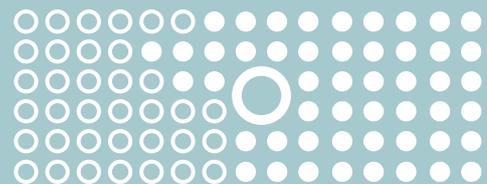
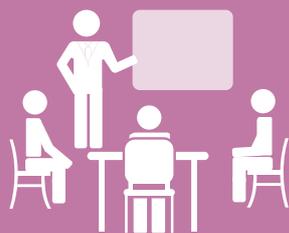
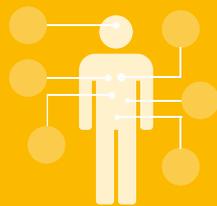
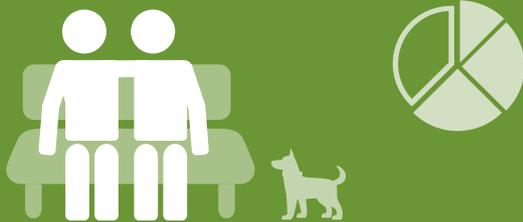
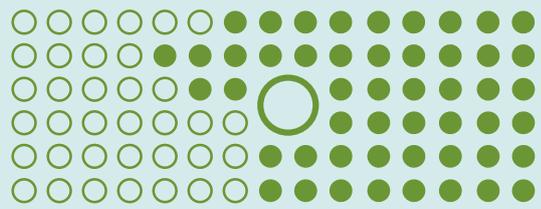


DEMENTIA PLAN
2020

A More
Dementia-friendly
Society



Norwegian Ministry
of Health and Care Services



Feeling like everyone else

” *“I don't have dementia when I'm in the swimming pool. There I'm just like everyone else!”*

This was said by one of the participants at a dialogue meeting on the Dementia Plan 2020. The plan is the result of a unique cooperation: in addition to professionals, organisations and the Ministry of Health and Care Services, people with dementia themselves, together with their families, have also been involved in the development of the plan. We held seven dialogue meetings in different parts of the country, and I myself took part in one of them. There I heard courageous people talking about their shock and grief on receiving their diagnosis. But they also shared other things with us. They told us how they coped with living with dementia. There were laughter and tears. Not many government plans have been developed under these circumstances.

The participants at the dialogue meetings were not only involved in drafting a plan that was to affect their own lives. They were drafting a plan that affects us all. Many of us will come in contact with dementia in the years to come – either because we develop it ourselves or because someone we care for has dementia.

In the work on this plan I met people who had been diagnosed in mid-life. It is not only older people with their working lives and child-raising behind them who develop dementia. It can also affect people with a busy working life and teenage children. Thus in future dementia care will have to involve much more than adapting nursing homes and other residential facilities with 24-hour care to the needs of people with dementia. It will have to involve attitudes and activities, the health services and working life. It will have to involve the whole of society.

Many of the contributors to the work on the plan emphasised participation: the need to participate in decisions concerning one's own life; the need to participate in ordinary daily life.

The new Dementia Plan therefore focuses primarily on developing a society where people with dementia can also participate. Each one of us has the right to be a whole person, even when we are ill.

The swimmer who was no different from all the others in the pool pointed out what is most important in this context.

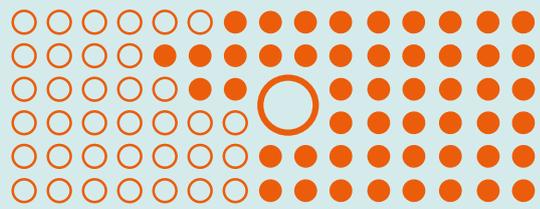
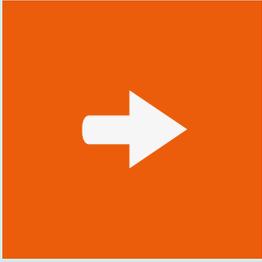
We must all be allowed to feel like everyone else.

We must all be able to feel part of the community. This, after all, is where we belong.



Bent Høie

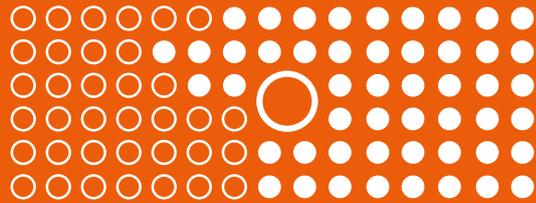
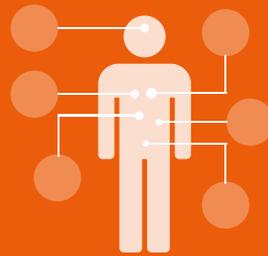
Minister of Health and Care Services



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1



Introduction

The Government's goal is to create a health and care service centred on and influenced by users and patients. This means that services development must be based on users' needs as defined by the users themselves. Without the experience-based knowledge possessed by people with dementia and cognitive impairment, it will not be possible to arrive at good solutions. The Dementia Plan 2020 has therefore been developed in close cooperation with people who themselves have dementia, together with their families. The plan is also based on the knowledge and experience gained from the Dementia Plan 2015 in addition to new knowledge.

The draft of the plan was widely circulated. Seldom has the ministry received so many responses in a consultation process and encountered such a high level of engagement from users and their families, professionals, municipalities and organisations. On the basis of these responses, we have clarified a number of points and provided more detailed information in certain areas.

Challenges

During the work on the plan, people with dementia and their families made it clear that there are a number of issues that need to be addressed. Many of them described the period after they had received the diagnosis as "a black hole". The need for timely diagnosis and close professional follow-up afterwards is therefore one of the main elements of the plan. A large number of people emphasised the importance of better tailored health and care services, day activity services and support and respite for family members. People with dementia wish to be involved in making decisions that affect them, and steps must be taken to facilitate greater user influence and involvement.

Although perhaps the most important result of the Dementia Plan 2015 was the extensive attention it received in the media, through information campaigns and in one of the annual telethons run by the Norwegian Broadcasting Company, as well as feedback from users and their families, indicates that there is still a considerable need for new knowledge and competence both in the health and care services and in society at large. Thus in the present Dementia Plan the focus has been broadened to include society as a whole in addition to the health and care services.

Purpose and scope

The goal of the plan is to build a more dementia-friendly society, where people with dementia are cared for and integrated in the community. This will require greater openness and knowledge about dementia in society in general and in the health and care services in particular.

One of the greatest care challenges we face as a result of longer life expectancy and changes in the age composition of the population is that the number of people with dementia is likely to double in the next 30–40 years. Most of them will require health and care services in their own homes or in nursing homes and assisted living facilities

with 24-hour care. Their families will need support and respite care. At present the municipal health and care services are not sufficiently adapted to the needs of people with dementia and their families. We have to make changes in the organisation of the services, their competence and expertise, and the design of the physical environment of people with dementia. The measures in the Dementia Plan 2020 are therefore mainly directed at the municipal health and care services.

Strategies and measures

On the basis of The Dementia Plan 2020 has six strategies, based on the needs of users and their families, new knowledge, and challenges that were not resolved by the Dementia Plan 2015:

- Self-determination, involvement and participation.
- Prevention.
- Timely diagnosis and close post-diagnostic follow-up.
- Activity, coping and respite care.
- A patient care pathway with systematic follow-up and tailored services.
- Research, knowledge and competence.
- Self-determination, involvement and participation.

The Dementia Plan 2020 is intended to promote the development of good, flexible and tailored municipal health and care services with a focus on prevention, timely diagnosis and post-diagnostic follow-up. Dementia is a serious non-communicable chronic disease that has many similarities with the four major non-communicable chronic diseases (NCDs) defined by the World Health Organisation (WHO): diabetes, cardiovascular disease, cancer and chronic respiratory disease. Like people with the other NCDs, people with dementia often suffer from multiple conditions accompanied by severe functional and cognitive impairment, which can make it difficult for them to carry out everyday tasks. Preventive measures are largely the same for all NCDs. In addition, a good patient care pathway, with reliable, coordinated follow-up, is essential for all these patients. The Government's NCD strategy of 2013 is therefore a good point of departure for developing services appropriate to people with dementia as well as those with an NCD. In contrast to the NCDs, however, dementia is progressive and ultimately fatal.

The Dementia Plan 2020 focuses on measures that can be taken before the person requires round-the-clock care and that can support and provide respite for the family. During the last years of their lives, people with dementia have an increasing need for an adapted environment, meaningful daily routines and activities, diet, care, pain relief and palliative treatment. People with dementia must be involved in decisions that affect them, and steps will be taken to increase user influence and involvement.

In order to achieve these aims, the Dementia Plan 2020 sets out a number of specific measures for the period 2016–20. These are presented in detail in connection with the strategies described in Chapter 5.

The Dementia Plan 2020 has more specific targets related to the general measures in the Government's plan for the field of care services (the Care Plan 2020) and in the NCD strategy. The measures to improve services for people with dementia should therefore be viewed in the context of the Competency Plan 2020, the Government's action plan for quality assurance in the health and care services, the investment grant for places in residential facilities for people in need of 24-hour health and care services, such as nursing homes and assisted living facilities with 24 hour care, the welfare

technology programme, the informal care programme, and the measures to promote research, innovation and development. They should also be viewed in relation to the implementation of the white paper *The Primary Health and Care Services of Tomorrow – Localised and Integrated* (Meld. St. 26 (2014–2015)).

Dementia is an increasingly serious public health issue, and efforts to improve prevention are part of the implementation of the white paper on public health (*Folkehelsemeldingen – Mestring og muligheter*, Meld. St. 19 (2014-2015)). The Government considers it important to develop a society that places greater emphasis on promoting physical and mental health through a focus on coping, a sense of belonging and a meaningful life. Activating older people is a new public health priority, and the Government will present a strategy for an improved, up-to-date policy for older people at the beginning of 2016. The strategy is intended to promote efforts to enable the older people of today and tomorrow to live more active lives by remaining in employment for longer and participating more actively in society.

The strategies and measures in the Dementia Plan 2020 are intended to help put dementia and its challenges on the agenda of ordinary municipal planning. The aim is to ensure long-term, integrated planning for the local community and the physical environment, and high-quality services designed to meet the needs of the growing number of people with dementia and their families.

What is dementia?

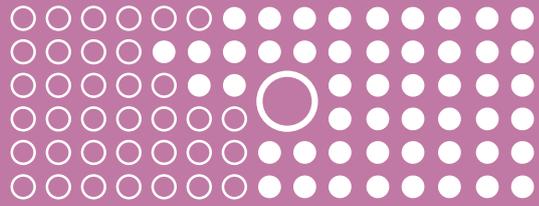
Dementia is associated with a number of brain diseases and characterised by cognitive impairment, changes in personality and emotions, and difficulty in performing everyday tasks. The main symptom of cognitive impairment is loss of memory. Dementia is a result of one or more progressive diseases and always has a profound effect on the lives of both the affected person and their family. People with this diagnosis undergo a gradual functional decline and finally become completely dependent on others.

Other symptoms of dementia are speech loss, difficulties with spatial orientation and communication and a deficient sense of direction. People with dementia have difficulty in using the skills they have learned and coping with activities of daily life. Some show a lack of emotional sensitivity, motor unrest or a tendency to become aggressive. Other symptoms are anxiety, depression, hallucinations and apathy. In the early stages many people become depressed, anxious and withdrawn. In later stages there may be considerable changes in personality, habits and behaviour.

Around 60% of all people with dementia have Alzheimer's disease. Other common types of dementia are vascular dementia, dementia with Lewy bodies, frontotemporal dementia and dementia in idiopathic Parkinson's disease.

Dementia may also result from a number of less common brain diseases.

2



Living with dementia

We retain our individuality in spite of dementia

The symptoms of dementia vary from person to person. But dementia will always influence the person's self-image, the way others behave towards them, and in the long run how they cope with life.

Thus a high-quality health and care service must be designed for and based on the needs of the particular individual.

Many of the families and close friends of people who develop dementia report that the situation is a great strain on them. The symptoms can be difficult to deal with, and the person with dementia may undergo considerable changes, such as speech loss or changes in personality.

People with dementia have seldom been listened to and asked for their views, and few studies have been made of what it is really like to live with dementia. A study based on in-depth interviews of people with dementia found that many of them have insight into their situation, and struggle to make sense of their lives and retain some dignity and self-respect (Wogn-Henriksen 2012). In the dialogue meetings that were held in connection with the present plan, people with dementia and their families drew our attention to precisely this aspect. They described what it is like living with dementia, what it does to them as a person, the kinds of problems and obstacles they encounter, and the kind of help and support they need. Many of the main points raised at the meetings represent universal human needs and values that are slowly but surely threatened as the condition progresses and functional impairment affects more and more areas of the person's life.

Loss of the sense of belonging

A large number of people with dementia report that they have a growing feeling of exclusion. They feel that their condition makes them gradually lose their sense of being part of the group of people around them and of society in general. Developing dementia makes them feel that they are no longer normal.

” *“I really had to work hard to get used to the fact that everyone now knew I had dementia. I felt singled out and inferior. It was a bit embarrassing.”*

Participant at a dialogue meeting

Few people in society at large know much about dementia, and many people with this condition encounter prejudice in social situations, which adds to the impact of dementia on their lives.

Loss of the sense of security

People with dementia often say that they have lost their basic sense of security. When they become aware that something is wrong, many of them go through a long period of uncertainty, soul-searching and frustration before they consult a doctor. But the diagnosis in itself does not always answer their questions: how will it progress, and what sort of life am I going to have? Many people with dementia say that during the period immediately after the diagnosis nothing much happens on the surface but that internally they experience emotional chaos and profound insecurity. Family members may also be frightened by the diagnosis and are uncertain how to behave. Depression is a normal reaction at this point. The future is unpredictable. Many people with dementia and their families have found it very helpful to receive information and support in the period immediately after diagnosis.

” *“I cried when I received the diagnosis. I’m grieving for all the things I haven’t done.”*

Participant at a dialogue meeting

Feeling unable to cope

People living with dementia often experience a feeling of defeat and loss. Not being able to manage, finding it difficult to perform ordinary tasks and being dependent on help from others all diminish their quality of life. Many people avoid certain activities and social situations, and this reinforces their feeling of defeat. But others also say how positive it is to feel that they can still be of use and have things to do that are interesting and enjoyable.

” *“I like being physically active – going for walks, seeing the children and grandchildren, I like lighting candles, drinking tea, reading poetry – I can do all this – and then life becomes enjoyable.”*

Participant at a dialogue meeting

Both people with dementia and their families are warmly in favour of finding suitable activities that are meaningful, encourage coping and give structure to the day. Family members also feel that a day activity service gives them a breathing space in which they can carry on with their own lives. And they stress the importance of being able to work outside the home and continuing their social activities. Those closest to the person with dementia need respite in order to be able to support the strain of daily care.

” *“The day activity service is just as important for me, without it I would go up the wall.”*

Participant at a dialogue meeting

Participating in one's own life

Both those with dementia and their social network find that as the condition develops it gradually undermines the person's ability to make life decisions. For many people this is the hardest feature to accept. Even in the early stages people with dementia feel that other people talk over their heads or make decisions without consulting them seriously. It is important for the individual's dignity and self-respect to feel that they have at least some control over their lives, that things they consider important are taken into account and that life choices are in line with their own values and preferences.

