Norwegian Ministry
of Health and Care Services

Action Plan

# Dementia Plan 2025

# Contents

# Foreword

“When I got the diagnosis, it was like walking into a fog. I knew nothing about what would happen, and no one told us anything.”

This is a quote from one of the participants during the input meeting for Dementia Plan 2025 Receiving a dementia diagnosis is often experienced as a crisis. Many describe feelings of grief, despair, fear of the future, and uncertainty in terms of work and family.

Dementia can occur in both young and old, and many are affected. It is estimated that at least 100,000 Norwegians currently have a dementia disease, and a sharp rise in cases is expected in the coming years. We must have good and predictable services for those impacted by the disease. For those who are ill and for the people around them.

Norway was one of the first countries in the world to present a specific plan for services aimed at people with dementia. Dementia Plan 2015 was followed by Dementia Plan 2020. Much has improved since the first plan arrived. Many municipalities have carried out educational programs for family members and support groups for people with dementia. Several of them have established interdisciplinary teams with competency in dementia. Several offer day activity services for individuals with dementia who are living at home.

Nevertheless, we have yet to reach our goal. While working on Dementia Plan 2025, we secured good communication with professionals, service user organisations, family members and individuals with dementia. This gave us a great deal of important knowledge, which helped us determine areas of priority.

We know that many people live with dementia for a long time before they are finally diagnosed.

We know that people with dementia receive different levels of care, depending on where they live in the country.

We know that many people with dementia feel disempowered and that others are making decisions on their behalf.

We know that many people with dementia want to experience greater mastery and to continue to be themselves.

Dementia Plan 2025 will focus on these and several other areas. The Government’s aim is to have individuals with dementia diagnosed in a timely manner, and to ensure that they receive good and adapted services. We want everyone to experience mastery and to live active and meaningful lives, despite their disease. We also want individuals with dementia to be met with understanding, respect, and services that promote a sense of security and predictability. Our goal is to ensure that no one else experiences the same issues as the participant at the input meeting.

Being thrown into uncertainty and “walking into a fog” when the disease strikes.

Bent Høie

Bent Høie
Minister of Health and Care services

# 1

# Introduction and summary

Dementia Plan 2025 is the third national dementia plan. It is the Government's five-year plan (2021–2025) to improve services for people with dementia and their families. Our overarching goal is to contribute toward a more dementia-friendly society. A dementia-friendly society is a better society for all. A society that promotes inclusion, equality and understanding. This means that we must reduce physical and social barriers in society.

The Government's objective is to create the patient's health and care services. In our work on the plan, we have been in dialogue with professional, user and service user organisations for people with dementia and their families, who have made valuable contributions and offered important perspectives for the plan.

## Experiences and challenges

Experiences gained from the two previous dementia plans have been positive, but the feedback received from the Norwegian Directorate of Health, individuals with dementia and their families, and professional and service user organisations is unanimous. We have not yet reached our goal.

It is well known that when the elderly population increases, more people will be developing dementia. This has an impact on the demand for health care services, and we must find sustainable solutions and try to ensure that these services plan for the future. Dementia is a significant public health problem, and there is a need for greater focus on the prevention of dementia.

In our work on the plan, we received feedback from individuals with dementia who feel they are losing control over their own lives. To make matters worse, many people encounter discrimination in society, which is an extra burden on the individual. Having dementia does not mean that your own values and preferences disappear. It is essential that people with dementia are given the opportunity to be involved in their own lives. Furthermore, there is a need for greater public knowledge about dementia, to help reduce discrimination.

There are still too many people with symptoms of cognitive impairment who are not being assessed and diagnosed. A timely diagnosis and post-diagnostic follow-up were one of the main priorities of Dementia Plan 2020, however, continued focus on this issue will be necessary. This involves encouraging people with possible symptoms of dementia to seek help and helping healthcare personnel to become more skilled at identifying signs of cognitive impairment. To this end, we must work to reduce the stigma associated with dementia, facilitate openness about the disease, and communicating knowledge of the benefits of getting a diagnosis and receiving adapted care.

The majority of people with dementia live at home and wish to continue doing so. At the same time, we know that it will become challenging to perform daily activities, which is a problem for individuals with dementia and for their families and friends. It is crucial that measures are implemented at an early stage. Through guidance and adjustments, we can facilitate self-mastery. Families of individuals with dementia put in a great deal of effort, and it is important for us to recognise this work. Family members must be ensured respite care services, guidance and support.

Another frequent comment we received during our work on the new dementia plan, is the lack of daily activities, both for those living at home and for residents of nursing homes. In Dementia Plan 2025, we will continue to focus on activity initiatives. It is important to ensure that the content of services is experienced as both attractive and meaningful. It is also important for the services to function as respite for family members.

Many patients in hospitals have dementia or acute cognitive dysfunction. Hospitalisation can be a confusing experience for persons with dementia, partly due to the unmanageable corridors, confusing signage, inaccessible or incomprehensible information, etc. There is a need for greater focus on physical adaptations, new routines, as well as better and more comprehensive communication between healthcare personnel, patient and family members, if we are to improve hospital experiences.

## WHAT IS DEMENTIA?

*Dementia* is a general term for several chronic diseases that affect the brain. These diseases progress over time and lead to changes in functions such as memory, language and behaviour. Dementia affects the ability to function in daily life. The most significant cognitive symptom is memory loss. Dementia is caused by progressive diseases that impact the entire life situation of both the individual who is ill and their family members. For those affected with dementia, the ability to function in daily life will progressively decline, until they are entirely dependent on assistance.

Dementia can also lead to language impairment, trouble with spatial navigation, impaired thought processes, communication difficulties, and problems with orientation. Individuals affected by dementia will experience problems with earlier skills or managing everyday tasks. Some will display a loss of insight, agitation or aggression. Other symptoms may include anxiety, depression, hallucinations or apathy. Many will initially appear depressed, anxious and withdrawn. Later, as the disease progresses, there may be significant changes in personality and behaviour.

## Goals and values

The Granavolden platform states that the Government will work to achieve a dementia-friendly society, strengthen dementia research, and promote early medical professional assessments of individuals with dementia symptoms.

**Dementia Plan 2025 has the following goals:**

1. Individuals with dementia and their families, must be identified in a timely manner and receive good and adapted services.

2. Individuals with dementia, and their families, must be ensured co-determination and participation in a dementia-friendly society, so that they can live active and meaningful lives, with physical, social and cultural activities adapted to their interests, wishes and needs.

3. Increased research, and better knowledge of prevention and treatment of dementia.

Dementia Plan 2025 builds on the perspectives stated in Dementia Plan 2015 and Dementia Plan 2020. The overarching goal is to contribute toward a more dementia-friendly society. The Government's aim to achieve a society for all. A dementia-friendly society is a better society for all. A society that promotes inclusion, equality and understanding of individual needs and challenges. This means that we must increase knowledge and reduce both physical and social barriers in society.

Individuals with dementia must be met with understanding and respect if they are to live good lives. The quality of the services will be tested through interactions between health care personnel and individual service users. High-quality services shall be ensured through good systems for person-centred care, with professionally competent health care personnel who treat each individual with respect and dignity, and who can translate reliable knowledge into good practice.

People with dementia are not a uniform group. Like everyone else, they have different needs and varying interests. Good dementia care involves seeing the individual and his or her needs and implementing individually adapted services based on the insight into the individual's life story and disease history. This means that individuals must receive information, treatment and follow-up in a language they understand, and we must have consideration for individuals' cultural backgrounds.

It is also essential to consider family members. Families of individuals with dementia often find themselves in highly demanding situations for lengthy periods. The Government will recognise family members as an important resource for health care services and will therefore work to promote good health and good services for family members in demanding care situations.

Dementia Plan 2025 will contribute toward greater knowledge of dementia throughout society, thereby facilitating the inclusion of individuals with dementia in society and ensuring good services for those who need them. Previous plans in this field have largely been limited to municipal health care services. There is still a need to develop good and flexible municipal health care services. However, it is also necessary to include specialist health services and other sectors in society. There is also a need for greater focus on preventive measures, at population, group and individual levels.

## PREVALENCE OF DEMENTIA IN NORWAY

A survey to determine the prevalence of dementia was conducted during the plan period for Dementia Plan 2020. This survey was carried out together with the fourth round of the Trøndelag Health Study (Hunt4) and included 9930 people ages 70 or older. Prevalence figures for those under the age of 70 were obtained from a different survey conducted in the same region. Dementia was diagnosed by at least two clinical experts, independent of one another, and with the use of all available data collected in Hunt4. These figures were made representative for Norway through a standardisation procedure, which took into account the differences between the respondents in Trøndelag and the country as a whole.

The survey shows that among the group of people ages 70 or older, 14.6 percent have dementia. The prevalence of dementia increases from 5.6 percent in the age group 70–74, to 48.1 percent in the 90 or older age group. Dementia is more common among women than among men. The most common type of dementia is Alzheimer’s disease (57 percent), followed by vascular dementia (10 percent), mixed dementia (9 percent), Lewy Body dementia (4 percent) and frontotemporal dementia (2 percent). The rate of dementia in nursing homes is 84.3 percent, while the rate among those living at home is 10.8 percent.

Overall, an estimated 101,000 people were living with dementia in Norway in 2020. This figure is expected to rise to 236,789 in 2050, and to 380,134 in 2100.

*Source: Norwegian National Advisory Unit on Ageing and Health*

## Priority areas

**Dementia Plan 2025 includes four main priority areas:**

1. self-determination and involvement
2. prevention and public health
3. improved quality of health care services
4. planning, competency and knowledge development

Dementia Plan 2020 included national professional guidelines for dementia,[11] and various measures aimed at service user and family participation. It also mentioned a model study of systematic post-diagnostic follow-up, and good patient care pathways in a selection of municipalities. This has given us important knowledge and information of what works or does not work well. At the same time, it is problematic that good local examples and experiences are not shared and made available to others. Based on the experiences from the 'Quality Reform for Older Persons, A full life – all your life', the Government wishes to use Dementia Plan 2025 to facilitate the use of services, and to implement proven and effective measures and solutions.

Strategies and measures of Dementia Plan 2025 will help to put dementia challenges on the agenda for municipalities and regional health authorities in their ordinary planning work. The goal is to ensure comprehensive, long-term planning of local communities and environments, and to determine the scope and quality development of services for a growing number of people with dementia, and their family members.

## KEY MEASURES OF DEMENTIA PLAN 2025

*Priority area 1: Self-determination and involvement*

- help to ensure that individuals with dementia who need additional and coordinated services, are offered an Individual Plan and a coordinator
- conduct an information campaign to raise awareness of dementia in society in general, and among health care personnel in particular
- promote the development of varied and adapted activity services
- continue educational programmes for people with dementia and their carers from Dementia Plan 2020
- present a comprehensive family strategy and action plan
- prepare an online knowledge and training programme for families of individuals with dementia (WHO iSupport)

*Priority area 2: Prevention and public health*

- promote a new strategy against noncommunicable diseases (NCD strategy)
- strengthen efforts in the volunteer sector to reduce loneliness among the elderly
- systematise and implement knowledge of architectural design and living arrangements
- present a nutritional strategy
- continue efforts to prevent falls among the elderly

## KEY MEASURES OF DEMENTIA PLAN 2025

### *Priority area 3: Improved quality of health care services*

- continue and strengthen efforts to ensure a timely diagnosis and systematic post-diagnostic follow-up
- prepare an e-learning course on dementia assessment for general practitioner and other healthcare personnel
- determine the appropriate organisation of specialist health services for cognitive impairment and dementia
- prepare guidelines for good patient care pathways
- prepare a "toolbox" for person-centred care and milieu therapy
- create a team-based general practitioner arrangement
- prioritise the planning and development of a comprehensive, coordinated services for the elderly, among others, through a health care service collaboration
- contribute toward the construction of dementia-friendly care facilities through the investment funding for long-term care facilities
- promote the development of more dementia-friendly hospitals.

### *Priority area 4: Planning, competency and knowledge development*

- conduct an information campaign to raise awareness of dementia in society in general, and among health care personnel in particular
- continue research efforts from Dementia Plan 2020
- continue efforts with Dementia Care ABC and Elderly Care ABC
- conduct a study on the incidence of dementia
- conduct a national survey of services for individuals with dementia
- continue participation in international cooperation on dementia

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# Living with dementia

In our work on Dementia Plan 2025, we have maintained a dialogue with organisations for persons with dementia, family members and advocacy organisations. Furthermore, the Ministry, in collaboration with the Norwegian Health Association, has participated in, and conducted input meetings with individuals with dementia, family members and peers.

In this chapter, the Norwegian Health Association has written about key aspects of living with dementia. As an interest organisation for people with dementia and their families, the Norwegian Health Association has a unique experience base.

## *From suspecting that something is wrong, to diagnosis*

> *"You don't stop being yourself the day you get the diagnosis."*
> – Participant at a dialogue meeting

Most people who develop dementia are over 70 years of age. However, younger people can also develop dementia. Dementia can affect anyone, regardless of background and education. Many of those who become ill notice that something is wrong, but they will often try to hide it. Family members, friends and work colleagues will also notice changes in the individual. This is a painful time for everyone. It is important to contact a general practitioner to find out what is causing these changes. The Norwegian Health Association, which is an interest and advocacy organisation for people with dementia and their families, have received feedback from many people who stated that they were not taken seriously when contacting their general practitioners with such concerns. It is essential that general practitioners have the appropriate competency and knowledge of dementia, and that they initiate an assessment, treatment and follow-up care according to current guidelines. Dementia is a serious diagnosis, both for the service user and for the family. Yet at the same time, it may be a relief to know what is wrong.

A timely diagnosis may make it easier to plan for the future, including retirement from work life. For those who are employed, it will be of great importance, both emotionally and financially, to know whether there is a medical reason for their inability to perform work tasks. If possible, employers shall adapt work tasks for the individual employee, and also allow employees to participate in the decision to end their employment. A good dialogue with the Norwegian Labour and Welfare Administration (NAV) is essential to ensure that the employee receives the financial benefits he or she is entitled to.

> ***The Black Hole***
> *"When I got the diagnosis, it was like walking into a fog. I knew nothing about what would happen, and no one told us anything."*
> – Participant at a dialogue meeting

Today, there is still no systematic follow-ups arranged for individuals diagnosed with dementia. Dementia affects initiative, which means that many people with dementia are unable to seek help on their own. We know that people with dementia receive different health care services, depending on where they live. Some have described a good and secure follow-up, while others have felt left to themselves in the midst of a serious life crisis. Many do not receive help until their disease has progressed to the point where they need health care services. General practitioners have a responsibility to follow up each individual and cooperate with the dementia coordinator or memory impairment team. It is essential, for both the individual with dementia and family members, to have a regular contact person in the municipality that has broad competency in dementia diseases. This contact person must initiate dialogue, provide individual support, and maintain a good overview of municipal services. If an individual with dementia is encouraged to be open about the disease, this could mobilise a network that can help make daily life as good as possible. Openness is also an important factor in reducing shame and stigma.

> ***Nothing about me without me***
> *"But it is so important to be included. We are paving the way for others."*
> – Participant at a dialogue meeting

Society must facilitate opportunities for individuals with dementia to participate and be involved. The goal is a more dementia-friendly society, where people are met with openness, respect and understanding, and where individuals with dementia are included in the same manner as others. Many people with dementia feel disempowered, as others are making decisions on their behalf. The right to self-determination is a human right, but individuals with dementia do not always feel that this is emphasised in their environment. The fear of being excluded from society prevents many individuals from being open about their disease. A lack of knowledge of dementia in society has led most people to believe that a dementia diagnosis is equivalent to an immediate loss of judgment and ability to make decisions. Dementia diseases have a long trajectory, and individuals with dementia want to use their competency and experiences and make decisions on their own behalf for as long as possible.

### ***Days with mastery and meaning***

*“It is important to have a reason to get up in the morning.”*
– Participant at a dialogue meeting

In the early stages of the disease, most people feel able to manage their daily lives. During this period, many express that they wish to use their resources as much as possible. Over time, they find that daily life becomes more challenging and less eventful, and they need help to fill their days and remain active. Family members have noted that assistance with structure and follow-up often becomes their task and responsibility. Family members need support throughout the entire course of the disease, also in the early stages of the disease.

As the dementia disease progresses, there will be a need for more structure and support to manage daily life, and to maintain the ability to function. In order to meet these needs, a variety of services that address social and physical needs must be available. These services must be adapted to individual needs and may include everything from low-threshold services from volunteers, to services from specialist health services. Many people also benefit from day activity services adapted to individual interests and needs. The structure and organisation of services must also be adapted to the family need for respite care services.

### ***For the days ahead***

*“I’m afraid of the future. I want to stay home as long as possible.*
*I don’t want to be a burden on my family.”*
– Participant at a dialogue meeting

For those who have a serious, chronic disease, it is common to have concerns about the future. It may be difficult to know how the disease will progress, and many fear losing control over their lives and becoming dependent on others for help. Dementia eventually affects the ability to plan and make decisions. It is therefore important to write a future power of attorney as soon as possible. This will ensure that the individual’s own wishes are safeguarded as much as possible during the entire course of the disease. Gradually, as the disease progresses, many will require comprehensive care. Many individuals and their families have found Individual Plans to be an important tool for planning and participation. As the disease progresses, most people will require a place in a nursing home. For many, the thought of living in a nursing home is frightening, and they do not feel they are involved in the planning process of moving. Family members have found that an advance care planning conversation and an assessment of the patient’s life history are useful tools in ensuring good cooperation. Experience shows that when personnel have good professional competency, and actively use a patient’s life history, it will result in good person-centred care and a better quality of life for the patient.

### *New family roles*

*"It's painful when my wife and I meet former colleagues, and they talk to her and not to me."*
– Participant at a dialogue meeting

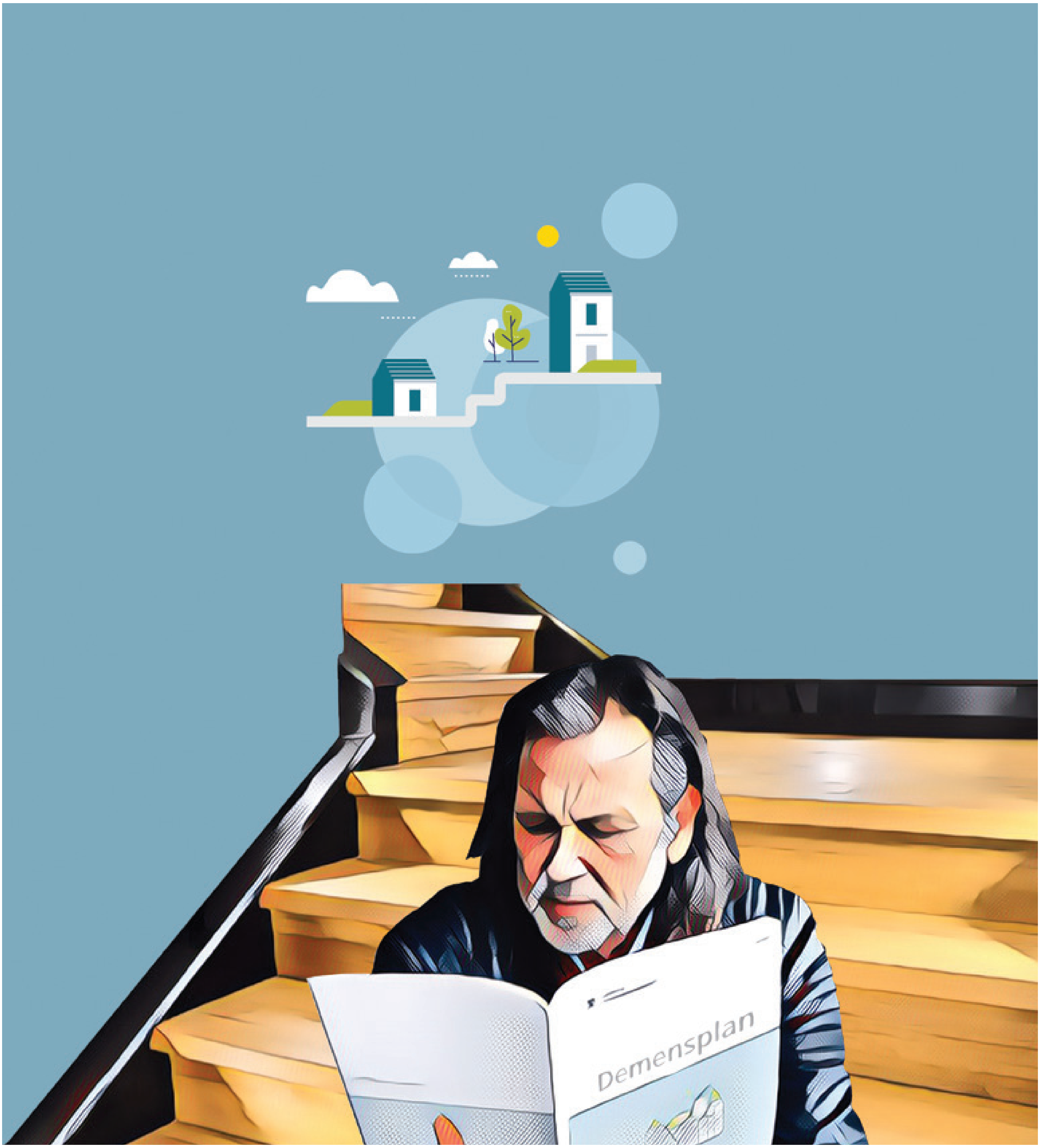
When someone in the family develops dementia, roles change. Many experience social isolation, where friends and acquaintances tend to withdraw. Family members find that they now have additional responsibilities. This applies to both practical and personal tasks in the family. Many family members say that they end up becoming the contact person for all the services the ill person needs, which can be a heavy burden. Family members mention contact with the municipality and the Norwegian Labour and Welfare Administration (NAV) as particularly demanding.

