



Ministry of Health, Welfare and Sport

# National Dementia Strategy

# 2021-2030



# Content

Chapter 1	<b>National dementia strategy - a bird's eye view</b>	<b>4</b>
	1.1 Introduction	4
	1.2 Mission, themes, and shared themes	4
	1.3 Further detailing and involvement of other parties	6
	1.4 Connection with Ministry of Health, Welfare and Sport programmes	6
	1.5 Covid-19	7
Chapter 2	<b>Analysis</b>	<b>8</b>
	2.1 Dementia as a national challenge	8
	2.2 Facts and figures	9
Chapter 3	<b>"A world without Dementia"</b>	<b>10</b>
	3.1 Problem analysis	10
	3.2 What are we aiming for?	11
	3.3 What are we going to do?	11
Chapter 4	<b>"Persons with dementia matter"</b>	<b>13</b>
	4.1 Problem analysis	13
	4.2 What are we aiming for?	13
	4.3 What are we going to do?	14
Chapter 5	<b>"Tailor-made support when living with dementia"</b>	<b>16</b>
	5.1 Problem analysis	16
	5.2 What are we aiming for?	17
	5.3 What are we going to do?	18
Chapter 6	<b>Shared themes</b>	<b>19</b>
	6.1 Innovation	19
	6.2 Young persons with dementia	19
	6.3 International	19
	6.4 Communication	20
Chapter 7	<b>Governance</b>	<b>21</b>
	7.1 Management group	21
	7.2 Steering group	21
	7.3 Sounding board group	21
	7.4 Programmes	22
	7.5 Coordinator	22
	7.6 Schematic overview	22
Chapter 8	<b>Monitoring</b>	<b>23</b>

# Chapter 1 National dementia strategy - a bird's eye view

## 1.1 Introduction

Approximately 280,000 persons are presently living with dementia in the Netherlands. That number is expected to increase to approximately 420,000 in 2030 and 520,000 in 2040. The care costs for dementia will increase accordingly: from 6.6 billion euros in 2015 to 15.6 billion euros in 2040<sup>1</sup>. As a result, dementia is expected to become the most important cause of death in the Netherlands as well as the illness putting the greatest financial burden on society.

Persons with dementia are faced with an increasing loss of cognitive skills. This has a great impact not only on the life of the person with dementia but also on their family members and loved ones. A person with dementia increasingly needs support and guidance, even though he or she may still be physically able to do a great deal. There comes a time when 24/7 supervision is needed. Due to the cognitive decline, the “person everyone loved and knew” gradually disappears. This leads to a process of mourning that can last for years before the actual death of the patient. The combination of these factors makes living with someone with dementia especially difficult. Especially for the partner, who is also often quite old. If dementia develops at a relatively younger age (< 65 years), additional issues such as the presence of (young) children still living at home and the loss of income also play a role.

Since 2004, the Ministry of Health, Welfare and Sport has targeted dementia with the following programmes: National Dementia Programme (2004-2007), Dementia Care Chain Programme (2008-2012), and Dementia Delta Plan (2013-2020). The above developments provide strong arguments not only for continuing the efforts of the Ministry of Health, Welfare and Sport in the area of dementia on the same level but also for intensifying these efforts, starting in 2021, via the National Dementia Strategy 2021-2030.

## 1.2 Mission, themes, and shared themes

### 1.2.1 Mission

The point of departure for the National dementia strategy can be formulated in terms of the following mission:

Persons with dementia and their loved ones can continue to function as valuable members of society and receive appropriate support and care. Sufficient scientific research is carried out into the possibilities for preventing, treating, and curing dementia.

---

<sup>1</sup> A coherent picture of dementia and dementia care; key numbers, needs, care services offered, and impact; Theme report on the State of Public health and Care, 2018

## 1.2.2 Themes

The strategy consists of three themes that are strongly interrelated.