” *“Don't talk over our heads. Sometimes the doctor talks to her and not to me, I feel they're not really taking any notice of me. In situations like this I think I'm justified in pointing this out. After all, it's me they're talking about.”*

Participant at a dialogue meeting

Life for the family

When life takes an unexpected turn with serious consequences, close relationships often become more important than before. Many people with dementia have to live with the extra worry of feeling that they are a burden on those closest to them. Most of them want their families to be included and supported at all stages of the illness, and to know that their needs are met.

” *“Before I got the diagnosis I withdrew into myself. Had to stop working. The worst thing was telling my children. They were afraid it was hereditary. They had a grief reaction. We got no help but we didn't ask for any either.”*

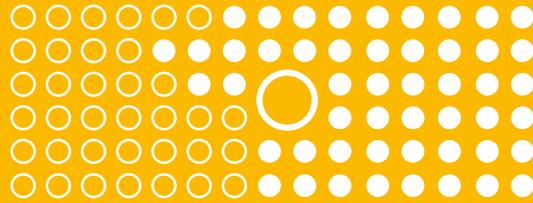
Participant at a dialogue meeting

As dementia progresses it puts an increasing strain on the family – physical, mental, social and financial. However, many family members say that there are also positive sides to living alongside a person with dementia. It can draw people closer, the time together is precious and meaningful, and many want to give the person with dementia loving support. In spite of this we know that most family members find that the uncertainty and impact of caring for the person with dementia wears them down, with the result that they too develop health problems. Many complain that too little is done to help them overcome the problems.

” *“I became so angry when everyone said I had a duty to look after myself: tell me how I can look after myself when I have to look after a person with dementia 24 hours a day in addition to having a teenager in the house!”*

Participant at a dialogue meeting

3



Perspectives for the Dementia Plan 2020

3.1 A more dementia-friendly society

A more dementia-friendly society benefits everyone. As is the case for other people with disabilities, barriers in the physical and social surroundings of a person with dementia have to be overcome if the person is to be able to participate and have equal status in society. This means that the focus should be just as much on the physical and social surroundings as it is on the qualities and resources of the individual.

This requires sound, integrated planning and contact across sectors, areas of responsibility and professional levels. All sectors of society have a responsibility to ensure the equality of people with disabilities. This involves applying universal design principles and adaptation to individual needs at the workplace and in homes, public buildings, transport, outside spaces, services, product design and electronic communications.

It is impossible for any one politician, caseworker, organisation or specialist to know everything about the obstacles encountered by people with disabilities and how to overcome them. To achieve the best solutions we also have to listen to users' and patients' experiences, including those of people with dementia and their families.

One society for all

Like all of us, people with dementia need and have the right to participate in different social settings. Many people live with dementia for many years, and some develop it while they are still working and caring for children. Dementia therefore concerns all sectors of society, which means that workplaces also need to know about it and deal with the impacts. The goal of a society with opportunities for universal participation imposes requirements on design of the physical environment and requires changes in our attitudes, ways of thinking and political priorities. The Dementia Plan is based on the view that we must seek solutions that reduce and compensate for the effects of dementia as far as possible.

Universal solutions divert attention from individual functional difficulties. This means that any feelings of helplessness or stigmatisation experienced by the individual with dementia in situations where they are unable to cope without special assistance or arrangements are no longer a focus of attention. At present the term can be defined as a discrepancy between the individual's abilities and the functional demands made on them by their physical and social environment (NOU 2005: 8), and this also applies to dementia and cognitive impairment. The goal is a dementia-friendly society and not a special society for people with dementia.

Universal design and adaptation of the physical environment can help to eliminate or mitigate conditions that are challenging for people with dementia.

Housing and the physical environment

In addition to the general requirements for universal design of homes and the physical environment, it has been documented that small, purpose-built housing units with few residents and a homely atmosphere have a beneficial effect on people with dementia. An easily navigable layout with clearly differentiated rooms helps to strengthen spatial orientation and a sense of direction. Short corridors limit the number of doors to choose from, and studies have found that the use of contrasts and differentiated colours lowers anxiety levels and reduces the need for prescription drugs (Dalsbø et al. 2014). Incorporating such features in the adaptation of the person's home and the design of assisted living facilities and nursing homes can help avoid factors in the physical environment that reinforce the impact of dementia and reduce coping skills. Hospitals should also strive for a physical design that makes it as easy as possible for patients to find their way around.

Working life

Adaptation of the workplace may be an option to allow those who are diagnosed at an early stage or with younger onset dementia to continue working. Although some functions will decline over time, many people will retain working capacity and want to stay in their jobs for as long as possible. Employees with dementia should be treated in the same way as other employees who suffer from an illness or disability. This calls for openness and close cooperation between management, the health and care service and the individual employee. Continuing to work for as long as possible, being part of a working community and feeling useful can make all the difference to how the individual copes with the initial period after the diagnosis.

The workplace may also be the first place where people notice that something is wrong. In such cases it is important not to focus exclusively on the inability to cope with tasks but to involve the health and care services, so that the possibility of an underlying disease can be assessed.

Transport

At a certain stage of cognitive impairment, driving becomes impossible and the driving licence has to be surrendered. For many people this represents a serious loss of freedom of movement and reduces the possibility of participation in activities outside the home. It often results in dependency on others for going shopping, visiting family and friends, taking part in activities and visiting the offices of public services. This means that the various forms of collective transport, such as busses, trains, aircraft and taxis, need to provide appropriate information and adequate services and be physically adapted to the growing number of people with dementia. Good transport arrangements must be included in the integrated services available to people with dementia.

ICT and welfare technology

ICT and welfare technology can give people with dementia and cognitive impairment new opportunities to obtain information about their condition and functional impairment, and the technological aids and services available to them. It also helps them keep in contact with organisations, establish web-based user groups and communi-

cate with the health and care services. The use of welfare technology can increase the person's sense of security and ability to cope with daily life, and provide respite for family members. Positioning technology such as GPS can also provide more security and freedom of movement. On the other hand, the fact that banks and public services are cutting down raises new obstacles, since it means that users have to operate advanced web-based solutions with codes and passwords in order to pay bills, order goods and services and make contact with private and public undertakings.

Box 3.1 A dementia-friendly society – Norwegian Health Association

The goal of the campaign for a more dementia-friendly society run by the Norwegian Health Association is to promote understanding, respect and support for people with dementia from the services that provide the help they need. This will make it possible for them to carry out daily tasks and activities, such as:

Shopping, using public transport and communicating with the public authorities;

Joining associations and clubs, being physically active and using cultural services, such as libraries, cinemas and concerts.

The association believes it is important that personnel in private- and public-sector services such as librarians, shop workers, waitresses and waiters, bus drivers and employees at municipal service centres receive training in how to make their encounters with people with dementia as positive as possible.

www.nasjonalforeningen.no

3.2 Openness, understanding and respect

“It’s important to be open, we received a lot of positive response when we decided to be open.”

Participant at a dialogue meeting

Many people with dementia shut themselves away and therefore suffer from loneliness. Social barriers can result in prejudice and needless isolation, and add to the impact of dementia. The increasing number of people with dementia makes it necessary to demystify the dementia diseases, promote awareness, enhance knowledge and overcome social barriers.

Providing conditions that enable people with dementia to live a good life involves more than developing the health and care services. It involves helping to ensure that the person is met with respect and understanding, which makes it easier to talk openly about the symptoms. It involves adapting the social and physical environment

so that the person is able to maintain an active, independent life for as long as possible. Dementia concerns society as a whole, and all members of society need to know about it and take it into account.

3.3 Being seen for what I am

"We have a lot of resources, apart from our memory."

Participant at a dialogue meeting

Dementia makes people vulnerable because it weakens the person's ability to express their needs and further their interests. People with dementia have the same fundamental rights as everyone else, and society must have effective systems for safeguarding these rights.

Although many people with dementia have difficulty in standing up for their rights in the later stages of the disease, the fact that in the early stages they are well able to participate and express their wishes and views is often overlooked. In order for the individual with dementia to be able to make use of their resources for as long as possible, and feel secure and in control, it is important to take their wishes, interests, habits, likes and dislikes into account. The services offered to that particular person must be designed with these factors in mind. A person-centred approach involves knowing the person's history, personality, cultural background, habits and state of health in addition to the facts about the cognitive impairment that accompanies dementia. In discovering these personal details, it is important to respect the fact that it is the individual, not someone else, who owns their personal history. During the consultation process for the Dementia Plan, a number of people pointed out the importance of also considering the person's spiritual needs. A focus on the person means taking account of their world view and enabling them to make use of their resources. People with dementia should experience a sense of belonging, feel that they are a valued member of the community, receive help to maintain their identity and dignity and support when they need it, and feel that their days are spent in meaningful activities and tasks that are in line with their life values.

3.4 Two tracks

The ageing of the population means that more people will develop dementia because the incidence of the disease increases with age.

There are no studies that provide precise figures for the prevalence of dementia in Norway. The organisation Alzheimer Europe has estimated on the basis of studies

from other European countries that over 77 000 people were suffering from dementia in Norway in 2012. Many of these studies are based on the number of people with a diagnosis of dementia. However, in many countries, including Norway, a considerable number of people with dementia diseases have not been diagnosed, which means that the estimate is probably too low.

In Norway there are reliable estimates for the prevalence of dementia in nursing homes and among home care service recipients living at home. Over 80 % of those living in nursing homes and over 40 % of people over 70 who receive home care services have some form of dementia (Wergeland et al. 2014). On the basis of these figures, over 70 000 people with dementia are recipients of home care services and residents of nursing homes today (Selbæk 2014). However, there are no estimates for the number of people with dementia in the rest of the population, although the figures for home care service recipients with dementia indicate that Alzheimer Europe's estimate is too low rather than too high.

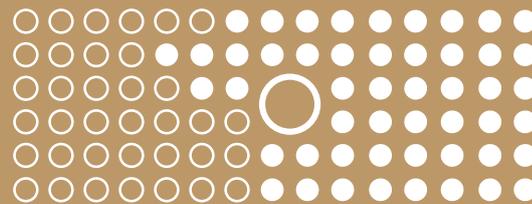
Although the incidence of dementia increases with age, it is estimated that over 4000 people under 65 are suffering from dementia in Norway (Alzheimer Europe Yearbook 2014a, Zhu, X. et al. 2015). People with dementia often have other diagnoses and some form of functional impairment as well. On the other hand, older people today are in better health than formerly, and a number of studies indicate that the proportion of people with dementia in the various age groups is declining. However, since the population is ageing, and the number of older people will grow in the next few decades, the number of those with dementia will still increase considerably.

A Norwegian study on dementia from a sociological perspective has recently been published. It evaluated the use of resources, estimated the total socioeconomic costs of dementia diseases, and calculated the cost-effectiveness of municipal services to people with dementia. It also estimated the expected need for resources related to dementia, and assessed the possible need for services in the time ahead in socioeconomic terms. According to the study, the average cost to society of a person with dementia is NOK 360 000 a year (Bergh et al 2015). This means that the total costs could amount to almost NOK 30 billion a year. Nursing home places are responsible for much of the cost. The study also showed that informal care accounts for a substantial amount of the care service needed by people with dementia. During the last month prior to admission to a nursing home, family members spend around 160 hours caring for the person, while over the same period only about 16 hours on average are spent by home care nurses and one to two hours by home helps. One-fifth of users had been offered access to a day activity service once or twice a week.

We are still a long way away from finding a cure for dementia. If curative treatment is discovered, it will have significant effects for the person concerned and alter all prognoses about the development of municipal health and care services. Curative treatment is thus an important research field. However, since a cure for dementia is unlikely to be found in the near future, it is also important to research measures that can delay the onset or the development of dementia and mitigate its consequences.

Thus we must base our plans for the future of the health and care services on the assumption that the number of people with dementia will increase substantially; demographic forecasts indicate that the number will have doubled by 2040. This will have profound consequences for the municipal health and care services in terms of capacity, competence, professional approach, the architecture and design of physical environments, interaction with families and voluntary workers, and cooperation with the specialist health service.

4



Experiences and needs

– from Dementia Plan 2015 to Dementia Plan 2020

The Dementia Plan 2020 will build on experience from the Dementia Plan 2015 and continue some of the measures from the three main priority areas of the 2015 plan:

- Further development of day activity services – the missing link in the chain of care services;
- Adaptation of residential facilities to people with dementia – small is beautiful;
- Greater knowledge and expertise – greater breadth.

Data have been collected on the implementation of the measures, development programmes and grant schemes established under the 2015 plan. Research was one of the priority areas, and the resulting knowledge has formed an important basis for the 2020 plan.

In cooperation with the Norwegian National Advisory Unit on Ageing and Health (Ageing and Health), the Directorate of Health conducted a national survey in 2014 that showed that there had been considerable changes in municipal health and care services for people with dementia and their families in the previous few years. The number of persons with access to a day activity service had almost doubled since the previous survey from 2010–2011 (Gjøra et al. 2015). New assisted living facilities, nursing homes and other forms of accommodation adapted to people with dementia and cognitive impairment have been built or upgraded. Professional training has become better and more widespread. According to a report from the Directorate of Health, around 20 000 employees in around 400 municipalities have improved their professional competence as a result of the two in-house cross-disciplinary education programmes for study groups: Dementia ABC education program and Care for the elderly ABC educational program. In the period 2011–2015, grants were awarded to dialogue groups and educational programmes for family members in 81 % of municipalities (Gjøra et al. 2015).

One of the results of the Dementia Plan 2015 has been to put dementia on the municipal agenda, and municipalities have implemented measures to improve the quality of the services to people with this condition. However, reports from the Board of Health Supervision, the 2014 national survey and input from people with dementia and their families show that there are still major challenges, and that many improvements still need to be made, especially with regard to evaluation and diagnosis and tailored home care and day activity services. People with dementia often have multiple diseases and several types of functional impairment. This means that a great deal needs to be done by the health and care services in terms of planning, capacity and adaptation in order to produce integrated, consistent services for people with dementia and their families. On the basis of these findings, the Dementia Plan 2020 has identified six priority areas where further work is necessary:

- Prevention;
- Knowledge and competence;
- Diagnosis and post-diagnostic follow-up;
- Flexible, differentiated day activity services and respite care;
- Tailored services throughout the disease course;
- Involvement and participation.

These main challenges largely overlap with those being addressed in the work on NCDs under the NCD strategy of 2013. More unified and coherent efforts are needed at all levels in the work with these diseases, and the special challenges posed by each disease must be taken into account.

A diverse group of users

People with dementia do not necessarily have anything in common apart from their condition. Their ages, life styles, likes, dislikes and disease picture vary widely. Knowledge about the interactions between various diseases, types of functional impairment and any resulting social problems is important for the diagnosis, treatment, follow-up and adaptation of services and the person's environment.

The evaluation and treatment of people with dementia who also have mental problems, i.e. behavioural and psychological symptoms of dementia, require special expertise. In many cases the evaluation has to be made by a specialist. The municipal health and care services may therefore need help and guidance from a specialist in connection with further treatment and follow-up, and this requires close cooperation between the different services.