As next of kin, family members make up a heterogenous group. Children and adolescents may also be next of kin of a parent who develops dementia, and some may be the closest next of kin. They will have to maintain contact with the general practitioner, municipality, and others. This may be experienced as an extra burden, as they are also going through the grief over the serious illness of a loved one. Although it should not be the case, many have stated that they must put their own lives on hold because their family needs them. A growing number of people now live alone and will have no close family members who can assist them should they develop dementia. The next of kin role may then be accepted by other relatives, friends or neighbours. This would require systems and routines for exchanging information between next of kin and the service system. Family members have also expressed that they need a regular contact person who can provide support and guidance. In order to remain in a demanding situation and perform care tasks over time, it is crucial that family members are given respite. If respite care services are to function as intended, it is essential that both the ill individual and his or her family trust that the quality of services will be good. Many family members have such demanding care tasks that it begins to affect their own health. This may result in sick leave, or they may reduce their work hours or quit their jobs. This will have financial and social consequences for the entire family.

### *Language and cultural diversity*

*"I dread getting old in Norway, even though I've lived here for many years and speak fluent Norwegian. What if I get dementia and lose my Norwegian? Would there be anyone who knows my native language? Will they serve food from my native region? Would they play music from my home country?*
– Participant at a dialogue meeting

The share of elderly with immigrant backgrounds will increase in years to come. Since higher age is the primary risk factor for developing dementia, it stands to reason that the number of individuals with immigrant backgrounds who develop dementia will increase. There is a broad range of diversity in this group, with many different cultures and languages. Some view dementia as part of a normal ageing process and may therefore not seek help. From what we have learned, minority populations do not receive the same health care services as other groups throughout the entire dementia pathway. Many are not aware of how health care services are set up. There are also sections of health care services that lack competency in working with minority populations. Individuals with dementia and their family members feel more secure when personnel have relevant professional competency, which includes an understanding of different languages and cultures, which is actively used in person-centred care. When the ability to communicate in Norwegian is affected by a dementia disease, there are major challenges for assessment, follow-up, treatment and involvement. Many will also feel ashamed of having a dementia disease, and family members may also feel a sense of guilt and shame for being unable to care for their family member without help from public services.


Demensplan

# 3

# Results from, and experience with Dementia Plan 2020

The Norwegian Directorate of Health summarised results from, and experiences with Dementia Plan 2020, partly through the Norwegian national assessment of adapted municipal services for persons with dementia 2018 (hereafter referred to as the 2018 national survey).[2] The review by the Norwegian Directorate of Health indicates that there has been a positive development during the plan period.

Dementia Plan 2025 will continue to build on positive experiences from previous plans.

Dementia Plan 2020 has six main strategies:

## Self-determination, involvement and participation

A key goal is for individuals with dementia and their family members to be involved in decisions that affect them, and to have a say in the design of their own services. Person-centred care is now the basic principle for services aimed at people with dementia. Values, methods, etc. related to person-centred care form the basis for all guidance materials prepared as part of Dementia Plan 2020, including the Norwegian national professional guidelines for dementia, the Dementia Care ABC, etc.

Municipalities throughout the country have been given funding for support groups for persons with dementia, as well as educational programs and support groups for their family members. These are important measures that can enable individuals with dementia and their family members to be involved in decisions that affect them. During the plan period, 77 percent of the municipalities have arranged support groups or educational programs for family members, and the feedback has been overwhelmingly positive. A large number of municipalities have also devised routines for determining family members' support needs.

Municipalities have been given a more explicit duty to conduct independent assessments of family members' needs, and to make decisions based on the provision of responsibility in the Health and Care Services Act.[3] The new provision requires municipalities to offer essential support to family members in the form of respite care services, training and guidance, and care benefits. This provision reflects the Patient and Service User Rights Act [4] and emphasises the rights of family members in terms of municipal health care services.

## Prevention – what's good for the heart, is good for the brain

The summary from the Norwegian Directorate of Health states that prevention of dementia is closely related to the prevention of other diseases. The Norwegian Directorate of Health will also follow WHO's recommendation to link the prevention of dementia to efforts to prevent noncommunicable diseases (NCD).[5] In 2019, the Norwegian Directorate of Health launched an e-learning course to enhance competency in fall prevention training and activities among staff at nursing homes, senior centres, day activity services and training centres.

## A timely diagnosis and close post-diagnostic follow-up

National professional guidelines for dementia were published in 2017, and include assessment of dementia, medical treatment, and other post-diagnostic follow-up of individuals with dementia and their family members. These guidelines provide recommendations for assessing and diagnosing dementia. This applies to how the assessment should be done, who should be assessed, and where it should take place.

During the plan period, there has been a positive development in the number of municipalities that have interdisciplinary teams with competency in dementia. In the 2018 national survey, 90 percent of the municipalities stated that they had interdisciplinary teams with competency in dementia (or dementia coordinators in smaller municipalities). This is an increase from 78 percent in 2014. These teams often participate in assessment work in cooperation with general practitioners. A model trial project on systematic post-diagnostic follow-up was carried out in 14 municipalities. Results of the project was positive.

The summary from the Norwegian Directorate of Health notes that the area requiring the most efforts is the goal for each individual to be ensured an assessment and diagnosis upon suspicion of dementia. To illustrate, the register data shows that only 45,000 people were registered with a dementia diagnosis in 2018. This is a low figure, considering that the number of people with dementia in Norway in 2020 is an estimated 101,000.

## Activity, mastery and respite care

In Dementia Plan 2020, a key measure was the development of adapted day activities for people with dementia. From 1 January 2020, the Government introduced a requirement for municipalities to offer adapted day activities for people with dementia, and funding from the grant scheme was incorporated into the municipal budget. In the 2018 national survey, 88 percent of municipalities stated that they offered services for day activities especially adapted for people with dementia, as opposed to 71 percent in 2014.

One of the goals of Dementia Plan 2020 was to develop flexible respite care services for family members. In the 2018 national survey, nearly all municipalities (97 percent) replied that they had made decisions on respite care services for families of people with dementia in their municipality. The national survey indicated that 74 percent of the municipalities had routines for determining families' need for support, and the majority had assessed the need for respite care services, care benefits, or training and guidance.

Figures from Iplos indicate that only 1331 people with registered dementia diagnoses had been granted a coordinator in 2018. The Norwegian Directorate of Health believes this figure is too low, and efforts should be made to ensure this service for people with dementia.

## Patient care pathways with systematic follow-up and adapted services

During the plan period, 14 municipalities developed and tested models for follow-up of people with dementia who lived at home and had extensive needs. Experiences from this project were used in preparing guidance material for other municipalities. There was a positive development in the number of municipalities that have units especially adapted for individuals with dementia in nursing homes or assisted living residences. However, there is still a large share of long-term care facilities that are not adapted for people with dementia. The Norwegian Directorate of Health has determined that palliative care for people with dementia has improved during the plan period, although there are still some challenges in this area in several municipalities. Much of the competency on palliative care is in the field of cancer care and cannot easily be transferred to individuals with dementia.

Dementia Plan 2020 emphasises that service users who need long-term, coordinated services should be offered a coordinator in the municipality and/or in the specialist health services, and that Individual Plans should be offered to those who need them. Figures from the 2018 national survey show that 54 percent of the municipalities had routines or schemes in place to offer coordinators to people with dementia who needed long-term, coordinated services. Correspondingly, 47 percent of municipalities had routines in place to offer an Individual Plan for people with dementia.

## Research, knowledge and competency

The summary from the Norwegian Directorate of Health indicates that a significant amount of information, guidance and instructional material has been developed and distributed during the plan period. However, the Norwegian Directorate of Health points out that there is still a need for continued efforts to provide information on dementia, as well as good services for improving knowledge of dementia and for reducing the stigma linked to dementia, both in the population and among health care personnel.

A total of 345 of the current 356 municipalities had staff members participating in the competency enhancement programmes *Dementia Care ABC* and/or *Elderly Care ABC*, since these started in 2004. Furthermore, 809 staff members in health care services between 2016 and 2018 completed continuing educational programmes in elderly care or dementia care with funding from Kompetanseløft 2020 (Competence Plan 2020). These included 470 employees in vocational training and 339 employees in the university and university college sector.

The Norwegian Directorate of Health points out the Norway has insufficient registry data on dementia. To remedy this, the Norwegian Directorate of Health has conducted regular surveys to obtain information on status and priority areas. This is time consuming for both the state and municipalities. The Norwegian Directorate of Health emphasises the need to build a registry-based information system for dementia, based on the recommendations of the World Health Organization.[6, 7]

# 4

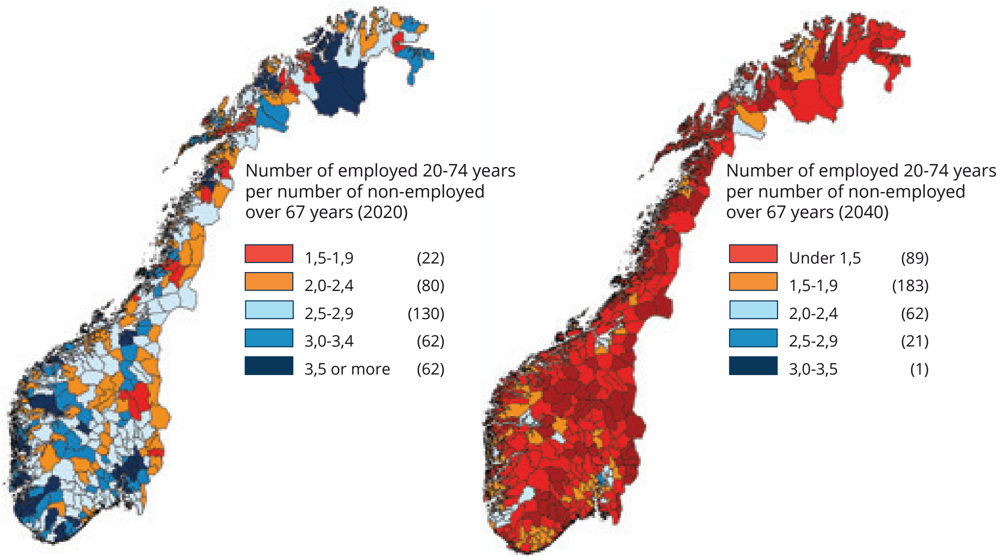
# Challenges and needs

Although there has been a positive development during the plan period for Dementia Plan 2020, it is clear from the Norwegian Directorate of Health, the 2018 national survey, and feedback with input, that many challenges still remain.

## *Demography*

The share of older persons, particularly those ages 80 and over, is expected to increase significantly in the years ahead. The incidence of dementia increases with age, and it is estimated that the number of people with dementia will double by 2040. This will impact and have consequences for several areas of society and will require new solutions. On the other hand, the elderly now tend to be in better health, and several studies indicate that the proportion of people with dementia in different age groups is declining. However, since we are living longer, the population of elderly people will be rising in the coming decades, and the rate of dementia is therefore expected to increase significantly.

**Figure 4.1** Number of employed persons ages 20–74 per person age 67 or older. 2018 (actual) and 2040 (projected)



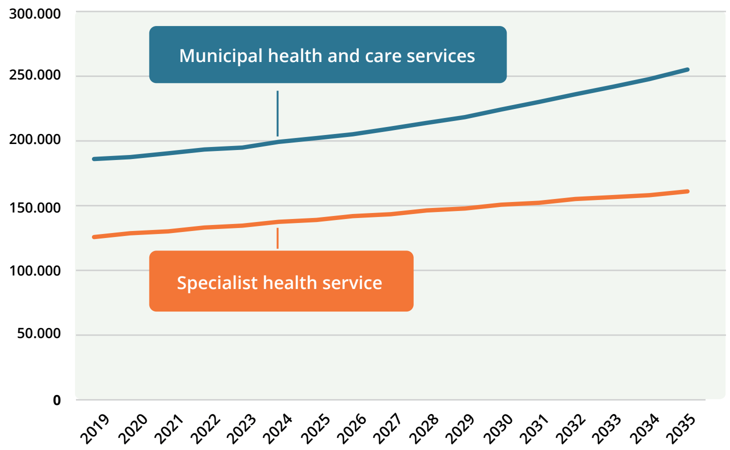
Source: Statistics Norway national population projects (main alternative) and register-based employment. Calculations: Ministry of Local Government and Modernisation

The share of older persons in the population will increase more sharply in less central regions of the country, which over time has experienced a weak or negative population growth and migration. This will put additional pressure on health care services and shortage of labour. The Government has therefore appointed a committee to study the consequences of demographic challenges in the less central regions of the country. The committee will present proposals for possible solutions.

The demographic development will result in a greater shortage of health care personnel, both in the municipalities and in specialist health services. There is already a significant shortage of nurses and health professionals. These challenges place great demands on the management, planning, organisation and administration of services in the years ahead. The growing need for health care services in the future cannot solely be met by an increase in personnel. Other means must be implemented. In the future, it will be necessary to make better use of the potential of available resources. There will be greater demands for collaboration, and a need for innovation and new solutions.

Projections by Statistics Norway indicate that the need for full-time equivalent employees (FTEs) toward 2035 could increase by just under 70,000 FTEs in municipal health care services and in the county authority dental service. This includes about 60,000 FTEs in care services and just under 35,000 FTEs in specialist health services.

**Figure 4.2** Projections of demand based on FTEs in health care services toward 2035*



Source: Statistics Norway 2019

* The projection path is based on the mean alternative in the population projections for 2018, 0.5 percent annual increase in productivity, 1 percent annual increase in standard (FTE per service user), and continual family care. These are the same conditions that formed the basis for the FTE projections in the Norwegian Health and Hospital Plan 2020–2023.

### *Social inequality*

There is a clear correlation between living conditions and health.[8] Life expectancy is five to six years longer among people with higher education than among people who have only completed compulsory school. Differences in smoking habits between the education levels is an especially important explanatory factor for social health differences in Norway. These differences also apply to the number of healthy life years. Figures from the Trøndelag Health Study (Hunt) show that people with only a compulsory school education tend to be in good health until age 60, while people with university educations are in good health until age 70.[9] There is a similar pattern in social differences in terms of living habits. Longer educations are associated with less smoking, more physical activity, better diets, lower blood pressure and less obesity. People with longer educations tend to have a higher alcohol consumption, however alcohol consumption appears to have more negative consequences in groups with lower socioeconomic status.

### *Participation*

During our work on this plan, we were told that many with dementia feel that others are “talking over their heads”, in encounters with services and in society in general. The Office of the Auditor General of Norway notes that individual needs are often not adequately assessed, and that there is often insufficient involvement before services are put in place.[10] For service users who require long-term, coordinated services, municipalities have a responsibility to offer a coordinator, and service users are also legally entitled to an Individual Plan. Figures from the 2018 national survey show that only 54 percent of municipalities had routines or schemes that offered a coordinator, and 47 percent had routines or schemes that offered Individual Plans.

There is also a need for greater public knowledge of dementia. Knowledge is essential if people are to understand that the challenges they or their family members are struggling with may be symptoms of a dementia disease. It is necessary to counteract stigma to ensure that people dare to talk about the situation and seek an assessment and help. It is also important for people with dementia to be met with understanding and respect by others in society.

The Norwegian National Advisory Unit on Ageing and Health carried out a study, on behalf of the Norwegian Directorate of Health, on the needs of people with dementia.[11] One key finding was that persons with dementia are concerned about mastery and express a clear need to continue being themselves after receiving a dementia diagnosis. It is essential for people with dementia to be included in social relationships and to participate in activities that they feel are beneficial and meaningful. The study also emphasises the importance of good relationships with loved ones, and the fear of becoming too much of a burden on them. It is essential for family members to receive guidance and support in order to maintain good relationships.

Studies show that many nursing home residents are not offered opportunities to talk with personnel about their values and wishes for future treatment, even though many of them would like to do so.[12] The advance care planning conversation is a tool that can help to determine what is important for each individual in the future and at the end of life. Individuals with dementia are often not offered advance care planning conversations in nursing homes.[13] Instead, the staff has conversations with family members when the service user becomes more ill or is about to die.[14]

### *Family members*

Many family members feel the need to be seen and heard to a greater extent than they are today. Several have pointed out that families have significant knowledge and information of their family member with dementia, which would be important to share with services. Feedback also indicates that some family members feel that their caregiving efforts are in many ways taken for granted.

Many have found it challenging to search for and understand regulations involving the rights and responsibilities for persons with dementia and for their family members. Many have also found that information on services and the system for assistance is insufficient, random and person-dependent, and that they are forced to locate and coordinate assistance on their own.[15] Several have pointed out the need for financial advice and more information on rights and benefit schemes.

Many family members want to help and support their loved ones when needed. However, when care tasks become too demanding and overwhelming, they will become a heavy burden. A study by Pårørendealliansen (Norwegian alliance for informal carers) showed that 63 percent of family members experienced a decline in health after taking on a caregiver role.[16] These figures indicate that many feel they are constantly on the alert, and that around half are experiencing stress due to caregiver strain.

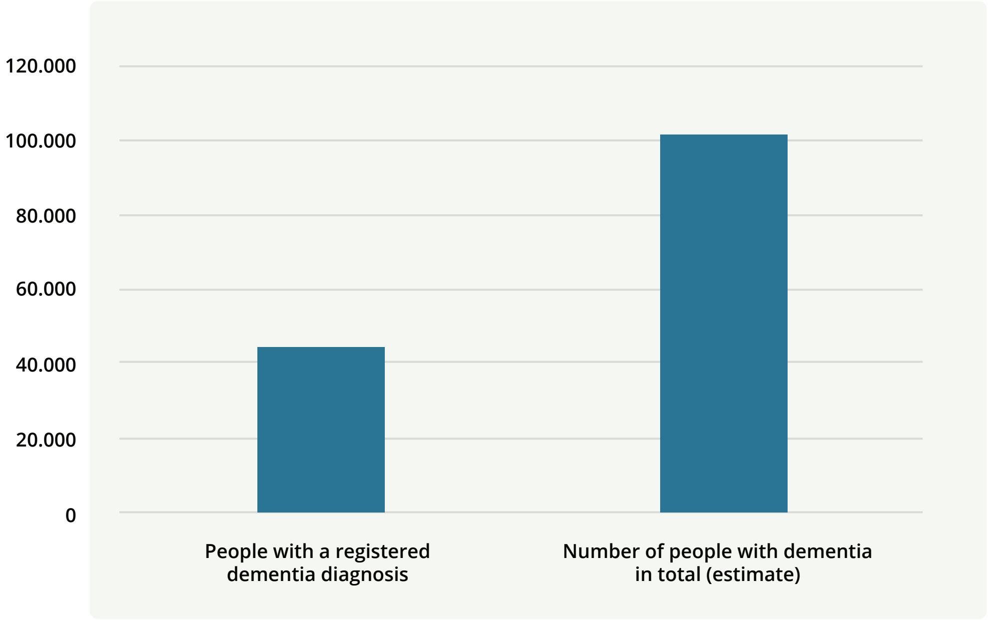
Respite care services are essential, as they provide family members the opportunity to recover and to maintain their work life, family life and other duties. Results of a Norwegian survey from 2014 indicated that municipal respite care services often involved standard solutions – such as traditional institutions.[17] Input from the survey also indicated that many family members are offered respite care services that did not adequately meet the family’s needs in terms of scheduling, scope and form.