### 1.2.2.1 *“A world without dementia”*

Since 2013, the research programme “Memorabel” has focused on carrying out research into all aspects of dementia. In the coming years, we aim to implement a research programme that will bring greater focus and synergy into the field of dementia research. We aim to do so, for example, by funding groundbreaking research by leading centres, specialised in dementia research, as well as multidisciplinary consortia. The ultimate goal is to be able to cure and prevent dementia. In addition, we will focus our efforts on improving the quality of life of persons with dementia, for example via research in the top sector Life Sciences & Health. Collaboration and coordination with other research initiatives, nationally as well as internationally, are crucial for achieving the ultimate goal.

### 1.2.2.2 *“Persons with dementia matter”*

A person with dementia is a valuable member of society and has the right to be recognised as such, without suffering from prejudices or stigmas. Our aim is to ensure that persons with dementia are given the opportunity to continue playing a role in society in line with their wishes and capabilities. This means, on the one hand, making an effort to provide persons with dementia with opportunities to engage in fulfilling activities. On the other hand, it also means contributing to a structural change in behaviour on the part of other people so that persons with dementia can continue to feel that they are a part of society.

### 1.2.2.3 *“Tailor-made support when living with dementia”*

In recent years, the “Dementia Care for Each Other” programme has taken steps in further improving the support and care provided to persons with dementia and their loved ones. In the coming years, we aim to continue this process, for example by strengthening the regional dementia care networks. This includes the neighbourhood care teams, implementation of the dementia care standard, and - at the national level - focusing on collecting, broadening, and maintaining and spreading knowledge about all aspects of support and care for persons with dementia and their loved ones.

## 1.2.3 Shared themes

In addition to the three themes mentioned above, the strategy also has four shared themes common to each of the three themes.

### 1.2.3.1 *Innovation*

Innovation, technological as well as non-technological, is important for all aspects of dementia. This includes, for example, the use of technology for groundbreaking scientific research, as well as developing innovative methods for persons with dementia to continue functioning as members of society.

### 1.2.3.2 *Young persons with dementia*

A special group within this strategy consists of young persons with dementia. They often have other forms of dementia than persons 65 years and older. In part due to their age, diagnosing dementia under these younger persons is more difficult as dementia is often overlooked in the first instance. As these persons often have a family with children still living at home, are physically stronger, and are still part of the labour force, their needs in terms of support and care are different.

#### 1.2.3.3 *International*

Dementia affects the entire world. Dementia research and dementia care in the Netherlands have an excellent reputation on an international level. All the more reason to focus on international collaboration in the field of research, for example via the global Joint Program for Neurodegenerative Diseases Research, especially Alzheimer's (JPND). In addition, we collaborate with various European and global initiatives and organisations in order to share knowledge and experiences regarding dementia care with other countries.

#### 1.2.3.4 *Communication*

Communication is a common theme in all programmes of the strategy. In particular communication about the results achieved and the sharing of the knowledge and experiences acquired, all of which contribute to realising our goals. We specifically focus on appropriate information about the possibilities for reducing the risk of dementia and about the support and care available in the region.

## 1.3 Further detailing and involvement of other parties

Drafting the strategy is a first, agenda-setting step. Working out the strategy in more detail can now begin, in close collaboration with the efforts already under way: translating strategy into activities and programmes/projects that, on the one hand, actually improve the quality of life of persons with dementia and, on the other hand, also advance the prospect of finding opportunities for treating and curing dementia and reducing the risk of dementia. We aim to do this together with the regional dementia networks, municipalities, care providers, insurers, scientists, the business community, and - last but not least - persons with dementia and their loved ones. We intend to involve all these parties in the further development and implementation of the strategy. We aim to do so in the short term in developing the first programmes as well as in the long term, when the first results have been realised and follow-up steps have to be taken.

## 1.4 Connection with Ministry of Health, Welfare and Sport programmes

The National dementia strategy cannot be viewed as a stand-alone entity separated from other programmes. After all, persons with dementia wish to remain living in their familiar and trusted environment for as long as possible. The Living Longer at Home programme also helps them realise this goal. Approximately 60% of the residents of nursing homes have dementia. A connection with At Home in the Nursing Home is indispensable. The programme One against Loneliness also targets persons with dementia. Informal carers are very important for persons with dementia. The Informal Care Agenda and the Young Informal Carers strategic alliance were also developed for these informal carers. Volunteers need to be deployed in providing support and care for persons with dementia. Volunteer work and citizen initiatives also need to be coordinated in the interest of persons with dementia. Volunteers can, for example, be deployed to deal with themes such as loneliness and acceptance among persons with dementia.