Although the risk of developing dementia increases with age, dementia can still affect younger people, some of whom may be still working or have minor children. A number of participants at the dialogue meetings talked about the enormously time-consuming and difficult processes leading up to a dementia diagnosis, and we need more knowledge in this area.

Life expectancy for people with developmental disabilities has risen since the mid-1900s, which has resulted in a strong growth in the number of older people with developmental disabilities (Westergaard and Larsen 2004). Research has shown that people with these disabilities have a higher risk of developing dementia than the general population (Strydom et al. 2013). This will make additional demands on municipal services. The rehabilitation service, which is part of the specialist health services, plays an important role in the evaluation and diagnosis of people with developmental disabilities who develop symptoms of dementia. Evaluation in these cases is time-consuming, complex and requires special expertise. It also requires close cooperation between those who know the person, the specialist undertaking the evaluation and the municipal health and care services.

4.1 Prevention



“I don't need any help yet.”

Participant at a dialogue meeting

A number of studies have been made on dementia prevention, but none of them have come to any clear conclusions. However, some have pointed to associations between certain risk factors, such as life style and living conditions, and the development of

dementia symptoms. Thus we need to pay more attention to risk factors. Secondary prevention measures have a great potential for preventing the unnecessary development of further symptoms and a reduction in general condition.

Primary prevention

Increasing age is the most important factor associated with susceptibility to dementia, with genetic susceptibility in second place. We have little control over these risk factors, but other important risk factors are connected with life style and living conditions, over which we have a much greater influence. A relationship between dementia and living conditions has been demonstrated for all life stages. A low educational level, high blood pressure, smoking and diabetes have also been found to pose a higher risk for the development of dementia. The World Alzheimer Report 2014, *Dementia and Risk Reduction*, summarises the research on dementia, risk factors and prevention, and concludes that priority should be given to dementia prevention (Prince et al. 2014).

Dementia has many risk factors in common with NCDs, and people with one or more of these diseases have a higher risk of developing dementia. However, the similarities should not be exaggerated. Unlike NCDs, dementia is ultimately fatal. While many of the efforts to address NCDs are directed at preventing disease progression, limiting late effects and unnecessary suffering, and preventing premature mortality, dementia prevention is primarily aimed at delaying the onset. This can lead to a substantial reduction in the incidence of the disease, with great benefits to both the individual and society.

Dementia prevention involves both structural and social factors. The work on NCDs has shown that health promotion and preventing health problems and disease onset are often overshadowed by a focus on diagnosis, treatment and prevention of late effects. However, if we wish to reduce the incidence of dementia, efforts should be directed at the underlying factors: reducing social inequalities in health and living conditions and promoting a healthy life style by making it easier for individuals to make healthy choices.

There is thus a need for both cross-sectoral population measures directed at environmental and social factors that influence health and quality of life, and more specific prevention measures under the auspices of the health and care services targeted at people who are exposed to one or more risk factors, including other diseases.

Secondary prevention

A diversity of needs must be addressed by a diversity of expertise. Many different services have to cooperate and many different elements must be in place for people with dementia to have effective and consistent follow-up. Falls, loneliness and cognitive impairment interact with each other and require attention from most of the services in the health and care sector (NOU 2011:11). Poor health in one area often has consequences for other areas.

Falls are the most frequent type of accident in older people, and a number of studies indicate that dementia and other forms of cognitive impairment increase the risk of falls resulting in broken bones. Physical activity is important for maintaining good motor functioning, preventing injuries and maintaining an optimal level of physical he-

alth and function. New recommendations for physical activity advocate strength and balance training for people in mid-life and older. Maintaining muscle strength, a good sense of balance and mobility can help to prevent falling and reduce or delay the need for care. Hip fractures are a frequent occurrence in older people, and often contribute to invalidity and admission to a nursing home. Preventive measures and physical training have helped to reduce falls in older people by 40%.

Good foot hygiene and footwear are necessary for a physically active life. Social stimulation and cognitive training enhance coping skills and make activities more meaningful. Day activity services are a good method for encouraging these and other activities. For many people, sight and hearing are essential for experiencing and maintaining contact with the world around them, and some people may need assistance in acquiring sight and hearing aids.

Undernourishment is a serious problem in people with dementia (Rognstad et al. 2013), and adds unnecessarily to other impacts of the disease. There are a number of steps that can be taken to combat undernourishment; for example, food can be prepared in a way that stimulates the senses and the appetite. Poor dental hygiene and distractions at mealtimes make eating more difficult. Social and cultural activities in connection with food and companionship at meals have been found to have positive effects, and this knowledge should be applied for the benefit of the individual, whether the meal is being eaten at home, as part of day activities or in an institution.

People with dementia living alone may have difficulty remembering to take their medication. There are a number of good aids in this field, but the person should start using them as soon as possible so that they become an integral part of the daily routine. In addition, the home care services can teach people how to use a medicine dispenser. In some cases an electronic medicine dispenser can be useful, if the patient and the family are trained to use it and followed up by the home care service. Use of medication should be regularly reviewed in order to avoid preventable side-effects and overuse. This is discussed in more detail in section 4.5.

A report from Alcohol and Drug Research Western Norway (KORFOR 2015) pointed out that long-term high-risk use of alcohol can affect cognitive functioning and contribute to the development of dementia. In older people the prevalence of dementia is much higher among those with an alcohol problem. According to the report, cognitive impairment resulting from high levels of alcohol use is often addressed later than it should be, and it points out the need for greater competence in detecting and dealing with this issue. The question of the relationship between dementia and long-term high-risk use of alcohol is also relevant in the context of the Proposition to the Storting on a plan for expanding efforts in the field of substance abuse (*Opptappingsplanen for rusfeltet* (Prop. 15 S (2015–2016))).

4.2 Knowledge and competence



“Shame must be annihilated! Information, information, information!”

Participant at a dialogue meeting

In a survey by the Norwegian Health Association, over half the respondents reported that dementia was associated with a feeling of shame (Rugtvedt 2013). This shows the need to demystify and normalise the diagnosis by disseminating knowledge about dementia among people with dementia themselves, their families and society at large. The personnel of the various services also need more knowledge and competence about dementia, so that services can be tailored more specifically to the needs of people with this condition and their families.

Training, awareness-raising and information activities

The Dementia Plan 2015 raised public awareness of dementia. National and local media, specialists and professionals, voluntary organisations, conferences, educational programmes for family members and carers, the Directorate of Health's information campaign and a very successful telethon have all helped to put dementia on the agenda. People with dementia, together with those closest to them, have come forward and given dementia a public face. They have made people aware of the seriousness and realities of the condition and what it is like to be close to someone with dementia, but they have also talked about the opportunities that are still open for people with dementia to cope and have meaningful experiences.

This is public education at its best. Information has helped to reduce the stigma and myths associated with dementia, and made life easier for people with this condition and their families. The plan also attracted international attention, and a number of other countries have since developed similar plans.

At the same time, however, the feedback from users and their families shows that even more knowledge is needed. Information and knowledge are important conditions for ensuring that people with dementia are diagnosed at an early stage, and that society and working life are adjusted more closely to their needs. Many of the participants at the dialogue meetings expressed the view that knowledge provides security; it is important not only to know about dementia oneself, but also that others have the necessary knowledge. Police officers and ambulance personnel, employees in service sectors like shops, banks, security guards, public transport and taxis, and the public at large should all be aware of the basic facts about dementia.

People with dementia themselves and their families also need to know more about dementia. Many people would like to have access to arenas where they can meet others in the same situation. Trials of educational models for carers of people with dementia (2007–2009) showed that dialogue groups and educational programmes for carers promote learning and coping. A project has been carried out to produce a manual for the establishment and operation of such educational programmes (Hotvedt 2010). In connection with follow-up of the project (2011–2014), grants were awarded to dialogue groups and educational programmes for carers in around 80 % of municipalities. Two other measures have been taken: *Møteplass for mestring* provides courses for younger people with dementia together with their partners, and *Tid til å være ung* provides information and an arena for children of people with dementia.

Family members who have followed the dedicated educational programme have in general been very positive, but many of them felt that the programme is not reaching everyone who would benefit from it. There is a need for a greater number of low-threshold activities that provide meeting places both for people with dementia and for their carers.

Competence in the health and care services

Increased competence in the health and care services was one of the key goals of the Dementia Plan 2015, and many of the measures were targeted at the personnel. A number of programmes have also been developed, including programmes for young people with dementia and people from a Sami or language minority background. Many of the measures in the Dementia Plan 2015 have served to implement more specifically some of the general measures in the Competency Plan.

Ageing and Health has developed the educational tools Dementia ABC education program and Care for the elderly ABC educational program for health personnel. These have been used in 94 % of municipalities, and the ABC model has proved to be a success. However, only a minority of health personnel have followed these programmes, partly because they have not been made available to temporary employees or part-time workers. Around a third of the person-years in the care service are filled by personnel without health or social services training (Gautun and Bratt 2014), and there is reason to assume that a large proportion of temporary and part-time workers belong to this group. Thus people with dementia and their families are highly likely to encounter a large number of personnel without relevant training, especially those on the evening, night and weekend shifts. The educational tool *Dette må jeg kunne* ("I need to know about this") has been developed for this group.

A number of different treatment methods were tested under a programme developed for milieu therapy, which was launched in 2008. Milieu therapy involves structuring the physical, psychological and social environment in such a way as to achieve optimal well-being, coping skills and personal growth. As a result of the programme, an ABC programme on psychosocial interventions has been designed. The aim of the programme is to develop and impart knowledge about how to improve well-being and quality of life in people with dementia.

However, people with dementia and their families still report that they are worried about the lack of knowledge and qualifications in both the municipal health and care services and the specialist health services regarding this condition. Lack of knowledge can mean that some people do not receive the help they need or the services they are entitled to.

Knowledge about dementia needs to be incorporated into all the relevant health and social welfare educational programmes. Several of the participants in the dialogue meetings reported negative experiences due to their GP's lack of knowledge, thus underlining the need for more knowledge among general practitioners. Others pointed to the need for more knowledge about diet, appropriate activities, medication and meeting the needs of carers. A number of participants felt that more knowledge was needed about the legal authority for the use of coercion in the case of people who lack the capacity to give consent. There is also a need for better awareness of cultural differences, understanding and ascertaining spiritual and existential needs, and knowledge about people with dementia who come from a Sami or language minority background.

Research and development

Like research on other diseases that mainly affect older people, dementia research has little prestige. The Dementia Plan 2015 therefore made research a priority area, and the capacity and infrastructure for research on care have been built up in the

period up to 2015. The Ministry of Health and Care Services finances research through three channels: the regional health authorities, the Research Council of Norway and the EU's framework programmes for research.

The regional health authorities have a particular responsibility for clinical, patient-oriented research. The programme portfolio of the Research Council of Norway covers research on health and care services, prevention and public health, clinical research and research on mental health and substance abuse. A Centre for Care Research has been established that is also responsible for facilitating access to research results and the dissemination of new knowledge in the health and care sector. NevroNor is a national initiative that supports Norwegian neuroscience research with a view to improving knowledge on the prevention, diagnosis and treatment of diseases of the brain and nervous system. NevroNor also functions as a coordinating body between national and international research communities through its participation in the EU Joint Programme for Neurodegenerative Disease Research (JPND). Another large dementia research programme has been initiated by the National Association of Public Health with funds from the telethon on dementia. There is a great need to coordinate dementia research within Norway and in cooperation with international partners.

Although research activity in this field has increased substantially since 2007, we are still far from solving the riddle of dementia. A number of recent pharmaceutical trials have had disappointing results, and there is as yet no sign of a cure. There will therefore continue to be a great need for basic medical research in the field of dementia. In addition, we need more knowledge about which measures can delay the onset or slow down the progress of the disease.

There are also large gaps in our knowledge in health and care services research. We still know too little about how municipal services should be designed and staffed to provide optimal services to people with dementia living at home. Norway lacks up-to-date figures for the prevalence and incidence of dementia (the number of people affected, and the number of people who develop the disease in a given time period, respectively). The estimates we are currently using are based on studies in other countries carried out in the 1990s, and they are unlikely to be completely accurate. The lack of prevalence data makes it difficult to interpret other data, and limits the long-term planning of services to people with dementia and their families.

4.3 Diagnosis and post-diagnostic follow-up

” *“Follow-up is the be-all and end-all after a diagnosis.”*

Participant at a dialogue meeting

Once dementia is diagnosed, patients, their families and the health and care services can plan and carry out the necessary measures. One of the priority areas of the Dementia Plan 2015 was therefore to develop and test models for evaluation and diagnosis of people with dementia. A programme for this, *Verktøy for bruk i demensutredning i kommunehelsetjenesten* (A tool for use in dementia evaluation in the municipalities), was developed, evaluated and revised during the plan period, and is recommended

by the Directorate of Health. One of the most important findings from the development process was that evaluation and diagnosis set in motion measures that have considerable consequences for people with dementia and their families. Through its teaching, guidance and follow-up of the municipalities, the programme has enhanced the competence of health personnel on the evaluation of people with suspected dementia.

The goal of the Dementia Plan 2015 was to ensure that individuals with suspected dementia are evaluated and diagnosed. The organisation of dementia evaluations has received much attention during the plan period. The municipalities are free to organise their health and care services in the way they consider appropriate to local conditions and needs. Many municipalities have set up dementia teams and/or dementia coordinators for evaluation and follow-up. Almost 80 % of municipalities now have a dementia team or coordinator, and one in three has both. However, there are still a considerable number of nursing home residents and people living at home who have signs of cognitive impairment but who have not been evaluated for dementia, and recent studies found that up to 50 % of nursing home residents with definite signs of dementia had not been diagnosed (Selbæk 2014).

The people with dementia and their families whom we consulted emphasised that timely diagnosis and better follow-up should be given priority in the time ahead.

Timely diagnosis



“I was relieved when he got the diagnosis. It was a relief to be believed.”

Participant at a dialogue meeting

The path towards a diagnosis can be long and difficult, and is marked by uncertainty, anxiety and frustration. Many of the family members at the dialogue meetings described situations where a person close to them had symptoms of dementia but resisted the idea of consulting a doctor and being diagnosed.

Dementia diseases may be difficult to diagnose, and many of the diagnostic symptoms of dementia can also occur in people with depression. The right diagnosis is therefore very important for excluding dementia and helping those with treatable diseases.

Many people with dementia have other chronic diseases at the same time. It can be difficult to discern somatic disease, pain disorders and side-effects of medication in people with dementia. Sound observation procedures and cross-disciplinary cooperation are needed to establish the correct diagnosis and treatment of both dementia and other chronic diseases. Diagnosing dementia requires medical expertise and is performed by a medical practitioner. The patient's GP or the doctor attached to the nursing home is responsible for evaluation and diagnosis, and cooperation between the medical practitioner and other health and care personnel is recommended.

The most common forms of dementia are diagnosed by the municipal health and care services. It is therefore important that municipalities ensure that their health and care services have the necessary competence and resources. In many cases, for example when a medical evaluation is so complicated that the municipal health and care services cannot be expected to have the necessary expertise or resources, the patient has to be referred to the specialist health service.