Due to the corona pandemic, numerous services were suspended or reduced, including respite care and activity services. These are essential respite services for family members. Results of a survey conducted by the Norwegian Health Association shows that home nursing and home assistance services were suspended or limited for around 30 percent of persons with dementia living at home.[18] According to 55 percent of respondents, day activities had been suspended, and 13 percent reported that day activities were limited. Closed or reduced services resulted in a greater strain on family members. More than half of the respondents to the survey by the Norwegian Health Association experienced the ban on visits to long-term care institutions as distressing.

### *Assessment and diagnostics*

Planning and implementing necessary measures for persons with dementia requires a correct and timely diagnosis. The 2018 national survey indicated that there are still many people with dementia who remain undiagnosed. The problem is that too few are diagnosed early enough, and far too many with dementia are never diagnosed. In its summary, the Norwegian Directorate of Health notes that we still have a long way to go before we are certain that individuals with suspected dementia are guaranteed an assessment and a diagnosis. The lack of assessments means that other diseases are never ruled out, and these individuals may not be treated for conditions that are unrelated to dementia. When persons with dementia are not diagnosed, they and their families will struggle to understand what is wrong. Lack of diagnosis may prevent them from seeking adequate information, services and other assistance and support. They are also denied the opportunity to plan their future with dementia. Without diagnoses, municipalities will be unable to develop adequate services for systematic post-diagnostic follow-up and will have trouble contacting people who will require such services. Identifying and contacting people who have recently been diagnosed was one of the major challenges for municipalities who participated in the development project on systematic post-diagnostic follow-up in Dementia Plan 2020.

**Figure 4.3** Registry data compared with estimates of individuals with dementia



Both the Norwegian Directorate of Health and service user and family organisations have noted the stigma associated with dementia. Stigma may involve condescending attitudes or beliefs that people with dementia are unable to participate in ordinary activities. The fact that there is no cure is also mentioned as a reason for the lack of assessments and diagnostics. Although there is no cure for dementia, there are treatments to manage the symptoms, as well as measures to help individuals with dementia to live good lives. There is therefore a need for continued focus on how to assess and diagnose dementia, and on why dementia should be assessed.

The risk of developing a dementia disease increases with age, however dementia can also affect younger people of working age. It may be more challenging to diagnose younger individuals, as cognitive symptoms tend to vary to a larger extent in younger people than in older people.[19] Early onset dementia in younger people can be challenging, and there is a need for greater knowledge in this area. Many are still working and wish to continue working with adaptations in the workplace, while others prefer to step down from working life, either partially or entirely. All, however, deserve a dignified end to their working career.

### *Systematic post-diagnostic follow-up and adapted services*

The period after the diagnosis is also described as challenging. The 2018 national survey showed that only half of municipalities have regular routines or models for systematic post-diagnostic follow-up of persons with dementia living at home and their families. This means that many newly diagnosed individuals are not identified and therefore receive no organised follow-up.

Some will already have progressed to the point where they need home services and day activities, as well as respite care services for family members as soon as a diagnosis is made. Many will not yet require municipal services. However, they and their family members will still need information and guidance with respect to the disease, their rights and relevant services that are tailored to this patient group. Family members may benefit from information courses, educational programs, or support groups.

There has been a positive development, yet it is still problematic that many people with dementia do not receive adapted services. The Norwegian Directorate of Health refers to the REDIC study (Resource Use and Disease Course in Dementia),[20] which shows that persons with dementia living at home who have comprehensive needs often receive inadequate help from their municipality. The lack of adapted services often places a great strain on family members. The summary by the Norwegian Directorate of Health shows that many family members do not feel they have received adequate information and respite care services. Knowledge gained from development projects, such as those carried out from Dementia Plan 2020, indicates that a contact person, preferably from the municipal dementia team, is essential for a good and systematic post-diagnostic follow-up. The Dementia Guidelines recommend that all persons with dementia *should* be assigned a contact person or coordinator that follows them and their family members from the time of diagnosis until they need long-term care. These guidelines also state that if a person does not already have a coordinator when they have the need for comprehensive and coordinated services, a coordinator must be provided, pursuant to the Health and Care Services Act. Knowledge gained from development projects, such as those carried out from Dementia Plan 2020, indicates that a contact person or coordinator is essential for persons with dementia and their families, to ensure that each individual has the right to services at the right time throughout the disease trajectory.

Nearly 40 percent of municipalities work systematically with training and the introduction of methods for person-centred care.[21] This means that about 60 percent of municipalities still do not work systematically. Furthermore, the general lack of healthcare personnel with relevant formal competency is problematic.

Many patients in hospitals have dementia or acute cognitive dysfunction. Hospitalisation can be a confusing experience for persons with dementia. The OECD report Care Needed – Improving the lives of people with dementia from 2018 shows that hospital staff in many cases are not aware that a patient has dementia, even if the patient actually has a dementia diagnosis.[22] This may in part be due to poor cooperation routines between municipalities, general practitioners and hospitals. It is also problematic that both the system and the environment of many hospitals are inadequately adapted for persons with cognitive impairment.

Sami patients with dementia will sometimes only understand and speak Sami, their native language. This is a particularly vulnerable group of patients who, due to their dementia, will struggle to understand and make themselves understood. This becomes especially apparent when encountering healthcare personnel who have no knowledge of the Sami language and culture.

The share of elderly patients with ethnic minority backgrounds is rising, as Norway becomes a more multicultural society. Many elderly people with minority backgrounds encounter significant challenges when they become ill, due to language problems, cultural differences and inadequate knowledge of how the Norwegian health care system works. These barriers may prevent them from receiving the health care services they need and are entitled to. The assessment of dementia in patients with ethnic minority backgrounds can be challenging, due to language and cultural differences that may hinder communication during consultations. Studies indicate that communication in the patient's own language is important for maintaining the best possible level of function and integrity.[23] Studies also highlight the importance of good interpreter services, and individual adaptations and support for both patients and their families.

Service users from LGTBQI groups (lesbian, gay, bisexual, trans, queer and intersex) report that some elderly individuals choose to 'go back in the closet' because openness may feel burdensome. Many have grown up in an era where breaching the norms for gender and sexuality was prohibited and considered shameful. Openness and awareness of LGTBQI issues should also be safeguarded in health care services for the elderly.

### *Activity services*

The 2018 national survey indicated an increase in the number of municipalities offering day activity services for persons with dementia who live at home. This figure increased from 71 percent in 2014 to 87 percent in 2018. During our work on the new plan, we received a great deal of feedback regarding the differences in municipal services. Some claimed that day activities are poorly adapted to individual needs and preferences. Others described services that are well adapted to individual preferences, and that the participants almost felt as though they were going to work. It is also problematic that many residents in nursing homes and long-term care facilities experience loneliness, and that their days lack meaningful content.[24],[25]

So far, in 2020, infection control measures against the coronavirus pandemic has had a significant impact on persons with dementia. Many have also chosen to self-isolate for fear of infection. Although most facilities have gradually reopened, many vulnerable groups have chosen to avoid activities, or they have encountered activities that are either restricted or closed. We know that social isolation and loneliness increases the risk of other serious physical and mental issues and diseases. It is therefore essential to facilitate activities and socialisation to the extent this is possible and responsible. We know that many municipalities and volunteer or non-profit organisations have contributed with innovative ideas on how to enable social interactions, and how to maintain activities and social contact with others.

### *Knowledge and competency*

There is a need for increased knowledge and understanding of dementia in the population and among healthcare personnel. Knowledge of dementia and cognitive impairment among healthcare personnel is essential for ensuring proper assessments and diagnostics, as well as good post-diagnostic services. In order to provide responsible services and other assistance, it is important to understand the challenges faced by persons with dementia and their carers.

There is no cure for dementia. Further research on causal relationships, prevention, diagnostics and treatment for dementia is therefore necessary. Research is also needed on measures that can postpone or reduce the consequences of dementia diseases, such as knowledge of best practice for services. In its summary, the Norwegian Directorate of Health noted the need for more research and emphasised that research funding should be more targeted.

In order to manage both current and future challenges, the health care sector must maintain a continuous focus on the development and improvement of services. Good health care services are created when service users encounter personnel with a high level of professional competency and professionalism, and through good interactions between service users and personnel, where service users feel secure and are treated with dignity. This requires a constant focus on competency and competency enhancement. This development places greater demands on cooperation. Innovation and development of services must be based on changing needs. Many individuals with dementia require long-term, multiple and concurrent services. This would require more team-based services and a multidisciplinary approach for greater continuity. It encompasses the need for mastery in daily life to prevent social problems and mental health issues. Multidisciplinary cooperation should therefore be part of the methodology in the follow-up of individuals with dementia.

### *Challenging behaviour*

Dementia diseases are progressive, and many will eventually require comprehensive assistance. Most patients with dementia will also alter their response patterns and behaviour. Some will gradually develop what is known as behavioural and psychological symptoms in dementia (BPSD), or neuropsychiatric symptoms of dementia. This may involve psychiatric symptoms such as delusions, hallucinations, anxiety and depression, or behavioural symptoms such as aggression, apathy, lack of inhibition, irritability, or motor symptoms such as wandering, etc. Some of these symptoms may be too difficult to manage for people in the individual's environment. Behavioural changes may be caused by both physical changes and external stimuli, where biological, psychological and social conditions may all play a role. Other aspects, such as pain and the dementia disease itself will also play a role. This behaviour may also be the patient's way of expressing or attempting to master their own dysfunction, or a reaction to a changed life situation. The development of dementia often involves a gradual loss of languages other than one's native language. It is essential to keep in mind that language barriers often create frustration and insecurity for the patient. This must not be confused with behavioural changes. It is important for personnel working in different services to have the necessary competency in managing this type of behaviour.

In recent years there has been a strong focus on the problem of violence and abuse in nursing homes. Both residents and personnel may be subjected to violence. The newspaper, Aftenposten, reviewed 128,000 non-conformance reports and found 1300 incidents of violence at Norwegian nursing homes in 2018.[26] The figure itself is far too high, and it is reasonable to assume that not all deviations were registered. Among the initial results from a 2017–2020 study by the Norwegian University of Science and Technology (NTNU) on violence and abuse of residents in Norwegian nursing homes, 76 percent of respondents reported that they had witnessed one or more incidents of violence, abuse or neglect against nursing home residents over the past year. Sixty percent of respondents reported that they had carried out one or more of these types of acts during the same period.[27]

It is crucial that violence and threats are reported and registered as deviations. This will provide municipalities and individual institutions with documentation on the scope of such incidents and provide a basis for introducing measures. When people are subjected to violence and abuse, it affects all of us. However, violence and abuse will primarily have consequences for the victim. At the same time, we know that more than 80 percent of nursing home residents have a dementia disease. Therefore, a large share of these residents do not have the capacity to make decisions or to give their consent.[28] Violence and challenging behaviour may therefore be associated with disease. It is essential that personnel in these services has competency in person-centred care and milieu therapy for the prevention of violence.

### *Housing*

Housing policies must take into consideration that individuals with dementia have a range of different needs. Most want to remain living at home for as long as possible. This places demands on public authorities, and also on the population. Many senior citizens feel that their own homes are poorly adapted to their new situation with a disability.[29] At the same time, few report that they have made adaptations or plan to do so in their own home. A large share of today's elderly own their own homes, and many enjoy a good financial situation. However, not everyone will have the same opportunity to make adaptations to their own home, or to buy a new home. There are also major geographical differences in housing prices. Adaptations and adjustments to one's own home cannot therefore be limited to homeowners. Funding is needed to enable as many older persons as possible to remain at home.

Housing policies must also consider that the share of those who live alone is higher among older individuals. Figures from Statistics Norway indicate that 35 percent of the population over the age of 67, and around half of the population over the age of 80 live alone, in contrast with 18 percent of the total population.[30] Living alone is not necessarily a challenge in itself, but many elderly people who live alone struggle with insecurity and loneliness. It is therefore essential to provide measures to counteract loneliness.

It is also important to adapt housing to the needs of individuals with cognitive impairments. Figures from the 2018 national survey indicate that around 13,800 of 40,000 nursing home places available are adapted for people with dementia. When the estimated prevalence of nursing home residents with dementia is more than 80 percent, a high percentage of people with dementia reside in units that are not adapted to their needs.[31] The corona pandemic has shown that many nursing homes have an architecture and structure that is unsuited for managing infection control.[32] This is partly because many long-term care facilities are old and do not provide single rooms with private bathrooms. There is a need for further knowledge on building design and infection control.

### *User-friendly and universal design*

Technological and digital products, and physical barriers in society are a few examples of things that can make it difficult to manage daily activities. There may be many obstacles, both large and small, from understanding how to use the TV remote control to keeping up to date with new digital devices. An unfortunate use of colours can make it difficult to see markings and signs. Many become depend on family members for directions, and those who do not have family nearby may find it difficult to ask strangers for help. Many of the barriers are due to poor product design and layout. There is a need for better involvement in design work and greater focus on the different user needs.

### *Nutrition*

Individuals with dementia may be especially vulnerable to malnutrition and particularly to undernutrition. Common nutritional problems include the reduced capacity or ability to go shopping and prepare meals by themselves etc. Poor nutritional status may have a negative impact on cognitive function. Undernutrition is associated with increased morbidity, functional decline, higher mortality and a greater need for health care services. On a national basis, quality indicators of nutritional care practices show that less than half of elderly residents in nursing homes, and less than 20 percent of elderly recipients of home care services were assessed for nutritional status in 2019. Among these, about 40 percent of nursing home residents and a third of elderly recipients of home care services were either undernourished or at risk of becoming so.[33]

### *Medication*

The survey shows that individuals with dementia tend to use multiple medications, although indications are often unclear. This especially applies to psychotropic medications, for the treatment of mental disorders, and to some extent, behavioural disorders. Statistics from the Norwegian Prescription Database shows a sharp increase in the use of psychotropic drugs among elderly patients. It is reasonable to assume that this is largely due to the use of psychotropic drugs among persons with dementia. Earlier studies have shown that a high number of nursing home residents use psychotropic drugs regularly, and most of them use such medications for more than a year. Psychotropic drugs have an uncertain effect on individuals with dementia and may cause severe adverse effects.

### *Dental health*

Dental health in the population has vastly improved in the last 40 to 50 years. Nevertheless, many individuals with dementia require assistance in maintaining their own oral hygiene. Personnel in nursing homes and home care services have varying degrees of competency in dental health, and there are few who receive training in oral health.[34] County Council Dental Health Services provide training in oral health for municipal health care personnel. However, practices vary from county to county.[35] The survey indicates the need for a learning network, and more frequent contact and better dialogue between municipalities and the county in order to improve competency in oral health care.

# 5

# Self-determination and participation

Individuals with dementia should have the opportunity to live safe and active lives. This applies regardless of where they are in the course of the disease, and whether they live at home, in a nursing home or in an assisted living residence. Life should be enjoyed and lived as long as possible. Public services must therefore contribute to a safe and meaningful daily life, where individuals with dementia and their families are involved in decisions that affect them and have some control over their own lives.

When a person develops dementia, it not only impacts that individual, but also their family and friends. Many family members exert a great deal of effort and may be burdened with a highly demanding care situation for years. Family members are important, both to the service user and for society. Families must be recognised and supported so that they can help and support their loved ones without risking exhaustion.

Dementia can make daily activities more challenging, and it is easy to lose a sense of connection with one's community and normal activities. Activity and community is one of five priority areas in the Government's Quality Reform for Older Persons, *A full life – all your life.* There is strong evidence that meaningful activity, both physical and social, has a positive effect on both physical and mental health. It is therefore essential that persons with dementia are offered meaningful activities, adapted to individual needs and interests.

### SELDOM HEARD VOICES

It is important for people with dementia or other forms of cognitive impairment to be heard in their local communities! The goal of the Norwegian Health Association's project has been to develop a model for participation, aimed at people with dementia or other forms of cognitive impairment, in the development of local community services. Participants in the project are 'experience groups' that include people with dementia in Trondheim, Stavanger, Lindesnes and Stange/Løten, in cooperation with the municipalities. Experience groups are led by volunteers in local dementia organisations. Experience groups share their experiences of living with dementia with the municipality, businesses, and other relevant parties (libraries, museums, etc.) in order to influence local issues or services. Topics for group support include health and welfare services, transportation and activities. The project has developed several tools, including a model, a course, and guidelines for municipalities and other cooperative partners for facilitating participation among individuals with dementia in the development of services. This project was financed by The Dam Foundation.

## 5.1 Long-term strategy

### User involvement

The Government's goal is for people with dementia to be heard. To live a good life with dementia, people with dementia must be met with understanding and taken seriously. One of our goals is to enable people with dementia to maintain daily activities, to feel safe and to have a sense of control over their own lives. This not only applies to encounters with public services, but also to the development of health care services. Another goal is to consult patients and service users on decisions to a greater extent. Dementia is a disease that gradually changes a person's ability to function in daily life. It is therefore essential to adapt involvement and participation to the individual's ability to receive information and provide feedback. Information and the opportunity to participate must be adapted to the patient or service user's language and cultural background. Participation in decision-making can be challenging for patients with cognitive impairment and dementia. Diagnosing dementia and assessing cognitive function would enable us to identify patients with cognitive impairment and determine their decision-making capacity more systematically.

### ACTIVITY FRIEND

Activity Friend is a service established in 190 municipalities in all Norwegian counties. This service organises nearly 3000 volunteer Activity Friends that engage in various activities together with individuals who have dementia. Activity Friends and persons with dementia are linked through common interests, either on a one-to-one basis or in larger groups. The goal is to ensure that the time spent together is beneficial and safe for both parties. Volunteers are given training and guidance from the Norwegian Health Association, to prepare them for providing support and friendship in daily life for people with dementia. Once they have completed training, volunteers are linked to a person with dementia who either lives at home or in an institution. Activity Friend is a service that allows persons with dementia to continue participating in activities that were important to them before they became ill. This also helps to counteract loneliness and isolation. Activity Friend is a health-promoting service that focuses on the healthy aspects of a person, and on what they can continue to do.

> *"Had I not had Edle-Marie, I would not have been as interested in things as I am now. I feel more awake, in better shape and have a much better quality of life."*
> – Person med dementia

Volunteers feel that they can be of use, and 96 percent of Activity Friends have recommended that others become involved. Activities range from exercising, going for walks, going to the theatre, going fishing, or simply meeting for a cup of coffee and a chat.

The Norwegian Health Association has created a cost-effective and innovative model in cooperation with the municipalities. The service is operated by the Norwegian Health Association, in cooperation with local working groups generally comprised of a dementia team and dementia coordinator, and other representatives from the health and care sector, volunteer centre, municipal volunteer coordinator or other representatives from organisations. The Activity Friend service is run through a flexible model and ensures cooperation between the public and volunteer sector. By offering Activity Friend services, the municipality is providing better care services for individuals with dementia.

## Activities

The importance of good day activity services was also emphasised in Dementia Plan 2015 and continued in Dementia Plan 2020. It is still important to include activities as a key part of services for people with dementia, as this contributes to mastery, meaningfulness and good experiences for the individual. It also provides respite for family members. Ensuring that people with dementia have the chance to experience a sense of inclusion and meaningful activities during the day is vital.