A great many care professionals work with persons living with dementia and their loved ones. As is the case with other care sectors, we aim to ensure that there is an adequate supply of professionals with the required expertise available. For that purpose, we have the Working in the Care Sector Action Programme to ensure that we can continue to offer appropriate care and support now and in the future. The Knowing Better programme aims to strengthen professional activities in the long-term care sector.

## 1.5 Covid-19

The recent Covid-19 pandemic has had major consequences for society. For some persons with dementia and their loved ones, it sometimes had an even greater impact than for persons without dementia. Some examples of the consequences for persons with dementia:

- day centres had to close down, which meant that informal caregivers had to provide 24/7 care and became overburdened more quickly;
- as persons with dementia are often over 70 years of age and therefore extra vulnerable, it was not possible for others to temporarily take over the task of providing care;
- after the day centres reopened, it became apparent that it was very difficult in particular for persons with dementia to comply with the Covid measures;
- it was often difficult for persons with dementia in nursing homes to understand why protective measures had to be taken; measures such as not being able to receive guests or being able to make contact only remotely or through a window or via video calling led to incomprehension and sometimes anger;
- the inability to receive guests over a longer period of time sometimes resulted in accelerated cognitive decline in persons with dementia.

No simple solution could be found for some of these issues. The consequences for persons with dementia and their loved ones are also taken into account in evaluating how this pandemic was dealt with and the measures implemented. In spite of the limitations imposed by the pandemic, various activities were continued, for example working to promote regional and national collaboration with regard to older persons, an appropriate range of support services for informal caregivers, including the care ladder of MantelzorgNL, and the “Working together for Informal Care” action programme. A more detailed overview is presented in the “State of affairs regarding care for older persons in the nursing home and at home”.<sup>2</sup>

---

<sup>2</sup> Parliamentary Papers 31 765, no. 494

# Chapter 2 Analysis

## 2.1 Dementia as a national challenge

Approximately 280,000 persons are presently living with dementia in the Netherlands. Somewhat more than 178,000 of them are on the radar of healthcare providers and have been diagnosed with dementia. This means that over 100,000 persons living with dementia are not receiving any form of professional support or care whatsoever. In some cases, these persons may be coping with the help of friends and family and may not need any additional help. But others may not be willing to ask for support and care due to their fear of the diagnosis itself or of the potential stigma/lack of understanding. They may also simply not be able to navigate the “care roadmap”.

Roughly 20,000 relatively young persons (< 65 years) have dementia. This has an extra impact and leads to different requirements in terms of support and care. These persons often have a family with children in the home setting, as well as a paid job. Their dementia can result in a lower income. They are also often fit and otherwise healthy, leading to different requirements in terms of daytime activities. The types of dementia prevalent under younger persons are also often different from what is common under the elderly. This results in different requirements in terms of diagnostics and treatment.

In the Netherlands, 98% of the population know what dementia is, and almost 60% know someone with dementia. But only 13% of the population know how to interact with and relate to someone with dementia<sup>3</sup>.

Professionals in many sectors interact with persons with dementia: in shops, banks, taxis and public transport, barbershops and hairdressers, dentists, etc. Members of the police, in particular, deal with persons with dementia in crisis situations, for example in the public space if persons with dementia show confused behaviour.

Dementia places a heavy burden on informal carers. Due to the cognitive decline, a dear friend or loved one with dementia needs an ever-increasing degree of support and assistance, even though he or she may still be fairly fit physically speaking. There comes a time when 24/7 supervision is needed. Due to the cognitive decline, the “person everyone loved and knew” gradually disappears. This leads to a process of mourning that can last for years, even before the actual death of the patient. The combination of these factors makes living with someone who has dementia extra difficult, especially if the informal carer also has a family and a paid job.

The care for persons living with dementia is quite intensive - in the home situation as well as the inpatient setting. This demands a great deal from the professionals working in the care sector. Due to the ageing population, the number of persons with dementia will increase, which in turn will lead to an increasing need for this type of care and an increase in the care costs.

