conditions.

One of the focus areas during the plan period has been young onset dementia. The term *young onset dementia* is used about persons who have dementia onset before the age of 65. Having dementia in mid-life involves different challenges than dementia in old age does. Many of these people will still be employed and have family obligations for children and youth. There is no consensus about how the assessment of younger patients should be organized in Norway. A relatively small number of young persons are diagnosed with dementia each year. A project conducted during the plan period found that a reduction in the number of assessment sites would help to provide the specialists with sufficient experience with this type of assessment. The period after the diagnosis is made is an extremely vulnerable phase for many families. A member of the family has received a severe diagnosis, and will in many cases gradually become more and more dependent on others. Relatives often have the experience of being alone with this responsibility. The healthcare system should increasingly take responsibility for the administration, coordination and implementation of assessments and services. There is a major need for support, guidance and information for spouses/partners, children and for the person with dementia. This may involve obtaining factual information about the disease and practical advice to cope with everyday life. Since 2007, the number of day care services adapted for younger persons with dementia has doubled. These services can be found in the municipalities with the largest populations. Experience from larger municipalities show that adapted services can be established as day care services and as nursing homes for younger persons with dementia. Several municipalities with fewer inhabitants

and short distances to neighbouring municipalities have considered inter-municipal solutions in order to provide services. Some of the smaller municipalities with long distances to their neighbouring municipalities have experience on developing individual services based on the resources that they already have available. Technical aids can support persons with young onset dementia and their families and many aids can be highly effective for a period. In order for the aid to be perceived as a real support, it must meet a need that is regarded as important for the person using it.

A prioritised focus during the plan period regarding medication management and the correct use of medicines has led to improved medicine lists and diagnostics lists, as well as better documentation and follow-up of medicine treatment. Feedback received from the field of practice indicates that structured medicine review in teams promotes interdisciplinary collaboration. This has led to increased knowledge and awareness about the proper use of medicines for the elderly, and increased knowledge about the patients diseases. This has provided more objective measurements, led to closer contact with the pharmacists and closer dialogue with patients and their families about medicine treatment.

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Active care

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.*
- *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.*

Personalised day care services are an important measure to improve the quality of life of persons with dementia living at home, and their family. An individually tailored and well-functioning day care service can help the person to stay at home longer. Over 70 percent of the municipalities in Norway now offer day care services specially adapted for persons with dementia. The number of persons receiving these services has increased threefold since 2007. A day care service may be a good and necessary relief for the family, the effect of this assistance is greatest when the day care service is provided on three or more days per week. The capacity of the day care services that is available at present means that, at best, only one in six persons with dementia living at home receive day care service. There is still a long way to go before all municipalities can provide personalized day care services for persons with dementia.

Development of person-centred dementia care requires long-term efforts. A set of core values must be formulated that employees and leaders in the organisation can embrace. The management must facilitate that person-centred treatment can be prioritised in the daily work on an equal footing with other treatment. There is no comprehensive overview of the extent to which or the manner in which person-centred treatment is used in healthcare. A goal within person-centred care for persons with dementia is to ensure that the individual person gets to use their resources to the maximum extent, and to help them maintain their independence for as long as possible. Creating enjoyment, well-being and good quality of life, and thus reducing anxiety and agitation, are important goals. The goal must constantly be adapted to the patients capabilities. In the plan period an evaluation was conducted of four different person-centred care methods. This entailed the assessment of frameworks for reflection and development of person-centred care in practice (The VIPS model), Dementia Care Mapping (DCM), Marte Meo and a structured person-centred treatment programme at individual, group and management level. In addition, experiences were gained with combining these four methods. It was concluded that the methods complemented each other well and they helped personnel with different cultural backgrounds to adopt a common approach. The spectrum of person-centred care measures that are used today is broad and ranges from general welfare measures to individualised treatment based on mapping and assessments.

Partnerships with families and local communities

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.*

Dementia affects not only the person who gets the disease, but also their family, friends and others in their network. The emotional strain of following a person with dementia through the course of the disease is often experienced as difficult for family carers. The burden of care may have an effect on relatives' own health and they are at increased risk of being affected by disease. There has been a great deal of emphasis on services for families, including through the development of support groups and schools for family caregivers. During the plan period, over two-thirds of the municipalities have implemented family school programmes and almost one third of the municipalities now offer support groups. The percentage of municipalities offering family school programmes has increased from 4 to 67 percent since 2007. The initiatives for families have created new learning services for several groups that have not previously had adapted services for families.

Overall, 270 different non-governmental organisations are partners in the family schools and support groups that have been arranged. A significant proportion of the volunteers have been cooperative partners in the provision of services for

families. Over a third of the day care services for persons with dementia have volunteers affiliated.

Meeting place for learning is a course where persons with young onset dementia participate with a family carer. Meeting others who are in a similar situation is of great importance in order to experience learning and fellowship. *Meeting place for learning* has helped both the persons with dementia and their families to experience greater openness and insight into their own situation, as well as greater knowledge and understanding of what dementia means in everyday life, and it has contributed to a stronger sense of belonging and reassurance.

Approximately one-third of those who are affected by dementia before the age of 65 have children under 18 when they are diagnosed. Children and youth need correct and relevant information about their parent's situation during the course of the disease. Many of them can also benefit from meeting other persons of the same age in the same situation. *Time to be young?* weekend workshops for young people who have a parent with dementia, are intended to provide these young people with support to help them cope with their situation and help to cope with the challenges of everyday life. There have been positive experiences with weekend workshops for young people. The *Who will see me?* project developed a programme for children under the age of 18 who have a parent with dementia. Two separate websites are currently under construction and summer camps will be organised for young children, where they will participate in the company of the healthy parent.

During the plan period, two national information campaigns about dementia were conducted in order to contribute to creating more knowledge and transparency about dementia in the community. The last was completed in 2013 and over two-thirds of the municipalities implemented their own information initiatives in connection with this information campaign. Following the campaign, the proportion of people who wanted to talk openly about dementia increased from 57 percent to 77 percent.