From 1 January 2020, municipalities were required to offer day activity services for people with dementia living at home, and many good services have been developed for this group of people. It is now essential for municipalities to ensure that these services are experienced as meaningful and attractive among people with dementia. Services must also be adapted to the needs of the target group in general, and to individual needs and preferences in particular, including language and cultural background. Day activity services for the general population of older people often fail to meet the needs of persons with dementia. Many find that they are unable to master the same activities and are therefore not included in this community. Neither would these services meet the needs of younger persons. It is therefore essential to provide day activity services that are especially adapted to the needs and interests of persons with dementia.

In some cases, it would be more appropriate for services for persons with dementia to be an integrated part of the local community. A community could, for instance, facilitate intergenerational groups and meet-ups. It is also important to ensure that persons with dementia can walk outdoors and run errands on their own as long as possible. Through its letter of expectation for municipal planning 2019–2023, the Government emphasises that good architecture and planning will contribute to the development of good local communities and residential areas that stimulate physical activity and a more health-promoting environment. There are many good tips and advice on these areas in the *Handbook on Age-Friendly Community Planning,* prepared by the National Association of Norwegian Architects on commission from the Norwegian Directorate of Health.

*'Inn på tunet'* (Green Care) is a programme for individually adapted and quality-assured welfare services on farms. Activities in this programme are related to life and work on farms. For years, the Norwegian National Advisory Unit on Ageing and Health has been working on the development, implementation and incorporation of the Green Care service in municipal dementia care services and have published a national handbook on Green Care and day activity services.[36] Farms provide unique opportunities for meaningful tasks and activities in stimulating environments that do not have an institutional feel. Caring for animals, working in kitchen gardens and orchards, chopping wood, and preparing shared meals are some of the tasks on the farm. There is a strong potential for many such services if municipalities and the agricultural sector cooperate on opportunities.

Another service known as *'Ut på vidda'* (Out on the Plains/Highlands) has been established in all Sami reindeer grazing areas. *'Ut på vidda'* is aimed at several different service user groups. A key group is individuals with early onset dementia. Through the *'Ut på vidda'* service, individuals with early onset dementia have the opportunity for physical activity, social interactions, varied activities and also a sense of belonging to their own Sami community. This service provides service users with a unique opportunity to participate in reindeer husbandry, speak their own language, eat traditional foods, and re-experience life as reindeer herders. The Government would like to continue its work to develop *'Ut på vidda'* and make it more visible as a relevant service activity in the field of dementia care.

There is also a need for more socialisation and activities for residents in nursing homes and assisted living residences. As described in Report to the Storting (white paper) 15 (2017–2018) A full life – all your life, many are pleased with the care they receive, but would like to experience a more meaningful daily life with social contact and activities.

### DAY ACTIVITIES ON FARMS, OUT IN NATURE, AND A VARIETY OF ACTIVITIES

The research project *Farm-based day care for people with dementia (2016–2020)* provided evidence of the effect of day activities arranged on farms. Such services have strong similarities with ordinary day activity services in terms of structure and the presence of health professional competency. Municipalities purchase this service and are responsible for the quality of the day activity service. The farm and surrounding areas offer opportunities for various activities adapted to each individual user. Service users have a genuine sense of participation as they perform ordinary and meaningful farm activities.

Service users on farms spend more time outdoors, are more physically and socially active, and generally have a more positive mood than those participating in regular day activity services. Being outdoors and in a group with others has a positive effect on quality of life. Family members have seen that the service users are well cared for and view the day activity service as respite care. When family members experience social support, this has a positive effect on their quality of life as well. In general, the project has shown that the farm environment, with its simple, intuitive and everyday activities, promotes good relationships and the opportunity for individual adaptations. This is of major importance for the quality of the day activity service, and it is easy to transfer to other care environments. More information can be found on the website *Demensomsorg på gård (Farm-based day care for people with dementia)*: demensomsorgpagard.no.

## Family members

During our lifetime, most of us will have family members in need of care, either for a shorter or longer period. In accordance with its Granavolden platform, the Government wishes to recognise family members as an important resource for health care services. The Government wishes to facilitate secure life situations for all families. The Government wishes to provide family members with the opportunity to have a say in assistance services when the service user is unable to manage their own care. There is focus on the fact that family members may have many different roles, as caregivers, respite care providers and decision-makers during the patient care pathway. Family members also have a need for information and support, both for their own sake and to safeguard the interests of the individual with dementia as the disease progresses.

Care given by family members and by significant others is an important resource. Recent estimates indicate that informal care in Norway comprises around 136,000 full-time equivalent positions. [37,(1)] This is approximately at the same level as municipal care services, which comprise about 142,000 FTEs. This is a very important resource from a social perspective, and a value the Government wishes to support. The Government believes that family members comprise an essential supplement to public services, and that we must facilitate solutions that help to support and provide respite care for family members who need it. We must also facilitate opportunities for family members to combine work and daily life with care for their loved ones.

## Safeguarding Sami language and culture

Everyone should have access to equal services of good quality, regardless of age, gender, ethnicity, functional ability, etc. The Sami population has rights regulated in Norwegian law and in international conventions. Sami service recipients need services providers that have competency in Sami language and culture. Older Sami service users may have particular difficulties with expressing themselves in the majority language. This applies especially to individuals with dementia.

During the Dementia Plan 2020 period, information material was prepared for the Sami population, partly through the Dementia Care ABC programme.[38] The Government wishes to continue the work on the dissemination of information and knowledge, where the goal is to enhance competency among employees in the health care sector who encounter individuals with Sami backgrounds and dementia. The aim is for Sami persons to receive information in their own language.

## Elderly immigrants and dementia

Older immigrants with dementia often come into contact with health care services at a later stage. There may be many reasons for this, but a report from the Norwegian Centre for Migration and Ethnic Minority Health (NAKMI) notes that there are a range of different views on dementia, and that many have called for greater respect for their customs and values in their encounters with services.[39] The general intent is for everyone to receive equal health care services. It is essential that information and knowledge is provided in the recipient's language, with respect for customs and traditions. The Government wishes to continue its focus on information and knowledge dissemination on among linguistic minorities who develop dementia. The national professional guidelines on dementia state the need to implement measures with necessary adaptations for diversity in the population.

## Working life

There are an estimated 2000 people with dementia under the age of 65[40]. This suggests that a fair share are employed at the time of their diagnosis. Many have financial commitments and rely on an income to fulfil these. Receiving a

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(1) These efforts were previously estimated as roughly 90,000 full-time equivalent positions (FTEs). Earlier surveys on living conditions (2008 and 2013) have only indicated the time spent outside one's own household. Earlier estimates of total time spent on family caregiving tasks has – due to lack of information – been based on the assumption that the time spent within one's own household is equal to the time spent outside one's own household; see Otnes (2013), Holmøy et al. (2014, 2016) and the Norwegian Directorate of Health (2017). More recent figures indicate that the time spent within one's own household is greater than previously assumed. Self-reported figures for the share of helpers and the time they spend implies that family caregiving in 2017 consisted of 52,000 FTEs in one's own household, and 83,000 FTEs outside one's own household, with a total of 136,000 FTEs.

diagnosis does not necessarily prevent a person from continuing work, though in some cases it does require individual adaptations. Others may no longer be able to manage their jobs, and the diagnosis becomes a reason to stop working. Solutions are therefore needed to assist those who wish to continue working and those who prefer to stop.

For those who wish to continue working, it will be necessary to provide their employers with knowledge of dementia. This could facilitate an inclusive workplace with adaptations for those who need them, so that they can continue to work as long as their functional level permits. The Norwegian National Advisory Unit on Ageing and Health prepared a booklet for the Norwegian Directorate of Health *'Fortsatt i arbeid – med demens (Continuing work – with dementia).*[41] The purpose was to provide guidance for employers who have an employee diagnosed with dementia.

The Working Environment Act has no special provisions that stipulate rights for persons with dementia. However, the law does have certain provisions that regulate rights for employees with respect to illness in general. According to the Working Environment Act, employers are required to ensure systematic efforts for prevention and follow-up of sick leave.[42] This requirement would also apply to sick leave related to dementia. According to the law, an employer must structure and facilitate adaptations based on several criteria, including work capacity, age and other conditions.[43] The Working Environment Act also regulates requirements aimed at employees with reduced work capacity, due to illness such as dementia-related diseases.[44] The law suggests that employees should be able to continue in their positions, either with the same work tasks or with adapted tasks.

The Working Environment Act also regulates the rights of employees who are caregivers for family members and stipulates the right to a leave of absence for up to ten days every calendar year.[45] This provision stipulates rights for family members who, for instance, have parents with dementia.

## NO ISOLATION

No Isolation is a Norwegian start-up company established in 2015, with a vision of reducing involuntary social isolation and loneliness, by developing communication solutions for different target groups. Many elderly persons are unable to use a smart phone or tablet to stay in touch with families and friends. In cooperation with service users, the company developed the tool KOMP, which is easy to use and requires just one button. KOMP can accept pictures, messages and conversations from an app that family members or friends have access to. All invited members can see what is shared, so that KOMP also functions as a social network for the entire family.

Many municipalities have begun to use KOMP for nursing home residents, and have reported good results, such as improved well-being and quality of life for the residents whose family members live far away, or who have not been able to visit during the pandemic.

## Greater freedom with the aid of digital assistive tools

In accordance with *A digital public sector – Digitisation for the public sector 2019–2025* the Government intends for digitisation to help make daily life easier for the population. Digitisation enables health care services to function in new ways. The use of technology adapted to individual needs and abilities can provide a better quality of life, increase the level of independence and create increased safety for persons with dementia and their families and relatives. This is shown in the National Programme for Welfare Technology, where the majority of the users are persons with disabilities, persons with dementia or persons with mental illness.

The National Programme for Welfare Technology was established in 2013, with the overall goal for municipalities to integrate welfare technology as a natural part of their welfare services. The National Programme for Welfare Technology has been extended and will continue until the end of 2021. The Norwegian Directorate of Health will, based on the experiences from the programme, present recommendations for future developments in the programme after 2021. Based on the recommendations, the Ministry of Health and Care Services will determine the future role of the national programme in the area of welfare technology. Through the National Programme for Welfare Technology, the Government has promoted welfare technology as an area of priority in the municipalities. Today, nearly 90 percent of the population in Norway lives in a municipality that participates or has participated in the programme. Municipalities are well on their way to achieving the goal of welfare technology as an integral part of municipal health care services.

Through the National Programme for Welfare Technology, municipalities have tested and adopted different welfare technology that can enable citizen's with failing health and cognitive impairment to stay at home longer and give them a sense of mastery and security Examples include notification and localisation technology (GPS), electronic medication dispensers, digital monitoring systems, and electronic door locks. Localisation technology is rarely a permanent solution. Dementia is a progressive disease, but localisation technology can be useful at a certain stage in the disease trajectory and as a temporary solution. The most frequently mentioned benefits from the right use of welfare technology includes increased degree of independence and dignity, higher quality of life and increased safety among both the elderly and their relatives. as well as for  health care personnel.[46] A study from Larvik municipality showed that a GPS led to less use of force, more active citizens, and better quality of life.[47] When nursing home residents were free to go out when they wished, the majority of the staff (70 percent) reported that the residents appeared calmer, and they experienced fewer conflicts. Welfare technology are an important contribution to health services for persons with dementia and provide respite for family members and caregivers.

Estimated quantitative benefits have been reported from many municipalities. For example many municipalities report a reduction in the number of search operations for people with dementia going missing. Moreover the municipalities report cost reductions since elderly people have been able to live at home for a longer period instead of going to a nursing home. The National Programme for Welfare Technology also includes the testing of telemedicine of service users with chronic diseases, technological tools for children and adolescents with disabilities, and technology aimed at reducing loneliness among the elderly. Experiences from the corona pandemic also indicate that welfare technology may have a potential for preventing the spread of infection, and for maintaining the best possible health care services during a pandemic.

### ONE PATIENT – ONE RECORD

Digital solutions make it possible to deliver high-quality health care services while also ensuring a sustainable health care service system. Therefore, the Government is working to realise its goals for the Report to the Storting (white paper) 9 (2012–2013) *One patient – one record,* prioritising good, digital services for the population, the modernisation of the sector's record systems, and better use of health data.

The Government is continuing its efforts to modernise health record systems using three strategic measures: a common health record system for the entire Central Norway health region, a coordinated development of the other health regions' health record systems, and common health record systems for municipalities outside the Central Norway health region. These measures for health record systems will be supported by both new and well-established national e-health solutions and shared components.

Healthcare personnel will have access to patient information, and patients will have good access to information related to their own health and treatment. Health care services will collaborate on providing the population with high-quality healthcare services.

## Universal design

The Government's goal is a society for all. Policies for universal design has been developed through several action plans, which are also of significance for obstacles elderly persons may encounter in terms of housing design, public buildings, outdoor areas, transport, technology and ICT. The Norwegian Directorate for Children, Youth and Family Affairs (Bufdir) is following up its plans to facilitate a network for a universal design of regional and local public transport, UnIKT – the forum for universal ICT, and the Norwegian Association of Local and Regional Authorities (KS) network for competency enhancement for municipalities and county authorities, in addition to a network for the universal design of buildings. DOGA (Design and Architecture Norway) is following up its initiative *Innovation for All,* which is one of the measures in the Government's action plan for universal design (2005), aimed at innovation in businesses. Design is important for creating an inclusive society, where everyone can participate equally. DOGA advises on inclusive and person-centred design processes in the development of user-friendly products, services, digital solutions and environments.

The Programme for an Age-Friendly Norway, which is one of the areas of the Quality Reform for Older Persons, *A full life – all your life*, is intended to promote cooperation between elderly persons, municipalities, workplaces and businesses and research groups in developing more age-friendly solutions (see the website aldersvennlig.no).

## 5.2 Key measures during the plan period

### Age-friendly community planning

The National Association of Norwegian Architects have prepared a handbook on age-friendly community planning, on assignment from the Norwegian Directorate of Health. This work is incorporated in the *Programme for an Age-Friendly Norway* and is a subject in a course for architects and community planning staff arranged by the National Association of Norwegian Architects. The Government will determine how recommendations from the handbook will be followed up in the work on future housing solutions for older persons, cf. chapter 6.

### Individual Plan and coordinator

The Government will work to ensure that individuals with dementia who need additional and coordinated services, are offered an Individual Plan and coordinator. This will be done through the sharing of experiences from model trials, with systematic post-diagnostic follow-up and good patient care pathways.

### Information campaign to counteract stigma

The Government seeks to achieve a dementia-friendly society that safeguards and includes people with dementia. In its work against stigmatisation, the Norwegian Directorate of Health will, during the plan period, conduct an information campaign to raise awareness of dementia in society in general, and among health care personnel in particular.

### Meaningful activities

The Government will work together with the Norwegian Association of Local and Regional Authorities (KS) and volunteer organisations in carrying out a cooperative project to fund the development of varied and adapted activity services for people with dementia. This will be done with the use of tools for service development and the sharing of experiences.

As a result of the infection control measures associated with the corona pandemic, the Government will be offering a non-recurrent grant in 2021 and help volunteer organisations to develop good activity and respite care services for persons with dementia through a separate grant scheme.

The Government will also continue its work to highlight and develop *Green Care* as a relevant service in the area of dementia care. Continued efforts will be based on research from the *Farm-based day care for people with dementia* and a separate pilot project for dementia care in the Government's programme *Green Care 2 (2020–2022)*. The Norwegian National Advisory Unit on Ageing and Health, in cooperation with the County Governors of Oslo and Viken, aims to develop a national e-learning programme for farmers on dementia care and activity and respite care services on farms. The Norwegian National Advisory Unit on Ageing and Health will place the e-learning course in "Dette må jeg kunne" (This is what I must know), which is a national and freely available e-learning module.

## Measures aimed at family members

The Government will maintain its funding for educating individuals with dementia and their family members as stated in Dementia Plan 2020. This includes information courses, educational programs, and support groups for families, meeting places, etc.

The Government plans to present a comprehensive family strategy and action plan in the fall of 2021. This strategy encompasses all family members, regardless of the service users diagnosis. The strategy has a holistic perspective of the family situation, and describes challenges associated with health, work and financial situation.

The World Health Organization (WHO) has prepared a web-based knowledge and training programme for families of individuals with dementia, called iSupport. The purpose of iSupport is to prevent physical and psychological strain on persons who are in close contact with individuals with dementia, and to improve quality of life for persons with dementia. During the plan period, the Norwegian Directorate of Health will ensure a translation and adaptation of the programme to Norwegian, so that it is accessible for family members.

In order to promote more innovative and flexible forms of respite care services for service users and family members in the home, the Government has proposed a non-recurrent grant for 2021, in the amount of NOK 15 million, for a separate grant scheme to mobilise volunteer efforts aimed at older family members of dementia service users living at home.

## Planning the future

Dementia Plan 2020 began work on developing advisory services on the assessment of patient capacity to make decisions or to give consent, future power of attorney, etc. This work will be continued in Dementia Plan 2025.

To ensure that each individual is given greater freedom of choice and co-determination in planning future treatment, the Government will strengthen its efforts to prepare, disseminate and implement advance care planning conversations, in accordance with Report to the Storting (white paper) 24 (2019–2020) *(Palliative treatment and care)*.

# 6

# Prevention and public health

In the prevention of dementia, the Government will build on the same principles that underlie public health policies, by facilitating good health for everyone, many good life years, and a better quality of life, and reducing unfavourable lifestyle factors and social equality in health.

We know that there is a strong correlation between lifestyle and health. The causes of social differences in healthcare are many, and some factors will likely be present throughout the lifespan. There is evidence that social and environmental conditions such upbringing and education, work, living conditions, financial security, social activities and support network, as well as a secure and inclusive local community all have significance for the general health of the population, and also for the development of non-infectious diseases and dementia. Public health work therefore focuses on promoting physical and mental health and reducing social inequality in health. It also focuses on reducing the lifestyle risk factors. There is still a need for better knowledge on the effect of preventive measures for individuals. Dementia cannot be cured or halted. Its prevention must therefore be based on a broad and comprehensive approach.

The Lancet Commission on dementia, prevention, intervention and care is a broad-based international research collaborative. In 2020, it summarised new and existing knowledge of the prevention, treatment and care of dementia in a report.[48] The report includes recommendations from the 2017 International Commission on Dementia.[49] Risk factors for dementia include a lower education level, high blood pressure, poor hearing, smoking, obesity, depression, physical inactivity, diabetes and social isolation. The report notes that new research offers evidence of three new risk factors: excessive alcohol consumption, traumatic head injuries and air pollution. The commission placed these twelve risk factors in a lifespan-based model for the prevention of dementia. It has been assessed that these factors can explain more than 40 percent of dementia cases worldwide, and that there is a significant potential for prevention in modifying these factors. The lifespan model shows that it is important to begin early with measures to prevent dementia.

There is a growing consensus that dementia may comprise the end stage of disease processes that began several decades earlier. To prevent dementia, it will be important from a global perspective to maintain and improve cognitive reserves throughout the lifespan, by investing in good schools and education for children and adolescents. Physical activity and a healthy diet are also vital throughout the lifespan, in addition to intellectual stimulation, social activity and recreational activities. Preventive healthcare should focus on smoking cessation, the prevention and management of high blood pressure, treatment and assistive devices for hearing loss, as well as treatment of depression, diabetes and obesity. The most recent recommendations also include measures to reduce head injuries, harmful alcohol use and high levels of air pollution.

Many of the same lifestyle factors that lead to a greater risk of cardiovascular disease also increase the risk of cognitive impairment and dementia diseases. The Norwegian Directorate of Health briefly sums this up by stating: what is good for the heart is also good for the brain.

## 6.1 Long-term strategy

### Ensuring more healthy years of life

In the Report to the Storting (white paper) 19 (2018–2019) (Public Health Report – A Good Life in a Safe Society) the Government continues its broad and intersectoral public health policy. Good health and quality of life are closely linked to social development. National goals for the public health policy are as follows: (1) Norway will be among the three countries in the world with the highest life expectancy, (2) the population will have several more life years characterised by good health and well-being and fewer social differences in health, and (3) we will create a society that promotes health throughout the population. This report emphasises three areas of priority: early measures for children and adolescents, the prevention of loneliness, and less social inequality in health. The Norwegian public health policies involve several initiatives and measures that address many of the recommendations for dementia by the Lancet Commission, which will have an impact on prevention from a lifespan perspective. Health is developed throughout a person's life.