There is still much to be done to ensure good cooperation procedures between the different levels of the health service on the evaluation and diagnosis of dementia. There is also a considerable lack of expertise in both the specialist and the primary health services. Some people have additional challenges that call for more specifically tailored services. Older people with developmental disabilities in addition to dementia are particularly vulnerable; other people with special needs are individuals with a Sami or minority language background and younger people with dementia. Older immigrants with dementia often come in contact with the health service when the disease is already advanced, and if they do not receive help that is appropriate in terms of their language, habits and culture, this adds to the strain on the family (Ingebretsen 2015). The health and care services need further training and guidance on the evaluation and diagnosis of dementia in people with special needs.

Post-diagnostic follow-up

Many people who receive a dementia diagnosis do not have an immediate need for services, but they still need follow-up to help them deal with their reactions to the diagnosis, maintain an optimal level of functioning and plan for the future. A very large number of those consulted emphasised the need for a contact person, a coordinator, at municipal level who can provide information on available services and guidance and support in this difficult situation.

A number of people with dementia and their families described the period after diagnosis as “a black hole”. Lack of follow-up may lead to depression, withdrawal, social isolation and needless functional decline. Family members may find themselves unable to cope or find it stressful to make the necessary changes in the new situation. Lack of follow-up may also mean that medical evaluation for other diseases where age is also a risk factor is neglected.

A dementia diagnosis is too seldom accompanied by an assessment of the patients’ and families’ need for follow-up, which means that appropriate measures are not taken. There may be a need to deal with grief or anger, make future plans, find out how to inform the family and the social environment, and for training in altering old habits or the use of welfare technology, or adaptation of the home environment. For some people the diagnosis also has work-related or financial consequences or requires profound changes in their way of life.

Good follow-up of people with a dementia diagnosis requires close cooperation between the home care services and the person’s GP. Many personnel find that there is too little communication between the different services. At the dialogue meetings it was pointed out that lack of cooperation between GPs and home care services impeded good post-diagnostic follow-up. Thus there is a need for better coordination of the medical services and cooperation between them and the home care services to ensure adequate follow-up throughout the course of the disease.

4.4 Flexible, differentiated day activity services and respite care

” *“Activity is just as important as medicine.”*

Participant at a dialogue meeting

The day activity service for people with dementia ought to include a more varied range of activities, and the activities need to be better adapted to individual preferences and interests. Carers need guidance and respite, which should be tailored to individual needs and preferences.

Day activity service

In the Dementia Plan 2015 it was emphasised that day activity services were among the most essential and fundamental elements in an integrated home care service for people with dementia, and developing such services has been a major priority.

As part of the Dementia Plan 2015, a programme was carried out in the period 2007–2011 to develop good models for the establishment and operation of tailored day activity services and respite arrangements. The results and recommendations have been published in the report *Mellom hjem og institusjon* (Between home and institution) (Taranrød 2011).

In 2012 a grant scheme was established for municipal day activity services for people with dementia living at home. The size of the grant was based on an estimated need for around 9200 places. To achieve this target, funds were allocated for the establishment of about 5000 places in the period 2012–2014. However, the annual allocations have not been fully used; funding for only about 2500 places was applied for and granted in the period 2012–2014.

The results of the most recent national survey of the services available to people with dementia showed that great changes have occurred over the last four years. A survey in 2010–2011 showed that around 44 % of municipalities had established tailored day activity services for people with dementia living at home. In the October 2014 survey, the figure had risen to 71 %. According to the survey, around 17 % of people with dementia living at home had access to such activities, as against only about 9 % in 2010. Thus a large number of people still have no access to this service.

The participants in the dialogue meetings were agreed that more people with dementia should have access to day activity services, that the service should be flexible and that the activities should be adapted to individual needs, interests and preferences. In the consultation process a number of people also pointed out that spiritual needs should be taken into account (cf. Circular I-6/2009 *Rett til egen tros- og livssynsutøvelse* (The right to practise one’s religion or philosophy of life) from the Ministry of Health and Care Services). Several people with dementia expressed a desire for more physical activity and more meaningful activities.

If the day activity services are to provide respite for carers, the activities must take place sufficiently often and last for a sufficient period of time. Experience has shown that

many users are offered access to such a service when the disease has progressed too far for them to benefit from it, that there are activities available too few days a week and that the activities do not take sufficient account of carers' working hours in particular. According to a report on municipal respite care (Jessen 2014), a number of municipalities do not provide adequate day activity services that give carers sufficient respite.

More day activities are also needed in nursing homes and as part of the home care service. Many participants at the dialogue meetings mentioned the need for an occupational therapist, support person or user-centred personal assistance.

More information is also needed on the services available in the municipality and better intermunicipal cooperation on providing adequate, differentiated services. In some municipalities, activities for people with dementia are offered by the municipal healthy life centre, which can provide an overview of activities run by voluntary organisations such as walking groups and physical and social activities in the local community. For example, in some municipalities, farms supply a range of activities adapted to the needs of people with dementia. All these activities have met with a positive response.

There are many indications that cooperation between public services and voluntary organisations should be improved and systematised. Voluntary work should be encouraged, since it has the potential to be an important supplement to public services for people with dementia.

Respite care

” *“There was little real discussion of what could give me a break.”*

Participant at a dialogue meeting

Caring for a person with dementia increases the carer's risk of developing problems of various kinds and injuring their health. Carers need to know about the condition and to be aware of the support and respite services available to them. Experience has shown that the carers and families of people with dementia have a better quality of life when they are given information and guidance.

An important measure in the Dementia Plan 2015 was therefore to establish educational programmes and dialogue groups to provide support and help for carers and families. A separate informal care programme has also been established in which models of respite care are being developed.

Carers' need for support and respite was stressed at all the dialogue meetings. Many of the carers talked about the demands that caregiving made on their everyday lives, and most of them said they needed support, guidance and adequate respite care that would enable them to combine working life with caring for the person with dementia, time to themselves and social activities. Many need respite in the evenings and at night, among other things to ensure that they could get sufficient rest and sleep. Thus respite services need to be flexible and differentiated, and integrated with the other municipal home care services.

4.5 Adequate, tailored services throughout the progress of the disease

” *“People at nursing homes don’t know much about how to curl hair and dress nicely and so on. But it gives me a good feeling when I see them touching her, and see that she likes it, so that I can be easy in my mind. Time and compassion are important.”*

Participant at a dialogue meeting

Dementia diseases are progressive, and many people with this condition develop behavioural and mental problems in the course of the disease. These can be difficult to deal with for the family, the personnel and the other residents of the home. Many people with dementia also have difficulty in eating enough. It is therefore important to make meals an enjoyable experience, and avoid long periods at night without food. Many patients experience a major decline in physical function, which requires comprehensive assistance and care.

Helping people with dementia with their personal hygiene can be demanding, and the borderline between persuasion and coercion may often be unclear, especially in everyday care. In 2013 amendments were made to the Patients’ Rights Act that clarify the authority of the health and care services to make decisions on the use of alarm systems and positioning technology, such as GPS, in caring for patients who lack the capacity to give consent.

Many people with dementia have a number of other diseases, and take several different prescription drugs concurrently. This increases the risk of unnecessary medication, unfavourable drug combinations and side-effects. Nursing home residents use on average seven different drugs, and one of three uses at least one that is unnecessary. A number of studies have demonstrated misuse of prescription drugs both for patients in hospitals and for those living at home. There are reports that, depending on which criteria are used, 10–25 % of drugs prescribed for older people were for the wrong medication. Studies also show that around 10 % of all admissions of older people to hospital are due to medication-related problems (cf. the white paper on the administration of pharmaceutical drugs (Meld. St. 28 (2014-2015) *Legemiddelmeldingen*). In Norway, over 30 000 people aged 70 years and older use antipsychotics, even though these drugs are not recommended as treatment for older people (Selbæk and Nygaard 2009). Several studies have also demonstrated that control of the medication administered by the home care services and in nursing homes is inadequate (Ministry of Health and Care Services 2015c). There needs to be a clearer division of roles and responsibilities, adequate professional expertise and better procedures to ensure correct medication management for older people in general and people with dementia in particular.

Language is closely linked to everyday tasks and activities, and people who can no longer perform these may also start losing their language abilities. This is particularly true of people with dementia, and the resulting passivity hastens the progress of the disease. It also applies particularly to those who seldom hear their native language being used. People with advanced dementia who have a Sami or minority language background often lose the ability to speak Norwegian before they lose their native language. Good communication is especially important in all these cases. Thus in order to ensure high-quality, tailored services throughout the disease course, the care service should recruit personnel who can speak more than one language.

Services to people with dementia living at home

The Government's goal is that everyone should be able to live in the comfort of their own homes for as long as possible and receive individually tailored services at home. It is challenging to tailor services to people with dementia in such a way that the person themselves and their families feel safe and secure. Their declining functional ability makes it difficult for people with dementia to remember things, adjust to the routines of the home care service and get used to new home carers who come to the house. Many live alone and are on their own most of the time. This underlines the importance of adequate municipal home care and day activity services.

People with dementia whose memory is failing are seldom able to assess their own needs. In order for them to feel secure, it is therefore necessary that services personnel are familiar with dementia and the person's background and circumstances, that the person does not have too many personnel to get accustomed to and that the routines are regular and predictable.

The home care service must pay attention to the needs of the person with dementia. Problems may arise if home care personnel have limited knowledge of dementia and insufficient competence in dealing with it, there is a lack of continuity in the service provided and the service is not organised in a way that facilitates good, systematic follow-up of people with dementia and cognitive impairment. New organisational models for home care services need to be developed and tested that will ensure continuity, predictability and sound professional follow-up (Gjevjon 2015).

Many of the participants at the dialogue meetings said they wanted to live at home for as long as possible, and stressed the importance of continuity in the home care service, day activity services, respite care and welfare technology, especially when provided at an early stage, in helping them to cope and live an independent life. Thus there is a need for more knowledge of the possibilities of welfare technology and for training in the use of new technological aids and how they can best meet the individual needs of people with dementia.

Adapted residential facilities

One of the goals of the Dementia Plan 2015 was that residential facilities for people in need of 24-hour health and care services, such as nursing homes and assisted living facilities with 24-hour care, that were being built, renovated or modernised with a grant from the Norwegian State Housing Bank must be adapted to the needs of people with dementia. Optimal conditions for meeting these needs are described in the Dementia Plan 2015: small groups of residents (four to eight persons) in an easily navigable physical environment, and stable personnel with the necessary competence. There should be direct access to a specially designed outdoor area and arrangements should be made to encourage social contact.

The findings of a number of recent studies can be summarised in the words "small is still beautiful" (Landmark et al. 2009, Gonzalez and Kirkevold 2014). Small, easily navigable home-like units with direct access to an outdoor area are associated with less restlessness, anxiety and depression, a better sense of direction, and more mobility and social contact than the large older institutional buildings with their unsuitable layout. These improvements in turn reduce the need for medication.

However, the small-is-beautiful concept not only provides a favourable living environment for people with dementia and cognitive impairment, it also has positive effects

cts for other groups in need of 24-hour care. A report by the research organisation SINTEF, commissioned by the Norwegian Association of Local and Regional Authorities (KS) (Haugan et al. 2015), concluded that small-scale residential care units encourage social interaction, give the residents a feeling of control over their lives, make them feel at home and take account of individual needs and the desire for privacy. In the period 2008–October 2015, investment grants for places in nursing homes and assisted living facilities with 24-hour care were awarded for the building or modernisation of 11 804 units, divided between 5345 places in assisted living facilities and 6449 places in nursing homes.

The national survey of the health and care services available to people with dementia showed that around 25 % of nursing home places were in special care units for people with dementia, and that almost 9 of 10 municipalities reported that the municipal nursing homes had such units. The number of places in assisted living facilities with 24-hour care for people with dementia has also increased by around 10 % in the last few years, and 24 % of municipalities reported that they had places in this type of accommodation (Gjøra 2015 et al.).

There still seems to be a need to make architects, planners and builders, the construction sector as a whole and municipal authorities more aware that people with dementia need specially designed indoor and outdoor physical environments. Experience gained from the use of existing buildings should therefore be evaluated, and user needs must be expressed and communicated more clearly.

Palliative care

Most people with dementia in Norway die in nursing homes or hospitals. However, many have spent a long time at home before admission to an institution (Agenda Kaupang 2012). Studies have shown that the majority of adult patients wish to be treated and cared for at home when they are terminally ill. Home nursing, especially if it is linked with palliative care by a specialist and a palliative team, seems to increase the proportion of terminally ill patients who die at home and to enhance a feeling of contentment in the terminal phase (Directorate of Health 2015). We need to know more about what constitutes adequate care for terminally ill people with dementia, and studies indicate that both home care and nursing home personnel need more knowledge about palliative and end-of-life care. More knowledge will help to reduce the number of hospital admissions and the need for treatment using advanced technology, and shorten stays in hospital (Directorate of Health 2015, Kunnskapssenteret 2014, Agenda Kaupang 2012).

Good palliative treatment is not confined to end-of-life care; it should also be an integral part of long-term treatment, including in the early stages of the disease, and take account of the fact that the disease course varies from person to person, even in the terminal phase. The basic principles of all palliative and end-of-life care are to treat the person who is dying as a whole person with physical, mental, social and spiritual needs, while at the same time caring for the family.

Most patients wish to be fully informed and take part in discussions about their end-of-life treatment and care. Good palliative care means a continuous dialogue with the patient throughout the disease process in order to identify and take account of their own and their families' needs and wishes. As in dementia, cognitive impairment may limit the person's ability to take in information and express their likes and dislikes, so that dialogues about end-of-life care should if possible be conducted early enough for the person with this condition to take part in them. It is often too late to discuss end-of-life plans when the person is admitted to a nursing home. Studies have also

shown that dialogues that include end-of-life planning may reduce hospital admissions (Kunnskapsenteret 2014, Robinson et al. 2012).

4.6 Participation and involvement

” *“I want to contribute. That’s what brings me happiness.”*

Participant at a dialogue meeting

Obstacles in the physical and social environments need to be overcome if people with dementia are to be able to participate on an equal level in society. Developing a more dementia-friendly society calls for measures outside the health and care sector as well, but it should still form the basis of plans for the health and care services. People with dementia and their families are a key element in the development of these services. Up to now, far too little attention has been paid to them in the planning and design processes. This may be one reason why the services are not sufficiently geared to people with dementia and cognitive impairment.

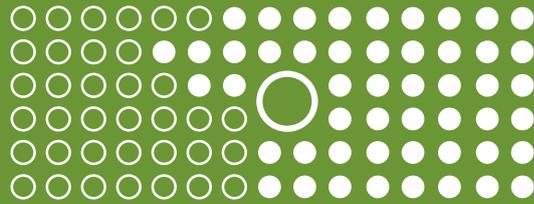
Given the necessary help, people with dementia can describe how they think the services they use can be designed and how they can take part in planning their own future. It is important for the individual’s dignity and self-respect to feel that they have control over their life, and that decisions are made in line with their own values and preferences. The dialogue meetings held during the preparations for the Dementia Plan, at which the participants were asked to describe the challenges they face and suggest solutions, is an example of how to draw people with dementia into the consultation and planning process. As a result, user needs form the basis of the present plan.