---

3 A coherent picture of dementia and dementia care; key numbers, needs, care services offered, and impact; Theme report on the State of Public health and Care, 2018



The cognitive decline associated with dementia in combination with the advanced age often accompanying dementia also makes demands on the home and residential setting in question. On the one hand, a person with dementia benefits from a familiar living environment, but on the other hand the home setting must be adapted to the changing needs of the person.

## 2.2 Facts and figures

The number of persons with dementia is presently about 280,000. If new possibilities for treatment, cure or prevention are not found, then this number will increase to 420,000 in 2030 and 520,000 in 2040.

In 2015, the costs of formal care for persons with dementia amounted to €6.6 billion. In view of the expected increase in the number of persons with dementia, these costs will increase to €15.6 billion in 2040<sup>4</sup>. Dementia will then be associated with the highest care costs and will also be the most important cause of death.

There are now approximately 350,000 informal carers for persons with dementia; 31% of them devote more than 40 hours per week on providing this care; approximately 126,000 informal carers, mostly the children, combine this with a paid job<sup>5</sup>. In 2040, 1 out of every 8 persons in the workforce will have a parent with dementia; that ratio is now 1 out of every 33 working persons.

Of the 178,000 persons with dementia who are on the radar of the formal healthcare providers, approximately 14% have a migration background<sup>6</sup>. The number of persons with dementia who have a non-Western migration background is increasing faster than the number of persons with dementia with a Dutch background. Dementia is 3 to 4 times more common under older persons with a non-Western migration background.

In 2017, 9% of persons with dementia over the age of 65 lived below the poverty line; 46% of them had an income between €10,000 and €20,000 per year<sup>7</sup>. For comparison: in 2017, 2.3% of all persons over the age of 65 lived below the poverty line<sup>8</sup>.

Of the persons with a dementia diagnosis, 62% live at home, of whom 24% live alone<sup>9</sup>. In 2018, 70,675 persons with dementia resided in a nursing home<sup>10</sup>.

---

4 Parliamentary Papers 31 765, no. 494

5 Alzheimer Netherlands, 2019

6 Statistics Netherlands (CBS) Statline, 2017

7 Register of Dementia Care and Support, part 1 Background characteristics of persons with dementia, 2020

8 Statistics Netherlands (CBS) Statline, 2017

9 Register of Dementia Care and Support, part 1 Background characteristics of persons with dementia, 2020

10 Statistics Netherlands/MLZ

# Chapter 3 “A world without Dementia”

## 3.1 Problem analysis

Over the last eight years, the Memorabel research programme was carried out by ZonMw focusing specifically on dementia. Research into dementia was also carried out in other contexts, nationally as well as internationally. This research provided a great deal of insight into all aspects of dementia. However, in spite of the often great results already realised, we are not yet where we want to be and more research is needed.

We still do not know enough about its origin as well as mechanisms for preventing or curing dementia. There is still no medicine available that can prevent or slow down dementia. In the meantime, differing research methods have been applied over the past years in investigating various other relevant aspects of dementia. These efforts have provided a great deal of knowledge on the early identification of risks for the development of dementia. Major steps have also been taken in terms of diagnostics. If we now make serious efforts to take the following steps, a cure may come within reach in the near future.

There is not yet a great deal known about the possibilities for reducing the risk of dementia. Research has shown that lifestyle can influence the development of certain forms of dementia. For example, good cardiovascular health can reduce the risk of vascular dementia. There are indications that the other lifestyle factors such as exercise, nutrition, not smoking, and social interaction also have a positive effect on the prevention of dementia. However, the exact mechanism involved is not completely clear. We also do not have sufficient insight into the causes of the various forms of dementia. As long as these causes remain unknown, an early (pharmacological) treatment that prevents the actual development of dementia will not be possible.

Research into dementia is still in an early phase, but there are promising technological developments – ranging from artificial intelligence to *deep learning* – which can greatly accelerate the research being carried out into this condition in the coming years. For that purpose, it is essential to introduce a greater degree of focus and synergy in the research carried out. This requires collaboration between (financiers of) research programmes active in the field of dementia, at the national as well as international level.