School and education provide many with some protection against health problems. In Norway, there is good access to preschools, schools and high-quality education. Reducing dropout rates in upper secondary schools is a priority. The Government has announced a new white paper regarding upper secondary education. The importance of competency enhancement and lifelong learning increases whenever there are major changes in the labour market. This is therefore an area of priority for the Government.

The Public Health Report also presents *Together against loneliness – the Government's strategy to prevent loneliness*. Loneliness is also a health risk, on the same level as the traditional risk factors such as smoking, unhealthy diet and inactivity. Preventing loneliness and social isolation would have a beneficial effect on both physical and mental health. The strategy is intended to highlight loneliness as a public health problem, and will seek to promote increased social participation, especially among young and elderly people. We also need more knowledge about effective measures to reduce loneliness, with preventive efforts. Cooperation with the volunteer sector is key in measures to reduce loneliness among the elderly.

## Reduce social inequality

There will be continued efforts to reduce social inequality in health. Everyone should be given the best possible conditions for good health. The underlying social causes of living conditions must be addressed in order to reduce social inequality. The foundation is the intersectoral public health policy, where all sectors have the responsibility and the means to ensure that all people can live good, safe and active lives. Universal schemes aimed at the entire population are the most effective in reducing social health differences. These apply to access to good health and welfare services for all, as well as education, employment and housing. Universal measures aimed at lifestyle habits, such as reducing access to tobacco and alcohol, are also effective. In the report *Social inequality in health* a research group recommends adding targeted measures for especially vulnerable groups.[50] The *Public Health Report* states that an external review of national policy for equalising social differences will be considered. The Government's new smoking cessation project aimed at heavy smokers is one example of such a targeted measure.

## Active and healthy ageing – an age-friendly society

Additional life years will hopefully involve longer lives with good health and functional abilities. Today's older persons have more resources than earlier generations in terms of financial resources, education and health. Findings from the Tromsø study indicate that the walking speed and grip strength of today's 75-year olds is just as good as that of 70-year olds a decade ago.[51] Yet many encounter obstacles for participation and find that their resources are not valued.

The World Health Organization has named 2020–2030 the *Decade of Healthy Ageing*. In Norway, this has been followed up through *More years – more opportunities*, the Government's strategy for an age-friendly society, and *The National Programme for an Age-Friendly Norway*, which is one of the areas of the Quality Reform for Older Persons, *A full life – all your life*. The purpose of this work is to show that all sectors have the means and methods to help elderly people become more active and participate to a larger extent in society. Municipalities have a central role in planning age-friendly solutions, by involving businesses, workplaces and volunteer organisations, as well as elderly persons. Participation is key. In 2020, the Norwegian Association of Local and Regional Authorities (KS) published a handbook for an age-friendly local community. In autumn 2020, the Council for an Age-Friendly Norway launched a campaign to have people plan their own old age. See the website planleggelitt.no. Better residential planning and safe homes are topics for the first part of the campaign. How older persons can take better care of their health, will also be a topic. The Norwegian Institute of Public Health has four simple recommendations for active and healthy ageing. Use your head, use your body, socialise and eat healthy.

## Residential planning and community development

The majority of people with dementia live at home, and we know that many have or will develop problems managing daily tasks and activities. We must therefore look at solutions that help as many as possible to live at home for as long as possible. Adaptations in the home and possibly in the environment may be needed to enable most people to continue living at home. This is to ensure individual needs for security and as much autonomy and independence as possible in daily activities. Adaptations may involve the use of assistive devices and welfare technology, in addition to simple changes in the home, such as removing or clearing away rugs, improving lighting, removing door stops, installing stovetop protectors, etc. Social relationships, a sense of security, the opportunity to continue doing daily tasks and community participation in general are also vital factors. Municipalities should collaborate with individuals to design plans and strategies to improve individuals' opportunities for mastery.

The Government has initiated work on future living arrangements, to facilitate good, adapted housing solutions for those who want to live at home, and for those who need assisted living housing or long-term care. Sintef, in its report, *(Home for life)* highlighted several projects where adapted housing services for people with dementia were integrated into a larger residential and urban structure.[52] This report referred to good projects that planned for diverse residential environments, neighbourhoods and meeting places, and combined different user groups and generations. Such integrated concepts also offer the opportunity for two simultaneous concepts: a focus on care and a focus on urban housing. These concepts can be adapted for shielded environments and outdoor environments for residents, as well as interactions in the local community.

### 'SENIORHUSET' NORDRE AKER

The *'Seniorhuset'* residential and activity centre in the Nordre Aker district of Oslo consists of homes adapted for elderly people, as well as services for other groups in the neighbourhood. Services include a smaller, integrated assisted living unit for persons with dementia. Another service at Seniorhuset is 'Pastor'n'. Pastor'n is a low-threshold, social meeting place for individuals who have cognitive issues or who have been diagnosed with dementia. It offers various activities, including guidance and counselling. Visitors can buy a good meal and meet with others over a cup of coffee. No applications or referrals are necessary for participation, but visitors must be able to get to the centre on their own. Cooperation with family members is an important part of Pastor'n services, and the district memory impairment team is available for questions and advice.

**ByOasen**
ByOasen in Copenhagen was established with a social vision of creating a meeting place for people of different ages, backgrounds and socioeconomic levels. The park grounds around a former institution have been opened to the public as an attractive urban green zone, with animals and spaces for various activities for people of all ages. An assisted living centre for people with dementia is incorporated in this environment.

*Age-friendly society* and *community planning* are established concepts and priority areas. Considerations for dementia-friendly aspects have not been explicitly mentioned here. Good community planning must be age-friendly, dementia-friendly, child-friendly and health promoting.[53] An age-friendly Norway will promote age-friendly residential housing and accessible local areas as something positive for everyone. In collaboration with Sintef, the National Association of Norwegian Architects has developed and introduced a handbook on age-friendly community planning, upon request by the Norwegian Directorate of Health.[54] Principles and qualities in this handbook would also be relevant from a dementia-friendly perspective.

The OECD report *Care Needed – Improving the lives of people with dementia* notes that few countries have clearly defined what "dementia-friendly" involves, or how it can be measured. In a Norwegian context, many municipalities have made efforts to ensure that persons with dementia are met with understanding and guidance in society, by training staff in service functions. This is an important measure. However, we still need a broader approach in determining how the environment, as a part of society, can best support and feel safe for people with dementia across the various stages of the disease trajectory. Sintef's knowledge summary emphasises the importance of meaningful activities, which until now have been described as the ability to participate in daily activities inside the home (meals and kitchen tasks), and the ability to spend time in a garden.[55]

## Mental health

Mental health challenges such as depression appears to increase the risk of dementia. The Public Health Report states that in terms of self-reported mental health, Hunt's results indicate that the prevalence of symptoms of depression among the elderly has increased over the last few generations, especially among the eldest participants.[56] The Government's strategy for mental health (2017-2022), *(Coping throughout life)*, describes how mental health will be included in public health work, how the different sectors will be responsible for promoting good mental health, and the importance of lifestyle habits on mental health. Preventive work in mental health will hopefully ensure additional life years for the population.

Certain mental health problems may, in some cases, be misinterpreted as dementia. Symptoms of depression, for instance, may resemble the early stages of dementia, with self-isolation and memory problems. However, many individuals with dementia will also develop symptoms of depression, and it is quite common to have symptoms of both dementia and depression at the same time. If the condition is depression and not the first stage of dementia, the patient can fully recover. It is therefore essential to contact a general practitioner upon suspicion of depression.

## Norwegian Brain Health Strategy (2018–2024)

'Brain health' is a general term that encompasses everything from measures aimed at preserving and developing a healthy brain, to diseases, injuries and conditions in the brain and other parts of the nervous system. Maintaining good brain health involves prevention and health promotion, early intervention, assessment, treatment, habilitation and rehabilitation, as well as research and innovation. *The Norwegian Brain Health Strategy (2018–2024)* is a national strategy aimed at developing better services. Dementia is one of the conditions highlighted in the strategy, which notes the need for good patient care pathways and solid knowledge.

## Noncommunicable diseases

*Measures to prevent dementia will be linked to the prevention of noncommunicable diseases (*NCD). Noncommunicable diseases include cardiovascular diseases, cancer, diabetes and chronic lung diseases. The World Health Organization (WHO) has listed mental health problems, musculoskeletal disorders and air pollution as risk factors for NCD, in addition to tobacco use, harmful use of alcohol, physical inactivity and an unhealthy diet. The Public Health Report has announced a new NCD strategy that will address mental health problems, musculoskeletal disorders and air pollution. As we have not been successful in halting the rate of obesity, the strategy will include further initiatives in this area. Initiatives aimed at noncommunicable diseases will largely involve measures to reduce common risk factors in the population. Preventive measures at a population level are generally the same for dementia as for diabetes, cardiovascular diseases, chronic lung diseases and cancer. Measures in the NCD strategy will therefore also have importance for the prevention of dementia. Initiatives aimed at noncommunicable diseases will also be followed up in other action plans and measures, such as Norway's National Strategy for Tobacco Control (2019–2021) and the Norwegian National Action Plan for a Healthier Diet (2017–2021). *Healthy diet, meal enjoyment and good health for all!*

## Preventive home visits

In its Granavolden political platform, the Government emphasises the importance of municipal home visits for elderly as a preventive measure. The purpose of preventive home visits is to utilise the individual's resources and assist in making adaptations to the home environment, thereby helping to maintain health and functional ability. Information, advice and counselling are all important aspects of preventive efforts. Preventive home visits are one of 25 solutions in the *A full life – all your life* quality reform.

In order to support municipal work with preventive home visits, the Government has prepared a circular (Circular I-2/2016) on preventive home visits, which also includes outreach services, in addition to counselling and advisory services. A preventive home visit is a practical and concrete measure that may enable more people to continue to live at home and experience greater mastery in their daily lives, thereby improving quality of life. The Government will encourage municipalities to conduct preventive home visits.

## Mastery

Service users with dementia and their families are groups that will significantly benefit from local municipal services. Short distances and proximity to professional environments, volunteer programmes, social arenas and networks are some of the benefits of municipal services. It is important to gather services in one place to promote continuity and to avoid fragmentation. Many will benefit from meeting places, where service users and their families can share experiences, develop social networks, and communicate with professionals. Such meeting places are key in the development of local learning and mastery services.

## Sensory loss

As people age, most will experience changes in vision and hearing. Sensory loss may become so severe that it impacts the quality of life. From 2020, municipalities will be required to provide ergonomic services. Ergonomists can help people with sensory loss to find solutions to improve their situation. Measures such as relevant assistive devices, along with physical adaptations may compensate for impaired vision and hearing and facilitate better communication. It is also essential for family members and people working with the elderly to have knowledge of living with sensory loss.

The Norwegian Directorate of Health, in cooperation with municipal health care services, specialist health services, service user organisations and research environments has evaluated services for the hearing impaired. The elderly comprise the largest group of people with hearing impairment, and the report particularly addresses age-related hearing impairment. The report is now being considered by the Ministry.

Elderly persons with hearing loss may be at higher risk of developing dementia. In some cases, hearing loss may not be identified, and the individual is instead mistakenly diagnosed with dementia. Research has shown that persons with hearing loss have a higher risk of cognitive impairment, and that there may be a correlation between impaired cognitive function and the development of dementia.[57,58] Hearing loss has also been defined by the Lancet Commission as one of the greatest risk factors for developing dementia, stating that this risk may be reduced through the use of hearing aids.[59] There is evidence that hearing loss among elderly persons in institutions could be linked to cognitive impairment in 30 to 40 percent of cases. It is therefore vital to reduce the risk of dementia by ensuring hearing tests and managing hearing loss in elderly persons and offering measures to facilitate better communication.

## Physical activity

The Government has presented its 2020–2029 Action plan on physical activity – *Working together for physical activity*. A primary goal is to create a more activity-friendly society, where everyone, regardless of age, gender, level of function or social background have opportunities for movement and physical activity. Elderly people are one of the target groups for this plan. Initiatives in the action plan are aimed at factors that affect people's opportunities for physical activity in daily life and recreation – through both universal and targeted measures. Health care services are included as a separate area of priority, with emphasis on measures to enhance knowledge and competency in physical activity in health care services to ensure that physical activity is integrated in practice. Physical activity, including strength and balance training will be included in professional guidelines. Residents in institutions will also benefit from physical activity, both indoors and outdoors, to maintain physical function and to manage daily activities.

## Other risk factors for dementia

### *Alcohol*

Middle-aged and older Norwegians now have a higher and more frequent consumption of alcohol than the generations before them. This increase is highest in the 66–79-year age group.[60] The elderly population is increasing, and elderly people are also consuming more alcohol, which gives cause for concern. Alcohol consumption is one of the main risk factors for loss of healthy life years in the population. The 2020 Lancet Commission listed excessive and harmful alcohol use as a significant risk factor for dementia.

Alcohol related dementia is a form of dementia caused by excessive alcohol consumption. Excessive alcohol consumption will affect both general intellectual abilities and memory. The link between excessive alcohol consumption and dementia is complicated. Those who drink a lot will often have many other issues that increase the risk of dementia. Many of them smoke, have high blood pressure, diabetes and depression.[61] It is essential that healthcare services are aware of alcohol as a risk factor for dementia, so that treatment measures for alcohol dependency can be implemented.

### *Falls, injuries and accidents*

Falls in the home are a source of numerous injuries, including head injuries, and since the elderly population will increase in the years to come, prevention measures aimed at this group is necessary. The Lancet Commission found that traumatic head injuries can lead to dementia, which emphasises the importance of the efforts to prevent injuries and accidents. Accidents such as falls and hip injuries, will often lead to a deterioration in a person's health condition and daily function. Currently, the Norwegian data on activities in conjunction with head injuries is insufficient, and efforts are underway to improve this. Figures will be determined for more complete disease data at each health authority. In February 2021, the Norwegian Directorate of Health, through the Norwegian Patient Registry (NPR) will introduce a web-based solution for NPR data, where data for head injuries will be included.

Accidents and injuries have significant socioeconomic consequences and costs, in addition to the injuries and their consequences for the individual. The Norwegian Directorate of Health will develop an action plan for the reduction of serious fall injuries in the home, *Nullvisjon (Target zero) 2019–2027*. Collaboration between public, private and volunteer sectors will be necessary in preventing accidents. The Government has provided funding for an Injury Prevention forum up to 2023. This is a contact and cooperative body for a network of actors working on various forms of injury prevention. Many municipalities are members of the organisation Safe Communities, a WHO concept with emphasis on systematic injury prevention and cooperation between the municipal sector and businesses.

### *Environmental factors and dementia*

We have gained more knowledge on the link between environmental hazards and health. Globally, air pollution (both outdoor and indoor) is one of the major factors for poor health, and the World Health Organization (WHO) has therefore included air pollution as one of the factors in the work on noncommunicable diseases. New figures from the *Global Burden of Disease* shows that air pollution raises the risk of dementia by 20 percent. The link between air pollution and dementia has been further specified in the Lancet Commission knowledge summary.

In Norway, outdoor air pollution, in the form of fine particulate matter, is among the ten risk factors that contribute to death and loss of health due to cardiovascular and respiratory diseases.[62] It has now been determined that even lower concentrations of fine particulate matter may cause health problems. The Norwegian Brain Council refers to new studies indicating a link between harmful effects of air pollution and both stroke and dementia. The Norwegian Environment Agency, the Norwegian Public Roads Administration and the Norwegian Institute of Public Health have assessed new limit values for fine particulate matter and have proposed a reduction from 2022.[63] Tools will also be developed to estimate the effects of air pollution and give municipalities better notification services.

### *Nutrition*

One of the government's goals is for all nursing home residents and recipients of home services, including persons with dementia, to be assessed for nutritional status. This will identify risks and ensure appropriate measures to prevent malnutrition and disease.[64] There may be a need for special considerations for people with dementia, such as access to traditional diets. Adapted measures that help to maintain or improve nutritional status also has an important psychological, social and cultural value. The development and improvement of national quality indicators will help to strengthen systematic nutritional efforts in these services to prevent malnutrition and undernutrition.

### *Dental health*

Individuals with cognitive impairment often have difficulties in performing daily routines. One example is daily oral hygiene and tooth brushing. Deteriorating oral health and dental health may therefore be an early sign of cognitive impairment. Dental health requires daily dental and oral hygiene, and problems with daily routines may therefore quickly lead to a deterioration of dental health. Regular check-ups for oral health are therefore essential. Public dental health services have organised preventive measures for the entire population, although most measures are aimed at preschool children and personnel in health care services. Persons in early stages of cognitive impairment living at home without municipal services are unlikely to be identified by dental health services. Once oral and dental health has begun to deteriorate, a number of different health problems may ensue. It is essential to prevent and treat these conditions, especially in terms of nutrition.

For years, the Government has been working to strengthen the structure of regional odontological competency centres to increase competency and improve oral health services for people with functional impairment and serious illnesses. Oral and dental health services at hospitals have been in place since 2012 through a pilot project with government funding. A scheme will also be initiated for municipal dental hygienists.

## 6.2 Key measures during the plan period

### New strategy for noncommunicable diseases

In early 2021, the Government will present a new Strategy against noncommunicable diseases (NCD). Preventive measures for dementia will be in line with the priority areas in this new strategy.

### Reduce loneliness

In accordance with the quality reform *A full life – all your life* the Government will strengthen its efforts in the volunteer sector to reduce loneliness among the elderly and will provide funding for volunteer and non-profit organisations to facilitate increased activity, participate and social community for the elderly.

In 2020, the Government allocated NOK 75 million for its stimulus programme for volunteer health services as a non-recurrent grant for volunteer organisations. The purpose is to promote activities led by volunteer organisations that will help reduce negative consequences of infection control measures. This grant will be administered by the Dam Foundation. The Government has proposed to continue this stimulus programme until the end of 2021.

In the budget agreement in conjunction with the revised state budget, the Government has allocated non-recurrent funding in the amount of NOK 400 million for a programme for vulnerable elderly persons. The purpose is to promote activity measures and reduce loneliness among the elderly, for both those who live at home and for nursing home residents. This includes both municipalities and volunteer organisations.

## Housing and community development

In order to ensure that more people can live at home if they wish, the Government has initiated work on future forms of residential housing, pursuant to chapter 8. It will also be necessary to share knowledge of architectural methods and universal design in the work on dementia-friendly residential housing, as part of the comprehensive residential and community planning. This perspective is also part of a comprehensive, health-promoting community planning. Here, *The National Programme for an Age-friendly Norway* will play a role.

## Nutrition strategy

To help create good meal experiences and to reduce malnutrition and undernutrition among elderly people, including those with dementia, the Government will devise a national strategy for 2020 on good nutrition and diet in nursing homes and home care services. This strategy will focus on systematic nutrition efforts, knowledge and competency, and individually adapted meal and nutrition follow-ups. This national strategy will be used as a foundation for municipalities to develop their own adapted nutrition strategies, as part of the regular planning work in conjunction with *A full life – all your life quality reform*.

The Government will be providing funding for volunteer organisations to provide good food and meal experiences for elderly persons. In its 2021 state budget, the Government has proposed a NOK 20 million non-recurrent grant for a grant scheme for meal companions as part of the “Golden mealtime moment” programme.

## Dental health

The Norwegian Institute of Public Health has been assigned the task of conducting a knowledge summary of research results in the use of dental hygienist competency in municipal health care services. This particularly involves preventive home visits, as well as experiences from other Nordic countries. Furthermore, the Ministry will prepare a pilot project on municipal dental care.

# 7

# Improved quality of health care services

The Government's objective is to create the patient's health and care services. People with dementia should be able to feel safe and receive predictable services. This means that services must be based on individual needs and wishes, and that involved agencies must act in the individual's best interests.

A dementia diagnosis does not necessarily mean that the individual will require extensive assistance. Many will be able to live at home without help for a certain period, preferably with some information and guidance. Some will require some adaptations and assistance at home, while others will need comprehensive care. Some will need long-term care services. The most important thing is for everyone to be met with respect and to be given adequate follow-up, so that they may live good lives.