The overriding goal of user involvement is that users should have real influence on the development of health and care services at the system and the individual level. This is a core democratic value, and the right of the individual to choose how to live their own life is a key ethical principle for the health and care services in their encounters with individuals. It is also laid down in the UN Convention on the Rights of Persons with Disabilities. The principle covers normal everyday activities, such as deciding when to get up or go to bed, when to eat and when to rest. Such personal choices all too often have to give way to regular routines in for example a nursing home. The individual’s right to choose how to live their life also applies to life-changing decisions such as leaving their job or moving away from home. Furthermore, this right means that activities such as participation in cultural events or the practice of a religion or philosophy of life must be adapted to the individual’s needs, background and affiliation.

Today the municipalities have a duty to ensure that patient and user representatives have a voice in the development of the municipal health and care services. They must also ensure that enterprises that provide health and care services establish systems for consulting the views of patients and users. Special interest organisations often serve as spokespersons for user groups, and it is important to recognise the role played by these organisations in the development of high-quality services.

Capacity and the degree of user involvement decline as dementia progresses, and a family member, friend or guardian has to take over the task of safeguarding the interests of the person concerned.

5



Strategies and measures

The Dementia Plan 2020 has six strategies for helping people with dementia live a good and meaningful life and ensuring a good patient care pathway with reliable, coordinated follow-up as their condition progresses:

- Self-determination, involvement and participation.
- Prevention – what’s good for your heart is good for your brain.
- Timely diagnosis and close post-diagnostic follow-up.
- Activity, coping and respite care.
- A patient care pathway with systematic follow-up and tailored services.
- Research, knowledge and expertise.

The main measures are in line with the priority areas in the NCD strategy (2013–2017). The Dementia Plan also contains targets based on some of the more general measures in the Care Plan 2020. The Dementia Plan covers measures in the Competency Plan 2020, the investment grant for building or modernising nursing homes and assisted living facilities with 24-hour care, the welfare technology programme, the informal care programme, and research, innovation and development. The plan must also be viewed in relation to the implementation of the white paper *Primary Health and Care Services of Tomorrow – Localised and Integrated*. Finally, the measures must be adapted to people with special needs, including young people with disabilities and people with a Sami or minority language background who develop dementia.

Box 5.1 The Care Plan 2020

The Care Plan 2020 is the Government’s plan for the care services field for 2015–2020. The document addresses priority areas set out in the Government’s policy platform and includes important measures for enhancing quality and expertise in the care services, while at the same time following up the Storting’s deliberations on the white paper *Future Care* (Meld. St. 29 (2012–2013)), cf. Recommendation 447 (2012–2103).

The following are included in the measures set out in the Care Plan 2020.

- The Competency Plan 2020 aims to strengthen the expertise and competence of the municipal health and care services and ensure that the sector has sufficient competent personnel.
- The investment grant for nursing homes and assisted living facilities with 24-hour care is intended to encourage the municipalities to build and modernise such institutions.
- The Programme for an Active, Future-Oriented Informal Care Policy 2014–2020 is intended to help secure better conditions for family members who perform demanding caregiving tasks and improve the cooperation between public services and informal care.
- The main goal of the welfare technology programme is that by 2020 such technology will be an integral part of the care offered by the care services.
- The aim of the grant for research and innovation is to strengthen the ability and capacity of municipalities to develop new, sustainable solutions.

To ensure higher quality in the health and care services, the Government has set out new, improved measures for the Care Plan 2020 in the white paper *Primary Health and Care Services of Tomorrow – Localised and Integrated*, including trial projects for state financing of the care services and a legal right to round-the-clock care.

5.1 Self-determination, involvement and participation

Long-term strategy

To make society more dementia-friendly, we need to eliminate disabling obstacles in the physical and social environment so that everyone is able to enjoy their right to self-determination and continuing participation on an equal level regardless of illness or functional impairment.

It is the people with dementia themselves and their families who are the experts on their own lives and know where the shoe pinches. They should therefore be involved in decisions that affect them, be able to influence the design of the services offered to them, and participate in society on an equal level with everyone else. The way in which a person exerts influence must be determined by their ability to provide and receive information. Achieving this aim makes it necessary to think along new lines about individual resources, the working methods and competence of the health and care services, and the adaptation of society in general.

User involvement can be enhanced on at least three levels:

- at the individual level: the person's ability to influence their own life situation and the services they need;
- at the group level: meeting, sharing experiences and joining forces with others in the same situation;
- at the municipal and societal level: through user representation.

In addition to the provisions of the legislation governing patient and user rights, the Government has implemented a number of measures that more directly strengthen users' position and influence at these three levels. The measures include increasing flexibility and accessibility, intensifying the efforts to provide information, improving communication between service providers and service recipients, and mechanisms for promoting greater freedom of choice for users. Quality indicators are being developed on the basis of the experiences of users and their families.

As part of the Government's informal care programme, which is intended to enhance the interaction between the health and care services and the family, arenas will be established for family members to influence the care services. Family members who are caring for a person close to them with dementia perform an invaluable service and deserve to be assisted by public services that cooperate with them, support them and provide them with respite care. The Government has proposed a new provision in the Health and Care Services Act obliging municipalities to offer the necessary support to family members who perform especially demanding care tasks by providing them with respite, information, training, guidance and care benefits. The proposal was submitted to public consultation in autumn 2015.

Special interest organisations may serve as spokespersons for user groups, and it is important for decision-makers at all levels to listen to them when engaged in developing high-quality services. The work on the Dementia Plan 2020 showed that people with dementia are capable of joining an organisation and coming forward to safeguard their interests. The municipal health and care services must have clear procedures for involvement and a mutual exchange of information with people with dementia and

their families. There is great potential for cooperation between local user organisations and municipalities in the work on strengthening user involvement in the development of primary health and care services. Information on user involvement must also be given weight in the education and training of personnel.

Box 5.2 Users' freedom of choice

The Ministry of Local Government and Modernisation has published guidelines for the introduction of freedom of choice for users in the municipalities. In the guidelines the definition of freedom of choice has been expanded to include not only the user's opportunity to choose the service provider they prefer but also the person who is to provide the service, what the service should cover, and how and when the service is to be supplied. Thus the user's freedom of choice covers who, what, when, how and where the service is to be provided.

Ministry of Local Government and Modernisation 2015a.

Box 5.3 Someone in the same situation

A dementia diagnosis gives rise to many questions and much uncertainty. It can be a great help to talk to someone who has been through a similar experience. The Norwegian Health Association is able to call on people who have themselves been close to a person with dementia and who can provide support and serve as a dialogue partner for others in the same situation. When a member of a family is diagnosed with dementia it affects the family's daily lives and alters their future plans. Many people feel at a loss in such a situation. The people chosen by the association are able to share experiences and give advice that may help families to cope. They have received training and signed a confidentiality agreement.

www.nasjonalforeningen.no.

Measures in the plan period 2016–2020

Educational programmes for people with dementia

A programme will be established for developing models of educational programmes for people with dementia. The aim is to provide information on dementia and serve as meeting places for mutual support and the exchange of experiences. User organisations will be closely involved in their development, and the programmes will be tailored to people of different ages and cultural backgrounds.

Models for user involvement

Arrangements will be made to enable people with dementia to speak for themselves and decide who is to represent them when this becomes necessary. Tools will be developed for involving people with dementia and their families in the design and practice of the health and care services at the system and the individual level.

Post-diagnostic follow-up

A three-year programme will be initiated for developing models of post-diagnostic follow-up of people with dementia and their families. The pilot projects will involve users and their families. This is described in more detail in 5.3.

Quality indicators based on the experiences of users and their families

The Government wishes to improve the quality of the municipal health and care services, and will introduce quality indicators based partly on the experiences of users and their families.

Importance will be attached to the outcome of the services for the individual user, and the knowledge provided by the indicators will be used for further learning and improvement of the service. User surveys will be further developed to record users' and their families' experience of the quality of the services, with a view to developing a national user survey that includes people with dementia and their families.

When the Dementia Plan has been implemented in 2020:

- People with dementia and their families will be involved in decisions that affect them and be able to influence the design of the services provided for them.
- Educational programmes will have been developed for people with dementia.
- The proposed amendment to the Health and Care Services Act requiring municipalities to offer the necessary support to family members will have been debated.
- Methods will have been developed for involving people with dementia and their families in the development and practice of the relevant services.
- Quality indicators will have been developed for the care sector based on the experiences of users and their families.
- A national user survey that includes people with dementia and their families will have been developed.

5.2 Prevention

– what's good for your heart is good for your brain

Long-term strategy

The health and care services are not the primary agent for promoting public health. The conditions for good health and quality of life in the population are to be found in every sector of society, and primarily in the municipalities, where people live their everyday lives. The responsibility for promoting public health applies across social sectors and at every level – national, regional and local. Under the Public Health Act, municipalities are responsible for promoting public health and helping to protect the population against factors that may have a negative impact on health, including by reducing social inequalities in health. '

We know that there are close links between living conditions and health. The causes of social inequalities in health are complex, and certain factors seem to have effects throughout the life course. It has been documented that social and environmental factors such as childhood and education, employment, housing conditions, degree of financial security, social activities and support network, and the existence of a secure and inclusive local community, influence public health in general and the development of non-communicable diseases and dementia in particular. The work for public health therefore consists of promoting physical and mental health and reducing social inequalities in health and the risk of lifestyle diseases. The Government wishes to develop a society that will promote mental health by strengthening people's ability to cope and their sense of belonging and of leading a meaningful life, as described in the white paper on public health.

Preventive measures for the population as a whole are in general the same for dementia as for diabetes, cardiovascular diseases, chronic respiratory diseases and cancer. The measures described in the 2013 NCD strategy will therefore also apply to dementia prevention. To quote Alzheimer's Disease International: "What's good for your heart is good for your brain." (World Alzheimer Report 2014).

Preventing NCDs calls for systematic efforts at population level. In addition to general public health measures, the Norwegian NCD strategy contains measures targeted at particularly vulnerable groups. In May 2012, the World Health Assembly (WHA) adopted a global target of a 25% reduction in premature mortality from NCDs by 2025. Measures for achieving the target will include reducing exposure to risk factors such as high blood pressure, tobacco use, high salt intake and physical inactivity. Norway endorses the global target and is playing a leading role in these efforts.

Preventing functional decline is crucial to preventing the loss of coping skills. To enhance quality of life and health in people with dementia and those close to them, the Government will attach importance to secondary prevention measures such as preventing falls, undernourishment and depression, and promoting physical activity and social and cognitive training.

Box 5.4 The Directorate of Health's recommendation on physical activity for adults and older people

Adults and older people should be physically active for at least 150 minutes a week. The activity should cause slight breathlessness (moderate intensity). For high-intensity activity, when the person breathes more quickly, the recommended figure is at least 75 minutes a week. Older people with reduced mobility are recommended to perform balancing exercises and strength training three or more days a week as well, to strengthen their sense of balance and reduce the risk of falling.

www.helsedirektoratet.no

Measures in the plan period 2016–2020

Preventing falls

Hip fractures in older people can result in a significant reduction in health and quality of life, higher mortality and huge costs to the health and care services. The efforts to prevent falls will be intensified, with a view to achieving a 10 % reduction in the number of hip fractures by 2018. Systematic prevention and training can reduce falls in older people by 40 %. Such measures will be included in the work on developing quality indicators, home visits, the patient safety programme and the cross-sectoral work for public health. The measures in the patient safety campaign for preventing falls in hospitals and nursing homes will be continued in the patient safety programme (2014–2018).

Alcohol and dementia

A clear association has been found between prolonged use of alcohol and the risk of developing dementia and cognitive impairment. For a description of the challenges and measures linked with dementia and prolonged high-risk alcohol use, see the Government's plan for measures in the field of substance abuse (Prop. 15 S (2015–2016) *Opptrappingsplanen for rusfeltet* (2016–2020)) and the implementation of the white paper on public health.

Preventive home visits

New guidelines will be drawn up to assist municipalities in developing preventive and health-promoting measures for older people. The guidelines will contain recommendations on models for preventive home visits and other measures to encourage municipalities and local communities to establish effective preventive, health-promoting services for their older inhabitants. The Ministry of Health and Care Services will issue a circular on preventive home visits.

When the Dementia Plan has been implemented in 2020:

- Norway will have been at the forefront of the efforts to reduce exposure to risk factors associated with NCDs.
- The number of hip fractures in people with dementia will have been reduced.
- A large number of municipalities will have instituted preventive home visits to older people.

5.3 Timely diagnosis and post-diagnostic follow-up

Long-term strategy

There are still major hidden figures for the diagnosis of dementia. Timely diagnosis is crucial if people both with and without dementia are to receive the correct treatment and follow-up.

The Government will seek to ensure that all individuals with suspected dementia are evaluated and diagnosed. The experience and knowledge gained from the programme for evaluation and diagnosis initiated under the Dementia Plan 2015 will be shared and put into practice during the new plan period. The competence of personnel to conduct needs assessments and undertake the necessary evaluation and diagnosis will be strengthened.

Many people who receive a dementia diagnosis are not followed up by the health and care services. Steps will be taken to ensure focused, cross-disciplinary assistance in the form of information and guidance, contact with other users and their families, and help in dealing with grief, so that the those affected by the diagnosis can begin planning how to re-organise their lives. In addition to follow-up, new technology is providing opportunities for people to obtain information themselves and communicate with the health and care services and user networks.

In addition to population and disease trends, the specialist health services of the future must be designed to take account of public expectations of standards and quality. Changes made in the period up to 2030–2040 will influence the specialist health services in terms of capacity, localisation and cooperation with the municipal health and care services, for example on the evaluation and follow-up of people with dementia.

Box 5.5 The Memory Clinic

The patients who are assessed at Oslo University Hospital's Memory Clinic are young – half of them are under 65 years of age. Most are suffering from mild cognitive impairment or very early dementia, while others are referred for a second opinion. The assessment takes two to three hours and is conducted by a doctor and a nurse. It includes a clinical investigation, cognitive testing and an MRI scan.

<http://tidsskriftet.no/article/2170754>.

Measures in the plan period 2016–2020

National professional guidelines on dementia

As recommended by the National Council for Priority Setting in Health Care, the Directorate of Health has begun drawing up national professional guidelines on dementia. The work is organised in the form of two projects: one on evaluation for dementia and medical treatment and one on following up people with dementia and their families. The work on the guidelines is based on existing research, which is discussed in working groups consisting of specialists in the various fields and representatives of municipalities and users. The work was begun in 2014 and continued in 2015 and 2016.

Programme for models of post-diagnostic follow-up

Everyone who is diagnosed with dementia, together with their families, needs follow-up in the practical, financial, social and emotional spheres. A three-year programme will be initiated for developing models for post-diagnostic follow-up. The work will draw on experiences from other countries, and the models will be tested in a number of different municipalities. The models will provide information and education on how to live with dementia, how to adapt activities and the home environment, support and advice, treatment for slowing down the progress of dementia and help in planning the

future. People with dementia of different ages and from different cultural backgrounds and their families will be involved in the development of a pilot project. When the project has been evaluated, it will be ready for use by other municipalities.