## 3.2 What are we aiming for?

Our goals in this regard are:

- Ensuring that, by 2025, a tailor-made diagnosis is available for every person with dementia as well as a treatment that focuses on the individual and their specific needs.
- Ensuring that, by 2025, greater insight has been obtained into the causes that are responsible for the remaining 60% of dementia cases, assuming that approximately 40% of dementia cases could have been prevented via lifestyle factors. The goal is to work out all the details of the above by 2030.

The ultimate goal is a world without dementia. In other words, being able to cure a person with dementia and being able to prevent persons from developing dementia. In order to achieve this ultimate goal, we wish to make strides in the coming years in developing opportunities for reducing the risk of dementia and for treating and curing different forms of dementia. In addition to insight into risk factors, greater insight is also needed into the role of resilience factors. Lifestyle is an important topic in this regard as well as cognitive resilience. Another important topic in this area is the use of pharmacological techniques, in the form of a vaccine or medication, that can pre-empt the illness, halt it, or slow it down. In addition, we wish to contribute to mission IV of the LSH top sector with the help of research. In 2030, the quality of life of persons with dementia should be improved by 25%.

## 3.3 What are we going to do?

Following up on the Memorabel research programme, ZonMw will carry out a dementia research programme from 2021 until 2030. This programme will introduce a greater degree of focus and synergy into dementia research. One of the ways we will do so is by funding groundbreaking research by top-level centres that have specialised in this field over the last years. We will also fund multidisciplinary consortia. This means that we will focus less on open subsidy rounds in which applicants are free to choose their own research topic.

This research programme will collaborate closely with the programmes that have their origins in chapters 4 and 5, Society and Support and Care. This will bring greater focus and coherence into the research efforts. An essential element of this programme is also the collaboration and coordination with other relevant research initiatives such as: top sector LSH mission IV and FAST-platform (Future Affordable Sustainable Therapies), NWO/NWA, Alzheimer Netherlands, and Brain Foundation (Head aspects) at the national level, and at the international level for example the global Joint Programme Neurodegenerative Diseases Research, and in particular Alzheimer's (JPND). We encourage the top centres and consortia to strive to improve the quality and effectiveness of their research in collaboration with other research groups, nationally as well as internationally.

For the research programme itself, this means a focus on:

### a. Basic research

At present, a great many researchers are still searching, independently of each other, for more knowledge about the development of dementia. By introducing more focus and synergy – and therefore designing research in a more trans-diagnostic and multidisciplinary manner – we can acquire a more complete insight into the development and ongoing process of dementia. We will invest in top centres and aim to use new subsidy instruments to provide greater opportunities for long-term studies and for establishing collaborative frameworks.

For example, collaborative brain research at the molecular-genetic and cellular levels can take place within a more umbrella type (multidisciplinary) research framework. Collaboration and coordination promote the transfer of knowledge between the various domains and also ensure that the research results are used to achieve practical results in terms of care as soon as possible. This should result in steps being taken on the path to the treatment and cure of various forms of dementia.

#### b. Diagnostics

Genetic information and biomarkers can tell us a great deal about the risks and origins of dementia. It's important to ensure that this knowledge is translated much more quickly into practical clinical results (and if possible also made available to general practitioners). This involves not only refining and combining existing biomarkers but also developing new markers. Diagnostic improvements are also essential for future treatments (aimed at prevention). We will focus on promoting research into diagnostics by working to promote specialisation at several centres and their associated networks.

#### c. Risk reduction

Acquiring insight into the possibilities for reducing the risk of dementia is in part a question of basic research, as described under a., but also involves research into the effect of lifestyle factors. A specific "risk reduction" theme will be part of the dementia research programme to be started by ZonMw in order to acquire more knowledge about dementia risk reduction. In collaboration with NWO and the top sector Life Sciences & Health, we will evaluate whether and how we can also incorporate this theme in the research programming activities of these organisations. This will lead to a broad-based and coordinated research effort focused on reducing the risk of dementia.