A key goal of Dementia Plan 2015 and Dementia Plan 2020 has been to ensure that people with dementia are diagnosed in a timely manner. This is a long-term goal that will require continual efforts. It may be difficult to diagnose dementia diseases, and the summary from the Norwegian Directorate of Health indicates that too few are being assessed and diagnosed, and some are diagnosed too late in the disease trajectory. There is stigma associated with dementia. Many still believe that there is little point in assessing and diagnosing dementia, since there is no effective medical treatment for the disease. However, there are many good measures and services that can make life easier for people with dementia and their families and improve their quality of life. There is still a need for continued focus on this issue, not only in terms of how dementia should be assessed and diagnosed, but also on why it is necessary to assess dementia.

Dementia Plan 2020 and Dementia Plan 2015 were primarily aimed at municipalities. Dementia Plan 2025 includes initiatives aimed at hospitals, as a high number of patients in hospitals have dementia or acute cognitive impairment. We need better cooperation routines and a better information flow between municipalities, general practitioners and hospitals. There is also a strong need to facilitate hospital systems and environments for people with cognitive impairment and dementia.

## 7.1 Long-term strategy

### Person-centred care

The Government notes that individual needs and wishes should provide the basis for the design and allocation of services for people with dementia. Person-centred care involves how people with dementia experience their situation and environment, and that we try to understand behaviour as an expression of needs. Person-centred care is included in the Report to the Storting (white paper) 15 (2017–2018) *A full life – all your life*. Where it is promoted as one of 25 solutions that contribute toward better continuity, security and predictability in care pathways for service users and their family members. Values, methods, communication techniques, etc. related to person-centred care have provided the foundation for the national professional guidelines for dementia. This is also a recurring theme in the revised version of the Dementia Care ABC, and in other guidance material prepared under Dementia Plan 2020. The person-centred approach has significance for the services that are offered, and for the prevention and management of behavioural and psychological symptoms of dementia. Person-centred care is a clear recommendation by the national professional guidelines for dementia. There is therefore a need for greater focus on this area.

A person-centred approach is especially important for certain groups. This may apply to persons with Sami backgrounds, linguistic minority backgrounds, those with early onset dementia, and individuals with intellectual disabilities who develop dementia. It is essential that persons with dementia who need specially adapted services will receive them.

## VIPS PRACTICE MODEL IN STAVANGER MUNICIPALITY

The 2017–2020 dementia plan for Stavanger municipality states that municipal services for people with dementia must be based on person-centred care. This is also embodied in the municipal action and financial plan for 2019–2022, which stipulates that courses in person-centred care must be offered to all personnel in nursing homes and assisted living facilities for people with dementia, as well as for home care service staff.

The municipality has determined that the VIPS practice model is a good method for promoting person-centred care. It includes an established and quality-assured educational programme from the Norwegian National Advisory Unit on Ageing and Health. This ensures that the courses are consistent with person-centred care. The VIPS practice model has been adapted for both nursing homes and home-based care services. The VIPS practice model is also consistent with Stavanger municipality's commitment to the "A full life – all your life" reform and "What is Important for You?" programme.

The municipality began the training in the city's nursing homes and assisted living facilities and continued with home-based services and dementia teams. Municipal service managers received information on the method and how to conduct staff courses. Each municipal service manager is responsible for implementing the method, which becomes part of the service's routines for care and treatment.

The competency centre at Blidensol nursing home in Stavanger is experienced in the use of the VIPS practice model. It holds courses and issues course certificates in use of the method. Everyone who completes the course is offered continued support and guidance from this Stavanger competency centre. Feedback from those who have used the VIPS practice model has been positive. Is a demanding method, and it takes time to systematically implement the model. Nevertheless, the model is actively used in practice. Staff members can discuss various challenges and issues at the VIPS meetings, where the group works together to come up with good solutions for individual patients. The municipality has registered greater awareness and interest in the importance of trust-promoting measures after the VIPS model was implemented.

## Assessment and diagnostics

Symptoms of dementia may be obscure in the early stages of the disease, and similar symptoms can be found in several other diseases. It may therefore be both difficult and time-consuming to diagnose dementia. Assessment and diagnostics, however, are crucial. A dementia diagnosis can be difficult to accept, but at the same time it removes doubt, uncertainty and suspicion.

National professional guidelines for dementia describe several conditions that suggest an assessment and diagnostics for suspected dementia.

- Other conditions that may cause similar symptoms and that can be treated must first be ruled out.
- Treatment to alleviate symptoms will be assessed and potentially implemented.
- The patient and his or her family members will have the opportunity to plan their lives around the dementia disease, and determine the power of attorney, last will and testament, inheritance, and other issues.
- Both the patient and family members will have access to adequate information and follow-up from municipal health care services.
- People in the environment will gain a better understanding of the situation and can make adjustments.

Even when there is no need for services, information and guidance will still be of importance to the individual and his or her family. It is also essential to secure a coordinator in the municipality.

In most cases, assessment and diagnosis will be conducted by a general practitioner, as recommended in the national professional guidelines for dementia. It is therefore essential for the individual or family members to consult the patient’s general practitioner upon suspicion of dementia. The general practitioner will then conduct a basic dementia assessment and possibly refer the patient elsewhere if needed. Individuals who visit their general practitioner with concerns of cognitive impairment must be taken seriously. An assessment should not simply conclude that dementia is present but should also provide answers as to the type of dementia disease, in order to initiate the best possible treatment and post-diagnostic follow-up. Once dementia has been diagnosed, the general practitioner should obtain the patient’s consent to alert the municipal memory impairment team or similar service, so that municipal personnel have the opportunity to offer follow-up.

Almost 90 percent of the country’s municipalities have established interdisciplinary teams that have competency in dementia. General practitioners will normally conduct an assessment and assist in further follow-up.[65] Such teams have different names in different municipalities but are often referred to as *memory impairment teams* or *dementia teams*. In the 2018 national survey, 74 percent of these teams stated that they had routines in place for cooperation with general practitioners on diagnostic assessments, while 60.2 percent stated that they had routines for cooperation with general practitioners on post-diagnostic follow-up. This is a positive development from earlier surveys, but it still illustrates the need for increased collaboration.

## BODØ MUNICIPALITY – MEMORY IMPAIRMENT TEAM

Bodø municipality's memory impairment team was newly established when the municipality joined the development project on systematic post-diagnostic follow-up, and the team was given a key role in the project.

Core activities for the memory impairment team include:

- assisting general practitioner in basic dementia assessments
- early post-diagnostic follow-up
- holding information courses for families, and management courses for families and service users, in addition to follow-up throughout the disease trajectory
- follow-up and check-ups in cooperation with general practitioners
- operation of the dementia contact network for home care services
- guidance and instruction for healthcare personnel and volunteers
- follow-up of volunteer Activity friends

When a person is newly diagnosed with dementia, they are offered an initial home visit to determine their needs. They are offered a contact person, and their primary needs are assessed. They are given information about the disease, how to care for their health, and the importance of continued activity. They are also given information and assistance on how to apply for assistive equipment and devices and begin the process of planning for the future. The next appointment is scheduled based on the needs of the service user and family members. A person-centred approach is emphasised to ensure that the service user and family members are involved in all areas that affect their lives.

A mastery course that includes physical training in cooperation with physiotherapy services has also been developed. Should there be a need for other services, the team works closely with the office for municipal funding and home care services. Efforts are underway to develop cooperation procedures and to identify roles for further follow-up. The municipality has a primary contact person scheme, with dementia contact persons in every home care service zone. These have special competency in dementia.

Communication with various actors in the field has been described as challenging. The municipality has therefore established regular routines, procedures and arenas for this. A special cooperation procedure has been established between general practitioners and the memory impairment team, with clear routines for how to send referrals, reports and feedback. Interdisciplinary meetings and cooperation meetings have also been established for the municipal funding office and rehabilitation services, among others. Major issues are discussed with the local dementia association and local experience panel.

Although assessment and diagnostics are usually carried out by a general practitioner, certain groups are referred to specialist health services for assessment, in accordance with the national professional guidelines for dementia. This applies to younger persons and persons with intellectual disabilities, as well as those with Sami backgrounds, and people with educational, linguistic or cultural barriers that make it difficult to properly assess the patient, or to involve them in the process. Specialist health services may have better competency in these cases.

Equal health care services for Sami patients include services that are adapted to Sami patient's language and cultural background. Sami patients may encounter challenges when meeting service providers, due to insufficient knowledge of the Sami language and culture. Finnmark Hospital has established the first Sami clinic in the country – Sámi Klinihkka, in Karasjok. This clinic has gathered specialist health services in somatic medicine, mental health care and substance abuse treatment for the Sami population. A geriatric team is also under development, which will work with the Sami administrative municipalities, in accordance with the Norwegian National Health and Hospital Plan (2016–2019). The team will conduct assessments of cognitive impairment and dementia for Sami patients.

Individuals with serious and chronic diseases may have the right to an interpreter, even if they speak Norwegian in daily life. Health care services have a duty and a responsibility to provide interpreters. Specialist health services also play an important role in assessing individuals who may have other illnesses that may complicate the situation, as well as individuals who have uncertain diagnoses.

## Post-diagnostic follow-up

Most people will naturally feel uncertain immediately after diagnosis. This is a difficult time for many. It is therefore essential that the service user and family are not simply sent home after the diagnosis, but that they are given information and an offer of follow-up. Even if patients do not yet need services, it is essential that they and their families receive guidance and information about the disease, welfare technology, future power of attorney, last will and testament, inheritance, pension benefits, and other rights, as well as relevant services adapted to this group. Family members may benefit from information classes or support groups. Respite care services for family members and day activity services for people with dementia should also be determined relatively early in the disease trajectory.

It is also important to offer a regular contact person in the municipality after diagnosis. This person will follow up the service user and family over time and determine needs as the disease progresses and more assistance is required.

Those with advanced dementia, who already require municipal services at the time of diagnosis, will still need thorough information, for themselves and their families. The goal is to meet the health care needs of individuals with dementia in a comprehensive and coordinated manner. Some will already be entitled to a coordinator and to an Individual Plan, based on their wishes. As stated in the review of the status for Dementia Plan 2020 by the Norwegian Directorate of Health, there is still a need to implement measures and models for systematic post-diagnostic follow-up of dementia. The 2018 national survey showed that only 55.3 percent of municipalities have regular routines or models for systematic post-diagnostic follow-up of persons with dementia living at home and their families. This means that about 50 percent of municipalities are still not doing so. National professional guidelines on dementia provide more detailed descriptions of recommended post-diagnosis follow-up.

A large share of elderly Sami people speak Sami as their native language. However, the majority of their children and descendants are not fluent in Sami. This may be challenging for both family members and services. In order to strengthen and develop Sami culture, language and society, the Sami Parliament has entered cooperative agreements with several city districts with larger Sami populations. These agreements have addressed culture, schools and health, and are important measures for putting Sami policy issues on the agenda. The Government will encourage municipalities with a larger Sami population to utilise the cooperative agreements with the Sami Parliament.

## Services for persons living at home

In order to enable people with dementia to remain living at home as long as possible, good services are needed that provide security and predictability for these individuals and their families. It is problematic for people with dementia to deal with frequent changes in service providers. Through its *A full life – all your life* quality reform, the Government presents recommendations that can enable each individual service user and their family to have fewer and more stable staff members, and to experience a greater sense of security and continuity of services.

Knowledge gained from development projects, such as those carried out from Dementia Plan 2020, indicates that a regular contact person, preferably from the municipal memory impairment team, is essential for a good and systematic post-diagnostic follow-up. People with dementia and their families would then have a regular contact person they can call, who will oversee post-diagnostic follow-up. This person will also keep track of any needs that arise throughout the disease trajectory, to ensure that appropriate measures and services are provided. Family members will require flexible respite care services and support, so that they have time for self-care, pursuant to chapter 5 on family members.

## DAY ACTIVITY CENTRES HAVE NEW ROLES – BERGEN MUNICIPALITY

Bergen municipality has prepared a model to provide persons with dementia living at home with an individually tailored service at day activity centres. Each individual service user is assigned a contact person who will follow up the service user and family. This model consists of a procedure for the contact person, as well as a toolbox with information and assessment tools. The model is intended to ensure that service users and their families receive predictable, individually adapted and comprehensive follow-up – regardless of which day activity centre they attend. Feedback from service users and families has provided an important foundation for the development of the model. Service users and their families now feel they receive the support, follow-up and information they need.

To ensure that service users receive systematic follow-up tailored to their needs, day activity centre staff has reviewed an educational training programme that includes courses on Individual Plan, coordinators and the VIPS practice model. All day activity centres have now hired healthcare personnel with higher educations, and the model is anchored in the municipality's board documents.

## Nursing homes and other long-term care facilities

More than 80 percent of those who have long-term care in nursing homes have a dementia disease. However, surveys indicate that only 55 percent have a registered dementia diagnosis. Identifying signs of a developing disease is essential for providing measures at an early stage. It is therefore important for residents in long-term care facilities to be assessed and diagnosed. In our work with the plan, we have received feedback stating that many people have had difficulties with the transition from home to nursing home. One of the goals is to ensure a smoother transition between home and nursing home, cf. the *A full life – all your life quality reform*. Furthermore, the Government argues that individual needs and wishes should provide the basis for the design and provision of services. This includes residents in long-term care facilities. See the introduction on person-centred care in this chapter.

The Government has allocated an investment grant to enable municipalities to renew and increase the number of institutional places and assisted living residences for people in need of 24-hour health care services. For those who need long-term care, the recommendation over time has been "smaller is better", cf. Dementia Plan 2020. This recommendation still applies, and the principles are incorporated in the recommendations for the investment grant scheme. Smaller units promote social interaction and a sense of autonomy in daily life for the residents. It also protects individual needs and opportunities for privacy.

It has been deemed necessary to replace or renew long-term care facilities. This was assessed in planning cooperation with the Norwegian Association of Local and Regional Authorities (KS). It will still be necessary to renew and adapt unsuitable buildings. New experiences during the corona pandemic have actualised the principle of smaller, more manageable residential groups and the need for rehabilitation from an infection control perspective.

## Challenging behaviour

Behavioural and psychological symptoms of dementia (BPSD) affect many people with dementia at some point during the disease trajectory. These symptoms, also referred to as neuropsychiatric symptoms, may present challenges in daily life for the individual, for family members, and for health care personnel. Some behavioural symptoms, such as apathy, present relatively few challenges, while other symptoms, such as aggression, poor impulse control, irritability, or physical agitation and wandering will likely cause bigger problems for the person's surroundings. It is essential that services are adjusted to manage behavioural incidents, to protect the individual, and to protect both the individual and their environment from potentially violent behaviour. We have recently acquired new knowledge of the scope of violence in nursing homes. The Norwegian Directorate of Health has been asked to summarise this knowledge. County governors will provide examples of municipalities that have been successful in preventing and managing violence and abuse in nursing homes. This will form the basis for continued work in this field.

Adequate knowledge and competency in addition to good routines to ensure that knowledge is systematised is essential for preventing and managing behavioural and psychological symptoms of dementia. A person-centred approach such as communication techniques, will have a strong significance for the quality of services for persons with dementia. It will also be important in terms of the extent to which behavioural and psychological symptoms develop, and how behavioural symptoms are managed. Services must have routines and systems in place to ensure person-centred care that can identify and manage behavioural and psychological symptoms Good leadership and management are essential to prevent and avert violence in nursing homes. Municipal leaders and managers of individual nursing homes are responsible for ensuring that residents in nursing homes are not subjected to violence.

Changes in health legislation from 1 January 2018 specify that services have a responsibility at a system level to prevent, reveal and avert violence and sexual abuse. This includes violence from fellow patients, staff members, and others such as visitors and volunteers. Regulations regarding management and quality improvement for health care services make it clear that the responsibility for ensuring that operational systems are responsible and functional at all levels lies with management. Municipal leaders and management for municipal services are responsible for the continual planning, implementation, evaluation and adjustments to services, to ensure that these are adequate and responsible. As part of the planning work for service activities, it is necessary to maintain an overview of deviations, including unwanted incidents. The Government has increased its allocations to the

National leadership educational programme for primary healthcare services in order to strengthen leadership competency in its services.

A good building layout adapted to resident needs will also have a positive effect. The “smaller is better” principle (localisation and size of nursing homes) is supported by research on violence in nursing homes.[66]

I Prop. 12 S (2016–2017) *The Norwegian escalation plan against violence and abuse (2017–2021)* is specified in the Government’s objectives for the efforts against violence and abuse. A key goal is to ensure that all sectors and services have good and appropriate competency on issues of violence and abuse.

## Palliative care and treatment

Studies show that many elderly people in the final phase of life are suffering and have no relevant measures to alleviate their symptoms. Pain is often undertreated. Assessments of pain and pain treatment for dementia patients can be challenging and become even more difficult as the dementia progresses. Palliative care and treatment should therefore be an integral part of the treatment and follow-up from an early stage of the disease trajectory. Individuals with dementia may struggle to express their needs and wishes in the final phase of life, and advance care planning conversations will therefore be essential.

One of the Government’s goals is to ensure that everyone is offered good, palliative treatment and care in life’s final phase. Therefore, the Government has presented the first white paper on this topic: Report to the Storting (white paper) 24 (2019–2020) *Lindrende behandling og omsorg – Vi skal alle dø en dag. Men alle andre dager skal vi leve (Palliative treatment and care – We will all die one day. But all the other days we will live)*. The Government’s goal with this report is to emphasise that death is a part of life, and to provide access to palliative treatment and care for those who need it. This will be done by facilitating the best possible quality of life and the freedom to choose palliative treatment and care. It also addresses where the individual wishes to die, also if they wish to die at home. To achieve these goals, the Government will assist by promoting more openness about death, and greater competency and knowledge. A few central measures in this report include a three-year programme to develop models for facilitating more time at home and the option to die at home for individuals in the final stage of life. A knowledge summary will be prepared on services for palliative treatment and care in nursing homes and in patients’ homes. There will also be greater focus on the preparation, information and implementation of advance care planning. Freedom of choice will be facilitated in services, partly through the grant to establish and operate palliative units, and by assessing the need for a specialisation in palliation.

## Collaboration – health community

One of the Government’s goals for health care services is to ensure that patients, service users and family members experience cohesive services, where each person is actively involved in their own health and treatment, cf. Report to the Storting (white paper) 7 (2019–2020), Report to the Storting (white paper) 15 (2017–2018) and Report to the Storting (white paper) 26 (2014–2015). Adequate follow-up of individuals with dementia requires internal municipal collaboration as well as collaboration with specialist health services.

In order to achieve the goal of more comprehensive and cohesive health care services, the Government and the Norwegian Association of Local and Regional Authorities (KS) have agreed on the introduction of 19 health cooperatives. Health collaboration in the healthcare community should particularly focus on developing and planning services for frail elderly people, children and adolescents, people with several chronic diseases, and people with serious mental health issues and/or substance abuse issues.

An interdisciplinary approach and good cooperation across municipal health care services and specialist health services will make it possible to safeguard the entire individual, and provide services adapted to the individual's needs. Elderly patients often find it difficult to cope with relocation. This will make them more vulnerable as their disease progresses. It is often best for the patient to receive health services where they are, rather to move them, as long as this is responsible. The Government wishes to have hospitals with outreach services. This would imply that specialist health services can assist municipal health care services, either with ambulatory services or virtual solutions. In the National Health and Hospital Plan, health communities are encouraged to set goals for the sharing of competency between municipalities and hospitals.

When elderly patients with cognitive impairment are admitted to hospital, both the patient and family members should be provided with a sense of security and predictability. The National Health and Hospital Plan describes measures that will ensure a better patient care pathway for all patients, including those with dementia. This includes ICT systems that support the sharing of information, opportunities for mutual consultations between healthcare personnel, methods for developing good patient care trajectories, and good routines for referrals, admissions and discharges.

## Digitisation – for better services

Another goal is for digitisation to become an integral part of the development of health care services. It should provide people who have cognitive impairment with a better, more effective and more secure treatment and follow-up. National e-health solutions can provide cognitively impaired individuals and their families with the opportunity to acquire information on the disease and functional impairment, and on assistive devices and services. It should facilitate contact with organisations and help people communicate with health care services.