Individual plan/coordinator

Many people with dementia have multiple diagnoses involving functional and cognitive impairment. This means that they need coordinated cross-disciplinary services and are thus entitled to an individual plan. Regardless of whether or not the person has expressed a desire for such a plan, users who need long-term coordinated services are offered a coordinator in the municipality and/or the specialist health service. The coordinator's task is to ensure that the user is followed up, coordinate the services they need and follow the progress of the work on the individual plan.

Cooperation between the municipal health and care services and the specialist health service

The specialist health service plays a key role in patient evaluation and the diagnosis and treatment of dementia. Diagnosis requires more than one specialist, and depends on their capacity and expertise and on effective cooperation between the different specialists and personnel in the different health services. Practical cooperation on diagnosis and treatment is regulated by cooperation agreements between the specialist health service and the municipalities. The specialist health service must comply with its legal obligation to provide advice and guidance to the municipalities. The aim is to fulfil the need for integrated, coordinated health and care services for people with dementia.

Implementation of the white paper Primary Health and Care Services of Tomorrow – Localised and Integrated

The white paper provides a basis for the development of future-oriented municipal health and care services that meet the needs of those in good health who require rapid diagnosis and treatment, those with a prolonged illness or a chronic disease and those with extensive, multiple needs and functional decline, including people with dementia.

One of the most important measures in the white paper is facilitating the establishment of more team-based services. The medical and cross-disciplinary resources in the municipalities can be used more effectively to care for patients and users with extensive, multiple needs. A team made up of the patient's GP and personnel from the health and social services can provide closer and more integrated follow-up of users, patients and families over time, facilitate education and training, strengthen prevention efforts and ensure that users are more actively followed up in line with national professional guidelines.

When the Dementia Plan has been implemented in 2020:

- National professional guidelines on dementia will have been developed and implemented.
- People with suspected dementia will be ensured medical evaluation and diagnosis.
- Models for systematic post-diagnostic follow-up will have been developed and tested.
- People with dementia who are in need of several different services will be offered a services coordinator and an individual plan.

5.4 Activity, coping and respite care

Long-term strategy

The health and care services must not only compensate for functional decline, they must build on the individual's resources. They must help people with dementia cope as well as possible with their daily lives. Family members must be ensured support and respite care. The Government will develop more flexible respite care arrangements through the informal care programme, and establish arenas for more formalised contact between users and family members and the professionals who provide health care. Welfare technology will be used to help people with dementia live an independent and meaningful life as far as possible.

In order for people with dementia to live a good life, they need an integrated service in which physical, social, cultural and spiritual activities are key elements. Municipalities have an obligation to help people who depend on practical or personal assistance to live an active and meaningful life as part of the community.

The day activity service is an essential part of the support provided to people living at home and nursing home residents, and the activities must be adapted to the individual user's needs and wishes. The Government will present a proposal for an amendment to the Health and Care Services Act that will require municipalities to offer day activity services for people with dementia living at home as from 1 January 2020.

Future developments will make it necessary to mobilise a wider range of society's resources. There is great potential in cooperation between municipal services and the voluntary sector on enabling people with dementia to live a good life. For example, the voluntary sector can contribute to the development of new measures and good solutions as regards the activities and content of municipal services.

Box 5.6 Green Care

Over 40 farms throughout the country offer activities for people with dementia. A farm provides a unique opportunity to take part in meaningful tasks and activities in stimulating surroundings with no institutional aspects. Activities include caring for animals, working in the kitchen garden or orchard, chopping wood, cooking meals and eating together. There is a great potential in this type of project if the municipality is able to establish cooperation with local farms. Many farms are interested in supplying this service, and when volunteers are also involved they have described their enjoyment of the social contact and activities. For the last 15 years, Ageing and Health has followed the progress of a number of such projects and contributed to the development of the concept. The municipalities are responsible for the content.

www.regjeringen.no/no/aktuelt/handlingsplan-for-inn-pa-tunet/id735254/

Measures in the plan period 2016–2020

Day activity services

Day activity services will be expanded so that all people with dementia living at home are able to participate in an activity if they so wish. Day activity services provide meaningful activities, encourage coping, are enjoyable for the individual and provide respite for the carer. They also help to prevent or delay admission to an institution. The grant scheme under the Dementia Plan 2015 will be continued, and will stimulate the expansion of day activity services up to 2020. There will be a focus on developing more flexible and differentiated activities that cater for different needs and interests.

Respite care

The efforts of family members who care for a person with dementia are crucial, and deserve support from public services that work together with them and provide relief. The informal care programme will be used to develop more flexible respite arrangements and measures for providing training and guidance to carers.

Educational programmes for family members and for people with dementia

The Government will continue the efforts to establish educational programmes and dialogue groups for family members that were begun under the Dementia Plan 2015. The aim is to provide information about dementia and offer support and guidance to families. The services for people with younger onset dementia, and children and young people who have a parent with dementia, will be continued. During the plan period educational programmes for people who themselves have dementia will also be developed that will provide information and knowledge on dementia to the participants and serve as meeting places for the exchange of experiences and mutual support. The educational programme for people with dementia will be developed in close cooperation with user organisations.

Cooperation with the voluntary sector

The Ministry of Health and Care Services has developed a strategy for voluntary work in the health and care field in cooperation with KS and the Association of NGOs in Norway. The strategy will form a basis for systematic cooperation between the public and private sectors, encourage more voluntary work and combat loneliness among people with dementia. It will also be used as a basis for the development of local strategies and local voluntary sector policy. The Ministry of Local Government and Modernisation has published an inspirational booklet on how NGOs and municipalities can cooperate more effectively.

Cooperation with and support for NGOs that carry out information activities at the local level will be continued.

Mobilisation against loneliness

The Government wishes to help prevent loneliness in older people and people with dementia. More social contact and activities such as walking groups, dance groups, visitors and activity friends for older people will be promoted through cooperation with the voluntary sector. Technological tools will be developed that can help the older person maintain and strengthen their ability to keep up their social network. Day activity services at day centres for older people will be expanded through measures to counteract loneliness, passivity and social withdrawal among older people in general and people with dementia in particular.

Strategy for a modern policy for older people

The Government will present a strategy for a modern policy for older people in 2016. The strategy is a response to the growing proportion of older people in the population, the longer life expectancy and the fact that older people are in better health than formerly and have more opportunities to live active lives and participate in society. The main aim of the strategy is to promote activity through employment, voluntary work, participation in the local community, social life and physical activity. The intention is to combat passivity in people in their 60s and 70s and to enable them to pursue their interests and social activities. More emphasis will be given to health promotion throughout the life course and to ways in which the community can strengthen the individual's functional capacity despite any physical or other limitations they may have. All social sectors are responsible for establishing schemes that enable older people to live active lives.

When the Dementia Plan has been implemented in 2020:

- The municipalities will have a legal obligation to provide day activity services for people with dementia.
- Flexible respite services will have been developed in line with the national informal care programme.
- Educational programmes for people with dementia and educational programmes and dialogue groups for family members should have been introduced throughout the country.
- Cooperation with the voluntary sector will have been strengthened.

5.5 A patient care pathway with systematic follow-up and tailored services

Long-term strategy

High-quality services for people with dementia are tailored to the individual and the disease phase. Treatment must be based on the person's resources and functional level, and should involve adapting their environment and the services they receive to encourage coping skills as far as possible. This requires time, competence and conditions that promote the development of differentiated alternatives and solutions.

Dementia is a progressive condition, and many people need extensive help and care over a relatively long period in the disease course. The care services must be organised in terms of content and practicality in a way that enables them to deal with behavioural and psychological problems and a decline in physical functioning. To reduce the use of coercion and foster cooperation and a sense of security, it is essential to establish relations of trust and confidence with the person with dementia. Personnel can develop awareness and effective methods for avoiding the use of coercion through a continual dialogue on training, guidance and best practices.

Many people with dementia have multiple diseases and take a number of different pharmaceutical drugs. There is a need for better medication management in both home care and nursing homes. The Government will therefore clarify the division of roles and responsibilities and establish better routines to ensure correct medication therapy for older people in general and people with dementia in particular. These efforts will include combating the widespread, detrimental use of antipsychotics and other psychiatric drugs. There is also a need to combat the practice of continuing the use of medication for symptom relief in one disease phase when the patient enters a new phase with different symptoms.

The need for care increases as dementia progresses and functional ability declines. This affects cognitive functioning, the ability to communicate, mobility, hygiene and basic body functions, leading to for example difficulty in eating and incontinence. Older people with dementia are at risk of undernourishment, and special attention must be paid to food, nutrition and meals.

The Government wishes to facilitate high-quality care and palliative treatment that will enable people with dementia to remain in contact with their family and friends and experience good moments despite serious illness and severe functional impairment. Surveys have shown that both users and family members are satisfied with the professional care provided by nursing homes and home care services, and that municipal care services are generally good. Given the growing number of people with dementia in the years to come, ensuring that the users of today and tomorrow receive proper care will be largely a question of capacity. It will require municipalities to make extensive, long-term investment in competence and person-years.

Another important measure for providing an integrated service to people with dementia and their families is to strengthen the mental health service and increase the use of team-based services, as discussed in the white paper *The Primary Health and Care Services of Tomorrow – Localised and Integrated*.

The Dementia Plan 2020 is based on existing knowledge that indicates that living in a small, easily navigable physical environment with few residents is beneficial for people with dementia, and that environments in residential facilities that aggravate the symptoms and the disease and reduce the ability to cope should be avoided. Assisted living facilities with 24-hour care built for those who can no longer live at home must have common areas for social interaction with others and should as far as possible be open to and integrated with the local community. The Government's goal is a society that is more dementia-friendly as a whole, and not special communities for people with dementia. We will therefore improve the services for people with dementia and their families by increasing the number of assisted living facilities that provide 24-hour care.

Research has shown that language barriers between professionals and users endanger patient safety. It is therefore important that the health and care services are aware of the risks and use qualified interpreters. According to the report NOU 2014: 8, *Talking i offentlig sektor* (on interpreting in the public sector), interpreters are little used by the health and care services. The Government will consider how to follow up the report.

Box 5.7 Livsarket mitt

The senior forum of the association of Norwegian occupational therapists has developed a project LIVSARKET (life story). LIVSARKET is a book of life: information about the individual's life, interests, preferences and habits, for use by those in everyday contact with them.

www.ergoterapeutene.org

Box 5.8 Work team in Hamar

Experience has shown that the way the services are organised can have significant consequences for people with dementia, their families and the professionals. Hamar municipality has had great success with its work teams, which ensure continuity and familiarity in relations with individuals with dementia. Task-based work teams serve as a model for the organisation of the home care services. They are small, stable groups of competent personnel who provide patients such as people with dementia with the security that comes from a clearly structured daily programme and predictable services. The team is responsible for particular tasks within a defined framework, and the members cooperate on all the processes necessary for a high-quality service.

Hamar municipality – Centre for Development of Institutional and Home Care Services (2014).

Box 5.9 Patient-centred coordination on discharge to a nursing home

Many older people with mental disorders also have complex, long-term health problems that make extensive demands on both municipal and specialist health services. Patient-centred cooperation on discharge to a nursing home is a collaboration between Oslo University Hospital (Alderpsykiatrisk seksjon (the geriatric psychiatry section)) and Oslo municipality. Under the project a number of measures were developed to strengthen coordination between hospitals and nursing homes within the framework of an increasingly complex health and care service. The project was terminated in 2014, and the measures are in routine use at the geriatric psychiatry section.

Jensen and Rekve 2014

Measures in the plan period 2016-2020

Better medication management

Medication management makes great demands on the municipal health and care services. All the services that medicate patients need to introduce adequate, quality-assured procedures for ensuring correct treatment and medication management. Under

the patient safety programme, around 230 municipalities participate in a project for the correct use of medication. In the white paper on the administration of pharmaceutical drugs the Government announced that it would issue regulations on the duty of municipalities to undertake systematic reviews of the use of medication for nursing home residents, most of whom have dementia.

Use of coercion under Chapter 4A

In 2009 new legislation came into force on health care for people who lack the capacity to give consent (Chapter 4A of the Patients' Rights Act), in order to limit and control the use of coercion. The rules were evaluated in 2013/2014. The findings indicated that there was no reason to amend the legislation, but that it was necessary to strengthen the competence of personnel in the health and care services, ensure that they are better informed about the use of coercion and develop a more consistent registration practice. The Directorate of Health has developed comprehensive educational and guidance material, which is used extensively under the auspices of the counties. The present efforts to improve competence and educate personnel will now be evaluated. The Directorate of Health has been made responsible for examining various network models for education and the exchange of experience.

Learning networks for an integrated patient care pathway

In order to strengthen the medical and health care follow-up of people with dementia who receive home care services, the learning network for an integrated patient care pathway for older people with complex needs will be continued as part of the implementation of the white paper *The Health Services of Tomorrow – Localised and Integrated*.

Strengthening the home care service

People with dementia will be given the opportunity to live as long as possible in their own homes, and a three-year programme for developing and testing models for home care services for people with dementia will be implemented. The programme is intended to test different ways of working and organising the home care service that will benefit people with dementia and their families. The services must take account of each individual family's situation, needs and resources. The aim is to provide more continuity, predictability and security.

Residential facilities

Under the investment grant scheme for places in residential facilities for people in need of 24-hour health and care services, such as nursing homes and assisted living facilities with 24-hour care, new buildings and modernisation of existing buildings will make residential facilities more dementia-friendly by creating small departments and housing collectives with space for community living and social activities. The grant scheme of the State Housing Bank imposes certain requirements on the design of living units. They must be based on universal design principles, adapted to people with dementia and cognitive impairment, and equipped for the use of electronic aids to daily living, communication and alarm technology, and other forms of welfare technology.

Cooperation has been established with KS on identifying and assessing future needs in connection with the building of residential facilities with 24-hour care up to 2020. The prognoses for future construction needs presented in the white paper *Future Care* (Meld. St. 29 (2012-2013)) will be revised and further analyses conducted in cooperation with Statistics Norway, and the need for the modernisation and upgrading of municipal residential facilities with 24-hour care will be re-assessed. The new institutions

and assisted living facilities built in the last few years should also be re-evaluated with a view to establishing how well they function for those who live and work in them and for the families and the local community. The Dementia Plan 2020 will be based on the presumed net growth in places in residential facilities with 24-hour care.

Together with Ageing and Health, the Directorate of Health has participated in the programme Joint Action on Dementia under the EU's Third Health Programme (2014–2020). Norway is responsible for leading the work on the work package Quality of Residential Care. The aim of the Joint Action is to promote the implementation in EU/EEA member states of coordinated actions to improve the situation of people with dementia and their carers, including the development of residential facilities with 24-hour care.

Palliative care

Through funding for competence-building measures in the area of end-of-life palliative treatment and care, projects have been established to raise the level of employees' expertise in palliative treatment. An educational programme on palliative treatment for people with dementia will be developed, which will be viewed in relation to the funds allocated for the information programme on palliative care and the Dementia ABC education program.

Palliative treatment is also available in the specialist health services throughout the country, and almost all health enterprises have a special team to provide such treatment. All health regions have established competence networks of nurses working with cancer care and palliative treatment.