Digital collaboration solutions should assist in improving transitions and creating a more cohesive patient care pathway for individuals with dementia and their families. One example is the 'kjernejournal' (summary care record), that provides healthcare personnel with access to essential patient information. Summary care records have been implemented in all hospitals, at all emergency medical services, and in 90 percent of general practitioner offices. They are currently being introduced to nursing homes and home care services. All residents of Norway have access to their own summary care records at helsenorge.no. At helsenorge.no, cognitively impaired individuals and their families can find quality assured information on their rights. They can also find advice and guidance, for instance on relevant benefits schemes, as well as how to seek help. It will be necessary to further develop this information to make it more comprehensive, so that it applies to many different groups of family members, including families of persons with dementia.

Helsenorge.no also has services that can make it easier for family members to assist individuals who do not have the capacity to make decisions or give their consent digitally. For instance, services have been established for family members with power of attorney to log in on behalf of the service user in order to gain access to information and maintain a dialogue with health care services. For families of persons in need of care and who live alone, it can be reassuring to know that home care services have stopped by. Municipalities utilising these services now cover 40 percent of the population. The Government will enable an easier access to vital and relevant information by further developing helsenorge.no.

Health record solutions are undergoing modernisations to improve the sharing of information and to provide more efficient work processes. Work is also underway to plan a shared municipal health record program (Akson) with comprehensive solutions for collaboration, which will also make things easier for people with dementia and their families.

## Medication use and medicinal treatment

A thorough medical examination, a review of medications, updated medication lists and proper follow-up of patients with multiple diseases is vital for reducing the scope of side-effects and other medication-related problems in people with cognitive impairment. Symptoms are often treated for a short period and in acute cases, without a more comprehensive approach and planning for an active follow-up of the individual’s use of medication.

A systematic review of the patient’s medications is an important measure to ensure the proper use and to prevent harm to the patient. In 2013, the Government made amendments to General Practitioner Regulations so that general practitioners now have a duty to review the medications of patients who use four or more medications when this is considered necessary based on a medical assessment. In 2013, the Government also introduced requirements for medication reviews for patients in nursing homes, initially when they are admitted and at least once a year after that. The action packages from the patient safety programme on the correct use of medications and medication reconciliation support this work in nursing homes and home care services. National quality indicators enable us to follow this development. There has been a slight increase in the share of residents in nursing homes who have had a medication review, but the number is still too low.

The are several studies that show an inappropriate use of medications in home care services and in nursing homes. Many people with dementia have multiple diseases and use several medications at the same time and for a long period. This applies, in part, to the extensive use of antipsychotics and other medications for the treatment of mental illness. It also refers to the problem where medications used for symptoms in one phase of the disease trajectory are not sufficiently discontinued when the patient enters a new phase. It is therefore necessary to improve medicinal treatment in home care services and in nursing homes. Through its 2020 allocation letter, the Norwegian Directorate of Health has been asked to acquire more knowledge on professional medical services for people in long-term care facilities. In accordance with the action plan for general practitioners, the Government will facilitate the use of new tools, such as the Patient's Medication List (PML).

The Patient's Medication List comprises various measures to provide a shared overview of medications that are available to healthcare personnel and the patient. A digitisation of the list of medications will provide healthcare personnel with access to accurate medication information, regardless of time or place, and will facilitate better patient safety. The patient's medication list will be realised stepwise through the development of existing e-health solutions, to ensure benefits in the form of better medication management, patient safety and quality.

## 7.2 Key measures during the plan period

### Timely diagnosis and close post-diagnostic follow-up

The Government will continue and target efforts from Dementia Plan 2020, so that individuals with possible dementia will be ensured an assessment and diagnosis. One of the Government's goals is to ensure that people with dementia are diagnosed early in the disease trajectory and receive systematic post-diagnostic follow-up. The Government will assign the Norwegian Directorate of Health the task of developing an information campaign aimed at the population and healthcare personnel. The purpose is to create a better understanding of why it is important to be assessed and diagnosed, when the patient and perhaps also family members have suspected and been concerned about signs of cognitive impairment. Dementia assessments should be performed earlier in the disease trajectory than they are today.

As a part of the implementation of the dementia guidelines, the Norwegian Directorate of Health will devise an e-learning programme for dementia assessment aimed at general practitioner and other healthcare personnel.

Some hospitals have memory impairment clinics, but assessments in specialist health services are currently conducted at outpatient clinics in the field of geriatrics, neurology or geriatric psychiatry, depending on the patient's situation and symptoms, and on the local structure of services. A more comprehensive structure is required to ensure that patients do not experience unfair differences in assessment practices in specialist healthcare services. At university hospitals, it may be relevant to establish interdisciplinary and multidisciplinary units for patients who need such services. It will be necessary to determine the appropriate structure of work with cognitive impairment and dementia in specialist health services.

Expected waiting time for a dementia assessment in specialist health services is between 6 and 23 weeks (helsenorge.no). There are differences between health authorities in certain health regions, and between health regions. Since 2016, one of the three overarching goals in the assignment documents for regional health authorities has been to reduce unnecessary waiting and differences in the utilisation of capacity. The specific goal of reducing waiting time in 2020, as compared with 2019, has been temporarily suspended due to the Covid-19 outbreak.

## Good and cohesive services

The Norwegian Directorate of Health will be asked to prepare pathways for good patient care pathways, based on experiences from the model trials with systematic post-diagnostic follow-up and good patient trajectories. In addition, there is a need for simple measures for housing, cf. the chapter on housing and community planning.

Municipalities that are participating in the trials with the primary healthcare team and follow-up team can use these teams to follow up people with dementia and help to improve collaboration with other municipal health care services. One of three target areas of the action plan for general practitioner services, presented in spring 2020, is a team-based future. One of the Government's initiatives in the plan is to create a team-based general practitioner scheme. The aim is to create broader and more cohesive health care services for the population. This service will particularly address service users with chronic diseases and complex needs, including people with dementia. One of the Government initiatives in this plan is to improve the quality of physician services for patients with extensive needs. Municipalities will also be urged to prepare local standards for physician staffing in nursing homes, and the Norwegian Directorate of Health has been asked to acquire more knowledge on professional medical services for people in long-term care facilities.

Figures from the national survey indicate that only 45 percent of interdisciplinary teams with competency in dementia had routines for cooperation with specialist health services. Through the establishment of health communities, the Government will prioritise the development of comprehensive, coordinated services for elderly people, among others.

In order to strengthen medical and health professional follow-up of people with dementia who receive home care services, the learning network for comprehensive patient trajectories for patients with complex needs will continue in accordance with the Report to the Storting (white paper) 15 (2017–2018) *A full life – all your life*.

## Person-centred care and measures for behavioural and psychological symptoms of dementia

Continued efforts are necessary for competency enhancement and systematic implementation of person-centred care and milieu therapy, partly through the ABC initiatives and the implementation of national professional guidelines for dementia. The Norwegian Directorate of Health will be assigned the task of preparing a 'toolbox' for person-centred care and milieu therapy, especially aimed at behavioural and psychological symptoms of dementia (BPSD).

We know that many individuals with dementia remain healthy and/or physically active for a time. Staying active will have a positive and preventive effect on agitation and aggression. In the Quality Reform for Older Persons, *A full life – all your life* we have referred to a number of local examples that can serve as inspiration for other municipalities and show how to promote more activity. Reference is made to measures under chapter 5 on activity services and chapter 8 on competency.

Working with people with dementia who have serious behavioural and psychological symptoms is challenging. In addition to competency and good systems for person-centred care, it is essential to reflect on ethical aspects. This should be done regularly, and it is the responsibility of the service leaders to set aside time for this. In the Government's action plan, Kompetanseløft 2020 (Competency Enhancement Plan 2020), special funds have been earmarked for competency enhancement in the municipalities. The aim is to assist municipalities locally and regionally, to enable both employees and leaders to increase their competency in identifying, reflecting on and managing ethical challenges in their practice. These funds will be also be earmarked in the new Kompetanseløft 2025 (Competency Enhancement Plan 2025).

## Long-term care facilities

The investment grant for long-term care facilities is the Government's main initiative for renewing and increasing the number of institutional places and assisted living residences for people in need of 24-hour health care services. The Government has therefore facilitated the construction and modernisation of a record number of placements in long-term care facilities, including nursing homes and assisted living residences. We have also increased the government subsidy rate for municipal long-term care placements, from 35 to 50 percent. In addition, VAT compensation means that the state assumes up to 70 percent of the cost of building or renovating long-term care facilities. The Government will therefore continue its scheme whereby 50 percent of the budget for the investment subsidy for long-term care facilities will be used for net growth.

A large share of the country's long-term care facilities are either new or have been modernised over the last decade. However, a large share of the existing structures are in need of modernisation or renewal, according to *Rom for omsorg (Room for Care)*.[67] The necessity for further modernisation has also been noted during the corona pandemic, where the need to view infection control in conjunction with building design has been addressed. The

Government will ask the Norwegian State Housing Bank, in collaboration with the Norwegian Directorate of Health, to study the need for guidance related to infection control and long-term care.

## Dementia-friendly hospitals

Hospitalisation can be a confusing experience for persons with dementia. This may be due to unmanageable corridors, confusing signage, inaccessible or incomprehensible information, etc. The lack of assessment tools and general poor knowledge of how to speak with and deal with people who have cognitive impairment may also cause difficulties. These are problems that must be addressed if hospitals are to become more dementia friendly. There is a need for greater focus on physical adaptations, new routines, and better communication between healthcare personnel, patient and family members, if we are to improve hospital experiences.

The Norwegian Health Association has initiated a project about dementia-friendly hospitals in Norway, partly inspired by a similar project in England. A larger project has been initiated at Aker Hospital. This project will, among other things, contribute to better care pathways for patients with cognitive impairment. Diakonhjemmet Hospital and Haraldsplass Diaconal Hospital are also working on the theme “dementia-friendly hospital” by offering classes on dementia for hospital staff.

For people with dementia, good transitions and cohesion between municipal services and hospitals are vital. Health communities are meant to form a foundation for better collaboration on patients who rely on this. In order to promote dementia-friendly hospitals, we emphasize the importance of

- knowledge and openness of dementia: Healthcare personnel and other staff members must have knowledge that enables them to understand the needs of individuals with dementia and their families.
- a structure that can improve situations for persons with dementia at reception, during admission and in outpatient services, and to ensure service user participation for persons with dementia and their families.
- physical environment: directions, signage, information, accessibility, colours, contrasts, predictability, universal design, user participation and technological solutions.

Cooperation between hospitals and municipalities with respect to this patient group must be improved to allow the transfer of essential information between levels.

## Follow-up of the Commission to assess the need for amendments to laws relating to the use of coercion

Dementia will eventually impair the ability to make informed decisions and provide consent. There may therefore be grey areas and uncertainty as to whether a decision is voluntary or if the person displays opposition to a measure. If the person displays opposition, the measure is considered coercive. Good competency among health care personnel is essential for reducing coercive methods and to ensure that the conditions for the use of coercion have been met, pursuant to chapter 8 on competency.

*Tvangslovutvalget* (Commission to assess the need for amendments to laws relating to the use of coercion) (NOU 2019: 14) has proposed a common and diagnostically neutral law, which will also include individuals with cognitive impairment related to dementia and intellectual disabilities. Increased self-determination is one of the primary proposals. The Ministry of Health and Care Services is working to follow up the proposals by the *Tvangslovutvalget* (Commission for the review of legislation on the use of coercion).

8

# Planning, competency and knowledge development

The “dementia riddle” is by no means solved. This is unlikely to happen for quite some time. More research is needed on the causes of dementia, and on measures that could contribute to better services for people with dementia and their families.

If we are to succeed in making society more dementia-friendly, increased knowledge and competency will be essential, at both an individual and systemic level. Knowledge of dementia in the population will be important for reducing stigma and for ensuring that the individual seek help. Knowledge and competency are crucial for services if they are to identify and diagnose this disease, as well as plan, develop, provide and improve services for people with dementia. A general focus on competency enhancement measures is still required. Furthermore, there is a need for competency enhancing measures to ensure that healthcare staff has enough knowledge of dementia to manage daily incidents and more challenging behaviour and situations. There is also a need for competency enhancement on palliative care for people with dementia, and on nutrition, physical activity and adaptations for groups with special needs, such as younger patients, immigrants, Sami patients, etc.

The number of elderly people in Norway is rising, which places demands on how we organise and plan services in the years to come. There is already a lack of qualified personnel, and even with a great focus on recruiting and maintaining personnel, this is not enough to meet the demands of the demographic development. Innovation and new solutions are required for health care services, and we must make better use of technology, service development and staff competency.

A prerequisite for both research and municipal and hospital service planning is good access to registry data and good and relevant quality indicators. This, in addition to good planning and analysis competency, is essential in order to place the challenges of dementia on the agenda as part of the services’ ordinary planning work. Furthermore, good data is essential for assessing the effect of treatment, such as the correct use of medication.

## 8.1 Long-term strategy

### Knowledge of dementia in society

Public knowledge is essential if individuals with dementia and their families are to seek help. It is also essential in order to prepare for future changes. The public also needs this knowledge in society, to ensure that people with dementia are met with understanding and respect. Competency on dementia among health care personnel is necessary to identity and diagnosing the disease, and to provide the right treatment and care.

One of the Government's goals, as indicated in *Et samfunn for alle (A society for all)*, is for all people with disabilities to have the opportunity to participate in society and live free and independent lives. This requires universal design and individual adaptations. The responsibility to provide equal services for individuals with disabilities concerns all areas of society and requires good contact and cooperation across sectors.

Organisations for service users, families and special interests, such as the Norwegian Health Association, are key actors in disseminating knowledge and information on dementia among the public. The Dementia helpline and its peer advocates, also contribute actively to increase public knowledge of dementia.

### Health competency

Health competency involves a person's ability to locate, understand, assess and use health information. Good health competency is important for making knowledge-based choices for one's own health. This ability declines over time in people with various degrees of cognitive impairment, such as dementia. Health competency among family members and healthcare personnel is therefore vital for people with dementia.

In 2019, the Ministry of Health and Care Services presented its strategy for enhancing health competency in the population for the period of 2019 to 2023. This strategy emphasises that health competency perspectives and health competency considerations must be integrated in the organisation, planning, evaluation and work with patient safety and quality improvement. Health care services must also provide training for staff members to promote health competency and must adapt verbal and written communication to the service user's level of health competency. In 2020, the Norwegian Directorate of Health led a study to assess health competency in the population. Any targeted measures will depend on the results of the study.

## Research and innovation

We do not yet know the causes of dementia diseases. There is therefore no curative treatment or disease modifying therapies. More research is needed to provide a better understanding of the causes of dementia, in order to prevent dementia or find a cure or effective treatment. Research that can assist in developing such treatment is likely a long way off. It is therefore essential to conduct research on measures that can help to postpone the debut of disease or halt the development of the disease, and to identify important measures for individuals with the disease. This requires knowledge of people with dementia, their environments, and services. All knowledge-based services and service development requires research and professional development.

Dementia is a disease that is often associated with other diseases, and dementia research must be viewed in conjunction with brain research in general. The Ministry of Health and Care Services provides funding for research and innovation primarily through regional health authorities, and through the Research Council of Norway. Through the Research Council of Norway, the Ministry funds research and innovation projects related to health care services, prevention and public health, clinical research, and global health research. Research and innovation projects regarding dementia are of relevance within all these areas. The programme for clinical therapy research in specialist health services is thematically open to all professional fields. Of special interest are disease groups with a broader scope that represent major challenges for society.

The aim of these programmes is to strengthen research to improve clinical practice in environments that provide education for professionals, including education with relatively recent research traditions. It is therefore essential that researchers in the field of dementia apply for funding when relevant calls for applications are announced. Their applications and projects must also have the expected quality and prospective benefits if they are to be successful. In 2020, the Government presented a national action plan for clinical studies. This emphasised the need for a variety of opportunities for participation in clinical studies, across disciplines, treatment methods and service levels.

An important requirement for research on knowledge-based services is that the knowledge must be made accessible, and it should be spread and utilised. NOU 2011: 11 *Innovation in Care Services* noted that a strategy for knowledge development in health care services must aim to strengthen arenas for collaboration between knowledge producers and knowledge users. It was also noted that research agendas should become more relevant for service production, and that experiences from the practice field should contribute to the design of research questions. To support this, the Research Council of Norway has established five centres for care research, which are localised regionally, and tied to various universities and university colleges.

In the follow-up of the Government brain health strategy, the Research Council of Norway announced and granted NOK 20 million for a period of up to eight years to the research centre Neuro-SysMed, which opened in Bergen in 2019. This centre will be researching neurological diseases that impact the central nervous system, such as ALS, MS and dementia. This will increase knowledge in the field and give more patients the opportunity to receive experimental treatment.

The Ministry emphasises the importance of user involvement in research. TheHealthCare21 Monitor indicates the share of funds allocated for research in the regional health authorities that will be used for projects with user involvement.

The HealthCare21 Monitor is intended to provide statistics on research and innovation activities in Norwegian health care services, in municipalities, businesses, hospitals, university and university colleges, etc. The aim is to collect relevant statistics in one place and provide a good knowledge base for decisions at all levels. Here, we can see how all research activity is distributed across various health categories. The category "The Brain and Nervous System" is listed third after "Cancer" and "General Health" as the categories receiving the most funding through the EU, the Research Council of Norway, the regional health authorities and the Norwegian Cancer Society.

### JOINT ACTION – ACT ON DEMENTIA

Joint Action is a collaboration between members states of the EU and EEA under the EU Health Programme. The Norwegian Directorate of Health's department for municipal health care services, and the Norwegian National Advisory Unit on Ageing and Health have participated as associated partners in the *Act on Dementia Joint Action*, from 2016 to 2019, led by Scotland. Norway has participated in two work packages: One on the assessment of dementia and post-diagnostic follow-up, led by France, and one regarding long-term care services, which was led by Norway via the Norwegian National Advisory Unit on Ageing and Health.

Actors in Norway, like their EU colleagues, participate in the EU framework programmes for research and innovation. The Government intends to participate in the next framework programme, *Horizon Europe*. Norway will participate in the EU programme for neurodegenerative diseases, *The EU Joint Programme – Neurodegenerative Disease Research*. This programme will be concluded in 2023. Other projects with Norwegian participation have been given funding as well. This shows that Norway has good professional communities in this field. The Norwegian Health Association also contributes with valuable research on dementia, through its own dementia research programme, offering both basic research and clinical research.

### *Knowledge dissemination*

In addition to increased research and knowledge development, it is essential that new research and good solutions are spread and implemented. The Norwegian Directorate of Health has a key role in compiling knowledge and experiences, and in presenting national standards. The Norwegian National Advisory Unit on Ageing and Health, the regional centres for care research, and the development centres for nursing homes and home care services all have key roles in the work on professional development and competency enhancement, and in the dissemination of new knowledge and new solutions. County governors also contribute by spreading national guidelines and guidance materials.

Centres for care research communicate knowledge of research and innovation in the care sector to enhance the professional foundation and reputation of care services. The establishment of a Care Library and Journal of Care Research has led to the establishment of platforms for research dissemination. This has increased the accessibility and use of research-based knowledge in subjects that are relevant for knowledge dissemination in the field of dementia care.

The primary aim of development centres for nursing homes and home care services is to improve the quality of health care services through professional development and competency enhancement, and to spread new knowledge, new solutions and national guidelines. One area of priority is to strengthen knowledge-based practice associated with dementia. Development centres are meant to be driving forces for knowledge-based practice. They offer various methods and tools to develop learning environments and are a resource for municipal development and implementation efforts.

The Norwegian National Advisory Unit on Ageing and Health has a particular focus on dementia and age-related conditions and diseases and provides professional education and training for healthcare personnel in nearly all of the country's municipalities.

## Experimental treatment

In its Granavolden platform, the Government notes that several cancer patients and other patients with serious diseases shall be given opportunities for experimental treatment. This should be done in a manner that is safe for the patient, and it should also have a value beyond the individual patient. Experimental treatment will contribute toward medical and technological development and will be part of the total service package. The Norwegian national guidelines for experimental treatment were published in 2019. The aim of the guidelines is to provide clear boundaries for how experimental treatment should be offered and followed up. The guidelines are based on national principles for experimental treatment from the White Paper on Quality reform from 2012.