Quality development in nursing homes – safety standard

As part of the focus on quality in the health and care services, a project will be initiated on designing tools for quality development in nursing homes. The goal is that all nursing home residents receive adequate services on an equal footing. The system will consist of a set of criteria for good practice and a method for fulfilling the criteria in the individual nursing home. The focus will be on five main areas: management, organisation, professional practice, innovation and patient outcomes. The final product will be a tool for quality development and a safety standard that can be used in all nursing homes throughout the country.

When the Dementia Plan has been implemented in 2020:

- Models for home care services for people with dementia will have been developed and tested.
- Residential facilities with 24-hour care that have been built or modernised with a grant from the State Housing Bank will be adapted to people with dementia and cognitive impairment.
- The standard of palliative treatment and care for people with dementia will have been improved.
- The medical and health care services for people with dementia will have been strengthened, among other things through a learning network for an integrated patient care pathway.

5.6 Research, knowledge and competence

Long-term strategy

One of the key elements in making society more dementia-friendly is to spread knowledge about dementia, including among individuals who live with a dementia diagnosis. The general public and the different social sectors need information to enable them to take account of and adapt to people with dementia.

Another major challenge for the dementia care services is to ensure access to a sufficient number of competent and qualified health and social services personnel. This can be done primarily by education and recruitment measures and by strengthening professional expertise in the areas of mental health, geriatrics and dementia. There is at present little interest in and knowledge about age-related illnesses, and little professional status attached to working in services for older people. All health care and social welfare educational programmes at university, university college and upper secondary school level should adapt their curriculums to take account of the challenges posed by the growing number of people with dementia, and there is a need to increase knowledge and competence concerning people with dementia with a Sami or minority language background.

The Government will implement the Competency Plan 2020 for recruitment, competency and professional development in the health and care services that was presented in the 2015–2016 budget proposal. The plan is intended to strengthen the professional competence of the municipal health and care services and ensure that the sector has adequate staffing and competent personnel. The measures are intended to ensure sound recruitment procedures, high levels of competence and a better division of expertise between the municipal health and care services and the specialist health services. The measures in the Competency Plan 2020 will be strengthened with a view to addressing the challenges to the competence and expertise of these services that are posed by users with chronic diseases with multiple conditions and complex needs, including people with dementia.

We need to obtain more knowledge about planning, developing and improving services to people with dementia, and to raise the status of dementia care. The Ministry of Health and Care Services will therefore give priority to research on the health and care services with a special emphasis on dementia.

The development centres for nursing homes and home care services in all counties will serve as a driving force for improving knowledge and quality in the care services through a focus on research, professional development and competence-building, and will contribute to the further development of trainee workplaces for school pupils, apprentices and students. The development centres are intended to serve as models for other home care services and nursing homes in the county concerned and to disseminate knowledge and professional skills, including in the area of dementia. The municipalities that have development centres are part of a common network linked to the Centre for Care Research, which is located in five educational institutions for health and social welfare personnel in the various health regions.

Box 5.10 The children's book *Bestefar på rømmen*

One day when Lukas came home from school he found grandfather in the bushes, hiding from the soldiers. Why has he suddenly started doing so many weird things? The writer Simon Stranger was commissioned by the Church City Mission to write the children's book *Bestefar på rømmen* (Grandfather Has Run Away), with illustrations by Kristin Berg Johnsen. This entertaining book proposes helpful things to do to make it easier for adults to discuss dementia with children and to remove some of the shame attached to this condition.

www.bymisjon.no

Box 5.11 The Norwegian dementia registry

Reliable registry data are an important source of knowledge, and can lead to improvements in quality and further research. The Norwegian dementia registry, which is administered by Ageing and Health, is the national quality registry for dementia. By 21 January 2015, 21 studies had been performed using data from the registry in the fields of dementia, depression, physical activity, treatment, patient evaluation, use of resources, genetics and respite care for families.

www.aldringoghelse.no

Box 5.12 The EU Joint Programme – Neurodegenerative Disease Research

The Joint Programme Neurodegenerative Disease Research (JPND) is a global research initiative that was launched in response to the extensive need for knowledge about the causes, diagnosis, treatment and follow-up of patients with neurodegenerative diseases. The challenge is so formidable that it can only be addressed by research at the international level. The JPND launched three Joint Transnational Calls for proposals in 2014, and Norwegian scientists achieved success in two of them. Counting the four researchers who received grants in 2014, there are now eight projects with Norwegian participation supported by the JPND.

www.neurodegenerationresearch.eu

Measures in the plan period 2016–2020

Information activities

The public needs to become more aware of dementia. The Directorate of Health will therefore launch a new information campaign on dementia in the course of the plan period. The campaign is intended to promote greater openness about dementia and increase knowledge and access to information about the various dementia diseases. There will be a focus on reducing physical and social barriers in society that prevent people with dementia from participating on an equal footing. User organisations will be involved in the development of the campaign.

Educational courses for relevant sectors of society – a dementia friend

In order to promote greater openness, understanding and knowledge about dementia in society at large, a three-year programme will be started to develop simple training courses for relevant areas of society, including working life and service industries. Enterprises and other actors will be invited to participate in the programme. The aim is to give the various sectors a basic knowledge of dementia so that they can contribute to a more dementia-friendly society.

Competence-building – patient evaluation and diagnosis

During the plan period, the Ministry of Health and Care Services will facilitate competence-building among health and care services personnel with a view to improving knowledge about patient evaluation and diagnosis in dementia. The goal is to raise the level of expertise through educational programmes, guidance and follow-up. The efforts are a continuation of the work done by Ageing and Health under the Dementia Plan 2015.

The Dementia ABC education program and the Psychosocial Intervention ABC educational programmes

The Ministry of Health and Care Services will further develop and disseminate the Dementia ABC education program and the Psychosocial Intervention ABC educational programme to municipal health and care services personnel. The aim is to strengthen competence on dementia.

Milieu therapy

A national competence centre on culture, health and care has been established to develop and disseminate therapeutic methods and ways of working in milieu therapy. Educational programmes on milieu therapy and the integrated use of music and singing designed for employees in the care services in general and in services for people with dementia in particular will be further developed and disseminated.

Building ethical competence

The Government will continue the focus on systematic ethical competence-building among employees in the municipal health and care services. This will be linked even more closely to quality and professional development. KS will assist municipalities in these efforts through national follow-up and local guidelines. The Centre for Medical Ethics at the University of Oslo will undertake systematic, long-term work on the development of ethical competence in the municipal health and care services.

Leadership training

Sound management is essential for the development of high-quality services. There is a need for a greater number of managers, primarily managers with good leadership skills. In 2015, the Government therefore established a national leadership training programme for the primary health service targeted at managers in the county and municipal health and care services. The programme carries 30 study points at master's degree level.

People with a Sami or minority language background

The Government will continue the focus on disseminating knowledge and information about people with a Sami or minority language background who develop dementia. The Centre for Care Research, North Norway, has published the booklet *Helse- og omsorgstjenester til samiske eldre* (Health and Care Services for Older Sami), which contains information on the aspects of Sami culture that are relevant for municipal health and care personnel. The booklet will be disseminated to all municipalities. The goal of these efforts is to enhance the competence of personnel who encounter people with a Sami or minority language background who develop dementia.

People with disabilities

A grant scheme for municipalities has been established for strengthening professional and services development and competence-building among personnel in the services for people with disabilities. Grants are awarded for activities that provide a high standard of professional and services development and have national application.

Competency and innovation grant scheme for municipalities

A competency and innovation grant scheme has been established to strengthen municipal capacity of and provide opportunities for municipalities to develop sustainable, high-quality health and care services. The grant will enable municipalities to implement competence-building measures and innovation and development activities based on local conditions and needs. It is also intended to promote the development of new activities and methods for collaboration with families and volunteers in the care sector in general and dementia care in particular.

Research

The Research Council of Norway will establish three new comprehensive cross-disciplinary 10-year programmes: a comprehensive programme for services research, *Gode og effektive helse-, omsorgs- og velferdstjenester* (Good and effective health, care and welfare services, under HelseVel), and two even more extensive programmes for practice-based clinical research and prevention respectively. Funding for care research and for building an infrastructure for care research will be included in the services research programme.

A knowledge of the prevalence of dementia in Norway has socioeconomic significance for the individual and for the ability to plan future health and care services, and in terms of the potential for prevention. A study on the prevalence of dementia will be carried out.

Municipal patient and user registry

The Government is in the process of establishing a patient and user registry for the municipal health and care services. There are considerable gaps in our knowledge

about the quality and activities of these services. The registry will compile and make accessible systematic, reliable data from all segments of the municipal health and care services, which will be used as a basis for administration, management, quality development and research. There is a need to strengthen the municipalities' workflow management systems¹ and ensure effective decision-making and process support for employees in the services.

Municipal planning

The implementation of the Care Plan 2015 strengthened municipal planning in the health and care field, and the national survey of services to people with dementia (Gjøra et al. 2015) showed that just over 70 % of municipalities have put the dementia challenges of the future on their planning agenda.

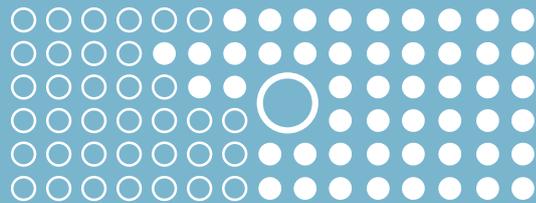
The evaluation of the Care Plan 2015 (Hagen et al. 2015) showed that municipalities that plan their care services are better at adapting the services to demographic changes and addressing major social challenges such as that posed by the increased prevalence of dementia. The challenge of dementia should therefore be incorporated into the ordinary municipal planning agenda.

When the Dementia Plan has been implemented in 2020:

- Systematic information activities will have been carried out.
- An educational programme for the relevant social sectors will have been developed and disseminated.
- Personnel who provide services to people with dementia will have been educated in the basics of dementia.
- Milieu therapy methods and ways of working will have been developed and disseminated throughout the country.
- The knowledge base for developing activities and high-quality services for people with dementia will have been strengthened through research and development activities.
- The municipalities will have put the challenges of dementia on the municipal planning agenda.

¹ Translation of the Norwegian term "fagsystemer".

6



Economic and administrative consequences

Economic consequences

The Government considers it important that municipal services to people with dementia are developed and integrated with the ordinary health and care services, tailored to local conditions and close to users. The Government also wishes to point out that the municipalities are primarily responsible for organising their ordinary health and care services to include people with dementia, for developing the necessary competence and for making the required building alterations. The Dementia Plan 2020 has more specific targets based on the general measures in the Government's Care Plan 2020 and the NCD strategy. The Dementia Plan must also be viewed in the context of the implementation of the white paper *Primary Health and Care Services of Tomorrow - Localised and Integrated*. The Government will revert to the measures in the Dementia Plan 2020 in connection with the annual budget proposals.

Financing of the day activity service

The Government will propose an amendment to the Health and Care Services Act requiring municipalities to offer a day activity service to people with dementia living at home as from 1 January 2020. The plan is to further develop the service in the period up to 2020.

A survey carried out in 2010 showed that only 9.3 % of people with dementia living at home had access to a day activity service. The need for such activities depends on the number of people with dementia who are interested, and the present grant scheme for the municipalities was based on the assumption that 75 % of people with dementia would want to avail themselves of the service. This meant that the day activity service would have to cater for around 23 000 more people than at present. On the assumption that each place is used by an average of around 2.5 people per week, around 9200 places in day activities would be needed. These are fairly rough estimates.

The underlying data for calculating the grant were presented in the annual budget proposals for the period 2012–2014. Each place costs around NOK 230 000 (2016 NOK). The earmarked municipal grant covers around 30 % of this and the remaining costs are covered by the increase in unbound income.

From 2012 to 2014 grants were allocated for around 2100 places in day activities, and in 2015 for a further 1070 places. When these places have been established, previous estimates show that there will be a need for a further 6000 places for people with dementia living at home. On the basis of the estimates on which the present grants for day activity service are based, this means that the total cost of the remaining places will amount to around NOK 1.385 billion. Around NOK 416 million (30 %) of this will come from the government grant and the remainder from the growth in unbound income. Municipalities must apply for grants and report on their use of the funds in accordance with existing rules. The scheme is administered by the Directorate of He-

alth. The grant will be included in the municipalities' unbound income when the legal obligation to provide day activity services enters into force.

Financing of competence-building measures

The Government will promote the development of professional expertise and an adequate number of qualified personnel in the health and care services through the Competency Plan 2020. The strategies and measures in the Competency Plan are presented in the budget proposal (Prop. 1 S (2015–2016)).

Financing of building and modernisation of residential facilities for people in need of 24-hour health and care services

The building or modernisation of all nursing homes and assisted living facilities with 24-hour care funded by the grant scheme administered by the State Housing Bank must follow universal design principles and be adapted to people with dementia and cognitive impairment. There is a considerable need for rebuilding and adaptation of older buildings, and also for more places in small, easily navigable housing units suitable for people with dementia. The present grant scheme covers on average 50 % of the costs of the building and upgrading of these residential facilities. The proposed grant framework for 2016 has a commitment quota of NOK 4100 million, which will cover investment grants for approximately 2500 places in nursing homes and assisted living facilities with 24-hour care. In the 2015–2016 budget proposal, the maximum facility cost per unit will be raised from NOK 2.972 million to NOK 3.06 million for municipalities outside densely populated areas, and from NOK 3.4 million to NOK 3.5 million for densely populated municipalities.

Administrative consequences

The Dementia Plan 2020 contains long-term strategies, targets for the period up to 2020 and specific measures that will be considered in connection with the annual government budget.

The Directorate of Health is responsible for implementing the Dementia Plan 2020, primarily through its cooperation with the county governors and municipalities. The municipalities will need incentives and assistance in planning the development of local communities and health and care services adapted to the growing number of people with dementia and their families.

The State Housing Bank has the primary responsibility for investment, and in cooperation with the county governors administers the grant scheme for places in nursing homes and assisted living facilities with 24-hour care.

National surveys of the municipal services available to people with dementia will be carried out every four years. Sample surveys of municipal and specialist health services will also have to be made in order to obtain documentation and data at the national level.

An evaluation programme will be initiated in 2016 for the Care Plan 2020, which will also include the Dementia Plan 2020. The evaluation will be results based and will examine among other things how well newly built residential facilities with 24-hour care function for those living and working in them, and for the families and the local community.

References

- Agenda Kaupang. 2012. En naturlig avslutning på livet. Mer helhetlig pasientforløp i samhandlingsreformen. Palliativ omsorg, trygghet og valgfrihet (A natural end to life. A more integrated patient care pathway in the hospital-municipal health and care cooperation. Palliative care, security and freedom of choice). Report, 31 October 2012, commissioned by KS. Oslo: Agenda Kaupang.
- Alzheimer's Disease International. 2014. *The World Alzheimer Report 2014. Dementia and Risk Reduction: An analysis of protective and modifiable factors.*
- Alzheimer Europe. 2014a. *Dementia in Europe Yearbook 2014. National care pathways for people with dementia living at home.*
- Alzheimer Europe. 2014b. *The prevalence of dementia in Europe: Norway*
[http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/The-prevalence-of-dementia-in-Europe/Norway/\(language\)/eng-GB](http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/The-prevalence-of-dementia-in-Europe/Norway/(language)/eng-GB)
- Berg, Grethe. 2012. *Måltider er mer enn mat; Personer med demens i dagaktivitetstilbud* (Meals are more than food. People with dementia and the day activity service). Norwegian National Advisory Unit on Ageing and Health. Published by Forlaget Aldring og helse.
- Bergh, Sverre, Corinna Vossius, Geir Selbæk, Arnt Egil Ydstebø, Jurate Saltyte Benth, Geir Godager and Hilde Lurås. 2015. *Ressursbruk og sykdomsforløp ved demens (REDIC)*. Kortversjon. (Resource use and disease course in dementia. Short version.) November 2015. Alderspsykiatrisk research centre, Sykehuset Innlandet.
- Blom, Svein. 2008. *Innvandrerers helse 2005/2006* (Immigrants' health 2005/2006). Report Statistics Norway 2008/35.
- Dalsbø, Therese, Kirkehei, Ingvild and Dahm Kristin Thuve. 2014. Effekten av botilbud til mennesker med demens (The effect of different types of housing on people with dementia). Notat 2014. Oslo: Norwegian Knowledge Centre for the Health Services.
- Gautun, Heidi and Christopher Bratt. 2014. *Bemanning og kompetanse i hjemmesykepleien og sykehjem* (Staffing and competence in the home care services and in nursing homes). Report, NOVA 14/14.
- Gjevjon, Edith Roth. 2015. Kontinuitet i hjemmesykepleien - vanskelige vilkår, men gode muligheter (Continuity in home nursing - difficult conditions but good opportunities). *Tidsskrift for omsorgsforskning*, 1:18-26.
- Gjøra, Linda, Arnfinn Eek and Øyvind Kirkevold. 2015. *Nasjonal kartlegging av kommunenes tilrettelagte tjenestetilbud for personer med demens* (National survey on the municipalities' tailored services for people with dementia). Norwegian National Advisory Unit on Ageing and Health.
- Gonzalez, T. Marianne and Kirkevold Marit. 2014. Benefits of sensory garden and horticultural activities in dementia care: a modified scoping review. *Journal of Clinical Nursing* 23, 2698-2715.
- Hagen, Terje P., Heidi Gautun, Anders Kvale Havik, David P. McArthur, Tron A. Moger, Bente Ø. Kjøs, Maren Sogstad, Laila Tingvold, Trond Tjerbo, Tor Inge Romøren and Marijke Veenstra. 2015. *Resultatevaluering av Omsorgsplan 2015: Faglig sluttrapport* (Final report on evaluation of the results of the Care Plan 2015).

- Hamar municipality – Centre for Development of Institutional and Home Care Services. 2014. *Funksjonsinndelte arbeidslag i hjemmebasert omsorg – i innovasjon i praksis* (Function-based work teams in home-based care – innovation and practice). Report February 2014.
- Haugan, Gørill, Ruth Woods, Karin Høyland and Øivind Kirkevold. 2015. Er smått alltid godt i eldreomsorgen? Kunnskapsstatus om botilbud (Is small always good in care for older people? Knowledge status on housing services). SINTEF notat 16.
- Haugland, Britt Øvrebø. 2012. Meningsfulle aktiviteter på sykehjemmet (Meaningful activities in nursing homes). *Sykepleien Forskning* 2012 7 (1):40-47.
- Ministry of Health and Care Services. 2007a. Circular I-5/2007. Aktiv omsorg (Active care).
- Ministry of Health and Care Services 2007b. *Delplan til Omsorgsplan 2015 Demensplan 2015 "Den gode dagen"* (Subplan of Care Plan 2015. Dementia Plan 2015: Making the most of the good days).
- Ministry of Health and Care Services. 2013. Meld. St. 29 (2012–2013) *Morgendagens omsorg* (white paper on the care service of tomorrow).
- Ministry of Health and Care Services. 2013. *NCD strategy 2013-2017. For forebygging, diagnostisering, behandling og rehabilitering av fire ikke-smittsomme folkesykdommer; hjerte- og karsykdommer, diabetes, kols og kreft* (Prevention, diagnosis, treatment and rehabilitation in the four main types of non-communicable chronic diseases: cardiovascular diseases, diabetes, COPD and cancer).
- Ministry of Health and Care Services. 2015a. Meld. St. 19 (2014-2015) *Folkehelsemeldingen – Mestring og muligheter* (white paper on public health).
- Ministry of Health and Care Services. 2015b. Meld. St. 26 (2014-2015) *The Primary Health and Care Services of Tomorrow – Localised and Integrated* (white paper).
- Ministry of Health and Care Services. 2015c. Meld. St. 28 (2014-2015) *Legemiddel-meldingen. Riktig bruk – bedre helse* (white paper on the administration of pharmaceutical drugs. Correct use – better health).
- Ministry of Health and Care Services. 2015d. *The Care Plan 2020. The Government's plan for the care services 2015–2020.*
- Directorate of Health. 2007. *Glemsk, men ikke glemt! Om dagens situasjon og framtidens utfordringer for å styrke tjenestetilbudet til personer med demens* (Forgetful but not forgotten! On the present status and future challenges of improving services for people with dementia). Rapport IS-1486
- Directorate of Health. 2013. *Fallforebygging i kommunen. Kunnskap og anbefalinger* (Preventing falls in the municipality. Knowledge and recommendations). Rapport IS-2114.
- Directorate of Health. 2015. *Tilbudet til personer med behov for lindrende behandling og omsorg mot livets slutt – å skape liv til dagene* (Report on the services available for people in need of end-of-life palliative treatment and care). Rapport IS-2278.
- Directorate of Health. 2010. *Landsomfattende tilsyn med kommunenes helse- og sosialtjenester til eldre 2010. Tilsyn med kommunenes tiltak for å identifisere, utrede og følge opp hjemmeboende eldre med demenssykdom, herunder samarbeid med fastlegene* (National supervision of municipal health and social services for older

REFERENCES

- people 2010. Supervision of municipal measures to identify, examine and follow up older people with dementia living at home, including cooperation with GPs). Internserien 12/2010.
- Norwegian Board of Health. 2011. *Samlerapport fra tilsyn i 2010 med kommunenes sosial- og helsetjenester til eldre. Krevende oppgaver med svak styring* (Report on the inspection and enforcement of municipal health and social services for older people in 2010. Demanding tasks and weak management). Rapport 5/211.
- Norwegian Board of Health. 2014. *Oppsummering av satsinga på tilsyn med helse- og omsorgstenester til eldre 2009-2012* (Summary of inspection and enforcement of health and care services to older people). Rapport 1/2014.
- Holthe, Torhild. 2013. *Kunsten å skynde seg sakte. Formidling av kognitive hjelpemidler til personer med demens* (The art of making haste slowly. Distribution of cognitive aids to people with dementia). Manual. Norwegian National Advisory Unit on Ageing and Health. Published by Forlaget Aldring og helse.
- Hotvedt, Kirsti. 2010. *Etablering og drift av pårørendeskole. Kunnskap, støtte og fellesskap for pårørende til personer med demens* (Establishment and operation of the educational programme for families of people with dementia. Knowledge, support and community). Manual. Norwegian National Advisory Unit on Ageing and Health (Ageing and Health). Published by Forlaget Aldring og helse.
- Iden, Kristina Riis. 2015. *Depresjon i sykehjem. Underdiagnostikk og overbehandling* (Depression in nursing homes. Underdiagnosis and overtreatment). University of Bergen.
- Ingebretsen, Spilker Sagbakken. 2015. *Eldre innvandrere og demens. Erfaringer fra eldre, pårørende og ansatte i omsorgstjenesten* (Older immigrants and dementia. Lessons learned from older people, their families and care service personnel). NAKMI – rapport no. 1. 2015, Norwegian Centre for Minority Health Research (NAKMI) in cooperation with the research institute NOVA, Oslo and Akershus University College of Applied Sciences.
- Jensen, Liv Helene and Karin Håvarstein Rekve. 2014. *PASSUS – Pasientorientert samhandling ved utskrivning til sykehjem* (Patient-centred cooperation on discharge to a nursing home). Skriftserien, University College of Southeast Norway, no. 5/2014.
- Jessen, Jorunn Theresia. 2014. *Kommunale avlastningstilbud* (Municipal respite care service). NOVA report 12/14.
- Jorm, A.F., Korten, A.E. and Henderson, A.S. 1987. The prevalence of dementia: a quantitative integration of the literature. *Acta Psychiatrica Scandinavica* 76: 465-79.
- Ministry of Local Government and Modernisation. 2015a. *Brukervalg i kommunal tjenesteyting. Veileder for kommuner som ønsker å innføre brukervalg* (Freedom of choice for users in municipal service provision. Guidelines for municipalities intending to introduce freedom of choice for users).
- Ministry of Local Government and Modernisation. 2015b. *Samarbeid mellom frivillige og kommuner. Råd og veiledning til kommuner som vil inngå samarbeid med frivillige* (Cooperation between municipalities and the voluntary sector. Guidelines for municipalities on cooperation with voluntary organisations). Booklet.

- KORFOR Alcohol and Drug Research Western Norway. 2015. *Eldres rusmiddelbruk. Alkoholbruk og alkoholrelaterte helsemessige og sosiale problemer blant eldre og helsemessige og sosiale problemer blant eldre i LAR* (Substance abuse in older people. Alcohol use and alcohol-related health and social problems among older people, and health and social problems among older people in drug-assisted rehabilitation).
- Norwegian Knowledge Centre for the Health Services. 2014. *Livets sluttfase – om å finne passende behandlingsnivå og behandlingsintensitet for alvorlig syke og døende* (The end of life – deciding on the appropriate level of treatment for seriously ill and dying patients). Rapport no. 18 – 2014.
- Landmark, Brynjar, Ingvild Kirkehei, Kjetil Gundro Brurberg and Liv Merete Reinar. 2009. *Botilbud til mennesker med demens* (Housing services for people with dementia). Rapport No 11 – 2009. Norwegian Knowledge Centre for the Health Services.
- National Association of Public Health. 2014. *Nasjonalforeningen for folkehelsens råd til butikker og servicenæring* (Advice to shops and service industries). See www.nasjonalforeningen.no/
- Official Norwegian Report 2005: 8 *Likeverd og tilgjengelighet – Rettslig vern mot diskriminering på grunnlag av nedsatt funksjonsevne. Bedret tilgjengelighet for alle* (Equal worth and access – legal protection from discrimination on grounds of disability. Better access for everyone). Ministry of Justice and Public Security.
- Official Norwegian Report 2011:11 *Innovasjon i omsorg* (Innovation in the care services). Ministry of Health and Care Services.
- OECD. 2015. *Adressing Dementia. The OECD Response*. Health Policy Studies 2015.
- Prince, M., Albanese, E., Guerchet, M. and Prina, M. 2014. World Alzheimer Report 2014: *The benefits of early diagnosis and intervention*. Alzheimer's Disease International.
- Robinson L. Dickinson, C. Rousseau N., Beyer F., Clark A., Hughes J. et al. 2014. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and Ageing* 2012 41:263-269.
- Rognstad, May-Karin, Idunn Brekke, Eva Holm, Cecilie Lindberg and Nina Lühr. 2013. *Underernæring hos eldre hjemmeboende personer med demens* (Undernourishment in older people with dementia living at home). *Sykepleien forskning* no. 4, doi: 10.4220/sykepleienf2013.0137.
- Rugtvedt, Lisbet. 2013. *Skam må bekjempes med kunnskap og holdninger* (Combating shame through knowledge and attitudes). *Tidsskrift for Den norske legeforening*, no. 23-24, 2013:133.
- Selbæk, Geir, Kirkevold Øyvind and Engedal Knut. 2007. The prevalence of psychiatric symptoms and behavioural disturbances and the use of psychotropic drugs in Norwegian nursing homes. *International Journal of Geriatric Psychiatry* 2007 September 22 (9) :843-9.
- Selbæk, Geir and Harald A. Nygaard. 2009. *Antipsykotika til eldre: Farene er kjent – forskrivningspraksis fortsetter som før* (Antipsychotics for older people: the risks are known, prescription practices continue as before). *Demens & Alderspsykiatri* vol. 13,no.1 2009.

REFERENCES

- Selbæk, Geir. 2014. *Recent research in old age psychiatry*. Landskonferansen i alderspsykiatri 2014, 30.04.2014. Bodø.
- Socialstyrelsen. 2014. *Demenssjukdomarnas samhällskostnader i Sverige 2012* (The public cost of dementia diseases in Sweden 2012).
- Strandli, Elin H. Aarø et al. 2007. *Den beste dagen på mange år. Dagtilbud for personer med demens i Grønn omsorg* (The best day I've had for years. Providing green care for people with dementia). Norwegian National Advisory Unit on Ageing and Health. Published by Forlaget Aldring og helse.
- Strydom Andre, Trevor Chan, Michael King, Angela Hassiotis and Gill Livingston. 2013. Incidence of dementia in older adults with intellectual disabilities. *Research in Developmental Disabilities* Volume 34, Issue 6, June 2013, pp 1881-1885.
- Taranrød, Liv Bjerknes. 2011. *Mellom hjem og institusjon. Rapport fra utviklingsprogrammet med dagtilbud og avlastningsordninger for personer med demens* (Between home and institution. Report on the programme for developing day activity services and respite arrangements for people with dementia). Norwegian National Advisory Unit on Ageing and Health (Ageing and Health). Published by Forlaget Aldring og helse.
- UNECD. 2015. Dignity and non-discrimination for people with dementia. Policy Brief.
- Van der Steen, Jenny T., Lukas Radbruch, Cees MPM Hertogh, Marike E. de Boer, Julian C. Hughes, Philip Larkin, Anneke L. Francke, Saskia Jünger, Dianne Gove, Pam Firth, Raymond T.C.M. Koopmans and Ladislav Volicer. 2014. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine* vol. 28 (39) 197-209.
- Wergeland, Jon N., Geir Selbæk, Lisbeth D. Høgset, Ulrika Söderhamn and Øyvind Kirkevold. 2014. Dementia, neuropsychiatric symptoms and the use of psychotropic drugs among older people who receive domiciliary care: a cross-sectional study. *International Psychogeriatrics* vol. 26 (3) 383-391.
- Westergaard, Britt-Evy and Frode Kipsgaard Larsen. 2004. Aldring hos mennesker med utviklingshemning (Ageing in persons with disabilities). *Demens* vol. 8/no. 3 2004.
- Wogn-Henriksen, Kjersti. 2012. *Du må ... skape deg et liv*. Avhandling for graden philosophiae doctor (You must ... get yourself a life. PhD thesis). Institute of Psychology, Norwegian University of Science and Technology.
- World Health Organization. 2015. *World report on ageing and health*. Published on: http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf.
- Zhu, Xi-Chen, Lan Tan, Hui-Fu Wang, Teng Jiang, Lei Cao, Chong Wang, Jun Wang, Chen-Chen Tan, Xiang-Fei Meng and Jin-Tai Yu. 2015. Rate of early onset Alzheimer's disease: a systematic review and meta-analysis. *Ann Transl Med*. 2015 March 3(3), 38.



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