Hospitals will have the primary responsibility for patient-centred clinical research. To meet the need for several larger national, high-quality clinical studies, with predictable funding, a national programme for clinical treatment studies in specialist health services was established in 2016. This will enable more Norwegian patients to participate in clinical trials for experimental treatment through clinical research. It will also enable a better coordination of competency, resources and infrastructure, and strengthen the basis for effective, safe and good quality healthcare services. The programme is thematically open to all professional clinical fields. It seeks to meet the need for knowledge and to fill the knowledge gap, which will be of importance for patient treatment. Of special interest are disease groups with a broader scope that represent major challenges for society.

## Competency and competency enhancement

As noted in chapter 4, it has been challenging to recruit and retain qualified personnel in health care services. Factors that make employment in services more attractive include opportunities for competency enhancement and professional development, as well as full-time positions and a good working environment. This will also make it easier to recruit qualified personnel.

Municipal health care services are in need of personnel who have greater competency, as well as a broader and more diverse competency. It is also necessary to provide education for personnel without professional training, as well as recruitment to vocational education programmes in health social services, and the provision of continuing education programmes. This is because some educational programmes do not provide adequate competency in necessary areas, and personnel do not have sufficient competency to meet the needs of their patients, service users and family members.

*Kompetanseløft 2025 (Competency Enhancement Plan 2025)* is the Government's plan for recruitment, competency and professional development in municipal health care services and in county authority dental services. The goal of Kompetanseløft 2025 (Competency Enhancement Plan 2025) is to promote professionally sound services and to ensure that municipal health care services, as well as county authority dental services have sufficient and competent personnel. The "Competency Enhancement Plan 2025" has been presented in Prop. 1 S (2020–2021) for the Ministry of Health and Care Services. Through the Kompetanseløft 2025 (Competency Enhancement Plan 2025), the municipal sector will be given assistance in recruiting and retaining healthcare and social services personnel, and in making use of the opportunities provided by competency enhancement to ensure personnel for healthcare and social services. There will be emphasis on enhancing competency in areas with deficiencies and problems with services needed by patients and service users. Additional focus will be placed on adapting measures to address the needs of municipal personnel and competency requirements.

Many municipalities have noted that available education and training will be crucial for competency enhancement for personnel, especially in the districts. Decentralised and part-time education programmes have been discussed in the Competency Enhancement Plan 2025.

Similarly, the National Health and Hospital Plan 2020–2023 indicates the direction for development of hospitals in Norway. A key goal of the plan is to ensure that there are sufficient and appropriate skills to meet future demand.

Another key goal for the Government is to create a full-time culture, and efforts to recruit and retain employees in all groups of personnel, pursuant to the Competency Enhancement Plan 2025 and the National Health and Hospital Plan 2020–2023. These should facilitate lifelong career paths for all personnel groups. There shall be a particular focus on nurses and health workers. Innovation is also needed in relation to technology, work methods and the like to ensure sufficient personnel in the future. Many users require long-term, concurrent services. This would require more team-based services and a multidisciplinary approach for greater integrality and continuity. Good health care services are created when patients and service users are met by personnel with solid professional competency and range of professional skills.

To ensure that basic education programmes for health social services are able to meet the needs of patients and service users, the Government has established a new system of control measures for health and social science educations, called RETHOS. The aim of this system is to ensure that education programmes are forward-looking and based on the needs of patients and service users. The guidelines state the minimum standards for competency upon completing an education programme. These are stipulated in regulations for each education programme. Nurses, for instance, should have broad knowledge of the ageing process and the unique needs of elderly people. Elderly care and geriatric medicine should also be among the fieldwork placements for nursing students.

The Government has facilitated a new master's degree programme in advanced clinical general nursing, in order to meet the needs of municipalities. The Government will also provide specialist approval for nurses who complete this education. Nurses specialising in this field would have an important role in the care of individuals with dementia.

### *Therapeutic milieu and person-centred care*

Dementia Plans for 2015 and 2020 have focused on developing and spreading milieu therapy methods and work. Person-centred care and milieu therapy are the cornerstones of the Norwegian national professional guidelines for dementia and the Dementia Care ABC educational programme. A national competency community has also been established for culture, health and care.

There is a need for new competency and new professional methods in dementia care. Good services for people with dementia must be adapted to individual needs. Person-centred care and milieu therapy are therefore a central part of dementia care. Milieu therapy involves the manner in which physical, psychological and social conditions can be adapted to achieve an optimal sense of well-being and coping and offers a good and meaningful daily life. There is a broad range of measures that can be implemented to prevent, improve or maintain function in daily activities. Systematic milieu therapy can also prevent and manage neuropsychiatric symptoms. One study, for instance, shows that staff use of singing and music for therapeutic purposes has a positive effect on agitation and depression among patients with dementia, and it also reduces agitation during hygiene care and daily activities.[68] This also results in a reduction of psychotropic drugs, a decline in sick leave among staff members, and happier family members. Patients for whom hygiene and grooming care previously required three people could now be managed by one person. The use of singing and music also promotes a better understanding of the residents and facilitates a better and higher quality relationship between residents and staff members.

Work on the development and dissemination of person-centred care and milieu therapeutic methods will be continued in Dementia Plan 2025.

*Competency in groups with special needs*

It is important that the services ensure that persons with dementia who need specially adapted services receive these. This may apply to persons with Sami backgrounds, linguistic minorities, those with early onset dementia, and individuals with intellectual disabilities who develop dementia. This means that individuals must receive information, treatment and follow-up in a language they understand, and we must have consideration for individuals' cultural backgrounds. Knowledge and competency in Sami language and culture must also be available for services.

The Government wishes to continue its focus on information and knowledge dissemination on linguistic minorities who develop dementia, as well as persons with Sami backgrounds, linguistic minority backgrounds, those with early onset dementia, and individuals with intellectual disabilities who develop dementia.

The Norwegian National Advisory Unit on Ageing and Health has collaborated with development centres for nursing homes and home care services for the Sami population of Finnmark on the development of assessment tools for dementia in the Sami language. This was assigned by the Norwegian Directorate of Health as part of Dementia Plan 2020. It is essential that assessment tools are also known and used in the assessment of Sami patients.

## ASSESSMENTS OF LINGUISTIC MINORITIES

The project's general objective is to offer assessments of cognitive symptoms and dementia for people with Sami backgrounds or others with minority languages and different cultural backgrounds. Clinicians should not have to spontaneously translate assessment tools to Sami or other languages when assessing a patient.

***Sami:*** The University Hospital of North Norway (UNN) has carried out work on translating the assessment tools of NorCog (. The Norwegian registry of persons assessed for cognitive symptoms)to the Sami language. This work was initiated by the geriatric outpatient clinic in Karasjok. The translation was funded by UNN. The translated version will be made available to all outpatient clinical participating in NorCog. The project began in 2018 and was concluded in 2020.

***Other cultural and linguistic needs:*** This project will include clinicians from Oslo University Hospital, St. Olav's Hospital and Vestfold Hospital Trust, who will prepare a proposal for an assessment package adapted for linguistic minority patients. Linguistic minority patients should be offered available and adapted cognitive tests as part of the assessment package from NorCog. This work was initiated by the Memory Clinic at Oslo University Hospital. The project began in 2019 and was concluded in 2020.

The aim of the grant scheme *Competency enhancing measures for care services for Sami service users* is to assist in building, implementing and improving the quality of health care services for service users with a Sami language and cultural background through professional development and competency enhancement. These measures will be aimed at areas with significant South, North and Lule Sami populations. The grant will provide the opportunity to obtain, initiate and disseminate knowledge of the needs of Sami residents who receive municipal health care services, and to address how these needs can best be met. It will also help to improve competency among health care professional who provide services to Sami service users. The criteria for this scheme were designed in cooperation between the Norwegian Directorate of Health and the Sami Parliament.

### *Dementia Care ABC*

The National Advisory Unit on Ageing and Health has developed the educational programmes *Dementia Care ABC* and *Elderly Care ABC*, which are important contributions for enhancing competency in health care services. The Ministry of Health and Care Services will further develop and spread Elderly Care ABC and the Dementia Care ABC among the staff of municipal health care services.

### *Palliative care and treatment*

The national professional guidelines for dementia provide professional recommendations for how palliative care should be adapted for individuals with dementia, including how services should proceed in identifying pain. Projects have been established to enhance healthcare personnel competency. These have been made possible through grants for competency enhancing measures for palliative, end of life care and treatment. E-learning courses on dementia and palliative care have also been developed for healthcare personnel. These are included in a new version of the Dementia Care ABC educational materials.

## Planning

A central goal of Dementia Plan 2020 was to ensure that dementia challenges were put on the agenda for ordinary municipal planning. Figures from the 2018 national survey show that 88.6 percent of municipalities have mentioned dementia in at least one of their municipal plans. The majority of municipalities have mentioned dementia in their sub-plans for health care services, while a few have mentioned dementia in their municipal action and financial plans. We have positive experiences from Omsorgsplan 2020 (Care Plan 2020), where municipalities that put general care challenges, with particular focus on dementia challenges, on the agenda in municipal planning work, gave these challenges a higher priority than municipalities that did not. The Government will continue to encourage municipalities to put dementia on the agenda for ordinary planning.

A poor overview of the number of people with dementia has been a problem for planning. The National Advisory Unit on Ageing and Health has conducted a prevalence study on dementia in Norway. As part of this work, it has prepared an interactive map that shows the prevalence of dementia in Norway. The map indicates municipal, county and national prevalence figures for 2020, with projections toward 2050 (2025, 2030 and 2040). There is some uncertainty regarding these figures, especially for the smallest municipalities, however information from the prevalence study will still be a good indicator, useful for municipal planning work, both in the short and long term.

## Long-term care facilities that promote activity and community

There is likely to be a higher number of Norwegians with dementia in the future.[69] This challenge must be met with a variety of residential solutions and measures in local communities. As noted in chapter 6, the Government has initiated work on future forms of residential housing. The goal is to ensure that everyone has the opportunity to live at home as long as possible. At the same time, we must ensure that long-term care facilities under construction will be adapted for individuals with dementia. The goal is a more dementia-friendly society, not a separate society for people with dementia.

The localisation of long-term care services tied to functions close to the city centre and other residential environments can be enriching for both residents and the community. There appears to be a greater focus on the importance of meaningful activities and social integration for people with dementia.[70] Planners and designers should ask themselves what the project can do for the community, what the community can do for the project, and what the environment can offer individuals in terms of meaningful experiences and quality of life. The transition to assisted living residences or nursing homes may be difficult for many individuals. It is therefore essential that the community environment seeks to maintain and create connections with the life the person has led so far, through the physical design and anchoring to the place and relationships. It is also possible to include activity facilities in such models, and in this way contribute toward contact with the local community.

Dementia villages is a relatively new phenomenon in Norway. Several projects are in the planning and establishment stages in Norwegian municipalities, inspired by international reference projects. There are different professional views on this concept. On the one hand, it could be considered a modernisation of traditional nursing homes. Dementia villages translated to a Norwegian context appear to involve a few key principles regarding normality and daily life, adapted activities, and smaller residential groups with access to safe outdoor areas. Others prefer a development of residential housing for elderly persons that is integrated with residential housing for other groups and placed adjacent to other services and activities in the local community. From this perspective, it could be argued that the concept does not adequately seek to interact with the surrounding community, and that it doesn't properly facilitate a mixed living environment. It will be necessary to follow the development of dementia villages and obtain knowledge of how the concept would work in a Norwegian context.

Designing environments that are dementia-friendly and also of benefit to others is a complex task. This perspective must not be limited to care facilities. Health in architecture is more than health architecture.[71] Known experiences and examples so far indicate that there is no one correct answer or concept. There is a need for a greater variety of integrated residential services to meet the future demographic development, and to facilitate better quality of life, participation and mastery for each individual. There are good reasons to try out different combinations of services that can bring new functions and age groups together. In light of the focus on future forms of housing, it will be necessary to utilise existing knowledge and promote further research on dementia-friendly environments, also in contexts outside the home. Architects, builders, contractors, planners and others have a special responsibility to include specific solutions, and for combining existing knowledge and considerations.

## Statistics and registry data

Good statistics and good registry data are an importance source of quality improvement and research. Up to this point, there has been no registry data or opportunities to connect registry data in a manner that provides a good overview of people with dementia, the services they receive, and when they receive them. This is information needed by health care services when planning and operating their services. This information is also necessary to provide a better foundation for research. With the establishing of the Kommunalt pasient- og brukerregister (KPR) (Municipal patient and user registry) the Norwegian Directorate of Health and other agencies now have the opportunity to use registry data in new ways. These figures are accessible at different levels. With access to national registry data from both primary health care services and specialist health services, patient care pathways can be displayed between service levels. Using the data, linked to the diagnosis and services, it is also possible to envision anonymous metadata for management information and research purposes.

Assessment tools for basic dementia assessment have been developed for general practitioner and health care personnel. There is also a national quality and research registry of persons assessed for cognitive symptoms and dementia receiving treatment from specialist health services (NorCog). The goal is to improve the quality of services patients receive during assessment and treatment of cognitive impairment. As there is a rising number of referred patients with linguistic and cultural backgrounds other than Norwegian, there has been a demand for registry sets in English, and tests in other languages. It is also necessary to include assessment tools that are adapted for people with different cultural and linguistic backgrounds. In order to improve the quality of services, it is essential to obtain more systematic feedback on patient and family satisfaction with the services that are offered.

## THE NORWEGIAN REGISTRY OF PERSONS ASSESSED FOR COGNITIVE SYMPTOMS (NORCOG)

NorCog is the national quality registry for the assessment of cognitive symptoms and/or dementia. NorCog collects data from standard assessments of cognitive symptoms and dementia in outpatient clinics of specialist health services. The registry has a status as a national quality registry. NorCog collects data with the aid of a standard assessment that includes cognitive testing and an interview with the patient. Information on the development of cognitive impairment and how the patient functions in daily life is also obtained from family members or others who know the patient well. NorCog collects data on social aspects, symptoms, how the symptoms have developed and how this impacts the patient's and family's daily lives. The registry collects data on diagnoses, use of medication, other diseases that affect the condition, and the type of post-diagnostic follow-up the patient has received. The aim of NorCog is

- to improve the quality of cognitive assessments and evaluations of dementia
- to ensure better assessments, care and diagnostics of cognitive symptoms and/or dementia in Norwegian hospitals
- to ensure that all patients in the country receive the same services
- to ensure more practical research and quality improvement

## 8.2 Key measures during the plan period

### Increased knowledge in the population

The Government seeks to have a dementia-friendly society that safeguards and includes people with dementia. In its work against stigmatisation, the Norwegian Directorate of Health will, during the plan period, conduct an information campaign to raise awareness of dementia in society in general, and among health care personnel in particular.

### Research and innovation

It is necessary to continue research on the causes of the different dementia diseases in order to prevent the condition or find an effective, medical treatment. More research is needed on measures that could contribute to better services for people with dementia and their families. In accordance with its Granavolden platform, the Government aims to strengthen research on dementia. It is recommended that research efforts from Dementia Plan 2020 are continued.

In its Granavolden political platform, the Government states that it will present an action plan for clinical studies in Norway. The action plan is expected to be presented some time during 2020. This action plan will have a broad approach to clinical trials, and these measures will also benefit people with dementia.

## Education and competency

The Government has presented the Kompetanseløft 2025 (Competency Enhancement Plan 2025). The plan will help to ensure that municipal health care services have the necessary and sufficient competency to meet the needs of patients and service users. A new competency enhancement plan will contain both general and targeted measures.

Dementia Care ABC and Elderly Care ABC are important initiatives to ensure that municipal health care personnel have updated professional knowledge and opportunities for professional reflection. A focus on Dementia Care ABC and Elderly Care ABC will be retained in Dementia Plan 2025. This initiative is also included in Competency Enhancement Plan 2025. Furthermore, the Norwegian Directorate of Health will evaluate an education programme related to the prevention and detection of violence in nursing homes and home care services.

Funding for basic, further and continuing education through the competency and innovation grants, and through Dementia Care ABC education programmes for staff is an important initiative of Competency Enhancement Plan 2025 for health care service employees. In 2019, roughly 270 employees completed further education in geriatric care or dementia care with funding from competency and innovation grants, and roughly 2200 employees completed the Dementia Care ABC programme.

## Increased knowledge of dementia-friendly care homes

Current guidelines for long-term care facility investment grants stipulate that facilities receiving grants must be designed for people with cognitive impairment, based on the “smaller is better” concept.

The Government has therefore, in the municipal proposition for 2021 (Prop. 105 S (2019–2020)) notified of the introduction of planning requirements for the investment grant. The aim is to promote more comprehensive needs assessments of long-term care services and other residential services. This will also promote a better awareness of preventive measures through good community planning – not just for one defined target group, but for a general sustainable society.

The Norwegian State Housing Bank administrates the investment subsidy scheme and has a key role in assisting municipalities in the planning of nursing homes and assisted living residences, in addition to premises for day activity services. Deliberate and knowledge-based measures can provide added value for everyone and is not necessarily more expensive. We must continue to create frameworks that provide good experiences and facilitate a meaningful quality of life and autonomy. More knowledge is needed on what a dementia-friendly society can and should be. More systematised knowledge is also needed on the concept of dementia villages. The Norwegian Institute of Public Health will be assigned the task of preparing a knowledge summary of this area.

## Statistics and registry data

The Government will facilitate better control data and easier access to registry data. The Norwegian Directorate of Health has also been assigned the task of improving the availability of registry data on dementia and developing indicators that would be useful for municipal health care services in general, and dementia care in particular. The Norwegian Directorate of Health will also consider whether to develop other quality indicators for dementia. This work must be viewed in relation to the development of quality indicators in the area of care services.

Until there is sufficient registry data on dementia, national surveys of municipal services for people with dementia will be conducted every four years.

A health data analysis platform is under development. This  will enable the Government to facilitate a better utilisation of health data for research and analysis in order to develop better and more accurate health services. A health analysis platform will streamline and simplify access to health data, while also improving privacy and security. This will make it easier to use registry data for research purposes, including research on dementia.

## Dementia incidence study

The knowledge and overview of the prevalence and incidence of dementia in Norway is based on estimates from foreign studies. A major survey of the prevalence of dementia was conducted as part of Dementia Plan 2020. We still do not know how many people develop this disease each year. In order to learn more about the disease burden and dementia care pathways in Norway, the Norwegian Directorate of Health has been asked to ensure the implementation of an incidence study on dementia.

## International cooperation on dementia

The Norwegian Ministry of Health and Care Services and Norwegian Directorate of Health have been participating in international cooperation on the issue of dementia for many years. This cooperation has resulted in essential contact and network building, with opportunities for sharing experiences and expertise. It has also enabled us to share our experiences from the work on Norwegian dementia plans with other countries. The Government will continue this work, especially in relation to the World Health Organization and the EU, and through the Nordic Council of Ministers and the Nordic Welfare Centre. There is also significant amount of international cooperation on dementia, with participation by Norwegian professional and research communities.

# 9

# Financial and administrative consequences

Services for people with dementia must be developed as an integral part of the collective health care services. The design of services should be based on local conditions and on the needs of the population. This means that services will generally be financed through block grants for the municipal sector and basic allocations to regional health authorities.

This goal is followed up through a strong growth in municipal economies and through grants for regional health authorities in recent years. This has provided the basis for increasing capacity, improving quality and enhancing competency in health care services.

Dementia Plan 2025 contains strategies and initiatives for the period up to 2025. Initiatives in the plan are within current political and budget frameworks. New initiatives may be added during this period if so indicated by new knowledge and development. Potential needs for changes or reallocations as a result of this will be managed in the ordinary budget processes and followed up in the annual budgets.

## Administrative consequences

The Norwegian Directorate of Health is responsible for overseeing initiation, implementation and evaluation of Dementia Plan 2025. This will be done in close cooperation with the county governors' offices and municipalities. One important task is to encourage and guide municipalities and health authorities through their planning work, to ensure that services are adapted to a rising number of individuals with dementia and their families.

The Norwegian State Housing Bank, in collaboration with county governors' offices will also be responsible for implementation through the administration of the subsidy scheme for long-term care in nursing homes and assisted living residences.

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