#### d. Promising technological developments

In addition to encouraging collaboration and the centralisation of knowledge, it is also important to take full advantage of the new opportunities offered by technology. This is dealt with further in chapter 6.1 Innovation

#### e. Integrating research, care, and education

It's one thing to generate new knowledge, but this will really change things only if we also integrate that knowledge into the (future) field of practice. One way to achieve this is to ensure that the knowledge acquired about dementia becomes a clear part of the training given to professionals. Knowledge generated by research becomes applicable and is actually used as such in educating professionals if that knowledge is acquired as part of a collaborative effort between researchers, educational professionals, and persons working in the field. In order to encourage this, we invest not only in research projects but also encourage the leading centres to integrate research, care, and training. If we wish to properly equip future professionals and specialists for the care needs of tomorrow, it's crucial to ensure that researchers are literally given a place, as it were, together with care providers "at the patient's bedside". The end result is then an interactive and dynamic "back-and-forth" between research, education, and practical care.

# Chapter 4 “Persons with dementia matter”

## 4.1 Problem analysis

One of the most important characteristics of dementia is cognitive decline in the course of the years-long development of the condition. Research and practical experience make it clear that, depending on the degree and type of decline, persons with dementia can continue to function in society for quite a long time. Particularly if they receive positive support in that regard. However, prejudices that, in short, are based on the assumption that a person diagnosed with dementia can do (almost) nothing, stand in the way of continued participation in society. But the fear of stigmatisation and a lack of information about the opportunities to continue participating are also obstacles in this regard.

Persons with dementia and their families and loved ones as well as other members of society often know little or nothing about what dementia involves and what its consequences are for the person’s functioning. Information and education is needed to fill this gap. This includes information about the diagnosis of dementia, talks with persons with dementia and their families and/or close friends about “the future”, and educating society as a whole on how to relate with persons with dementia. These topics are already in focus. For example in projects that provide information at the time of diagnosis and that focus on how society relates to dementia, and in the programme Dementia-Friendly Together. These cannot be limited to short-term efforts. Everyone who is diagnosed with dementia in the future will need information. Every (young) adult should be able to learn how best to relate to persons with dementia in the private space as well as in the workspace. That is also why we are investing a great deal of effort early on in providing appropriate education at schools.

The residential setting is also an important factor in continuing to function within society. Just like every older person, a person with dementia needs a suitable home setting. That is one of the goals of Action point 3 of the Longer at Home programme.

## 4.2 What are we aiming for?

The initial targets are:

- In 2030, 80% of persons living at home have access to a meeting centre for persons with dementia in the vicinity of their home. Here they will be able to participate in meaningful activities.
- In 2025, the number of “dementia friends” will have doubled to 750,000 persons. The focus in this regard is on young people and on dementia friends actually being able to offer help to persons in their neighbourhood.

A person with dementia is a valuable member of society and has the right to be recognised as such, without suffering from prejudices or stigmas. Our aim is to ensure that persons with dementia are given the opportunity to continue playing a role in society in line with their wishes and capabilities. This improves the quality-of-life and reduces the burden placed on their informal carers<sup>11</sup>. This means that persons with dementia meet each other in meeting centres for persons with dementia, receive information about dementia, and have the opportunity to participate in meaningful activities such as volunteer work.

Our aim is to ensure that persons with dementia and their families and loved ones are given the opportunity to talk with a professional about the consequences of having dementia. And that they can receive support from volunteers.

We also want to ensure that every member of society can learn how to relate to people with dementia and can learn about these conditions. So that they also come to see persons with dementia as a part of society and can lend a helping hand when necessary. We also want to ensure that persons with dementia can find a suitable place to live in.

### 4.3 What are we going to do?

We want to create opportunities for persons with dementia to make the most of their remaining capabilities, in accordance with their personal wishes. So that they can continue to participate in society in a dignified manner. This can be accomplished by providing opportunities for doing work, including volunteer activities, for example in Dementalent projects. A focus on the design of the public space and on structural behavioural changes in society as a whole, with an emphasis on collaboration and facilities in the local neighbourhood, is important for continued participation in society.

The programme “Dementia-Friendly Together” was successfully implemented over the past few years. Together with Alzheimer Netherlands and the business community, we would like to evaluate how we can use the programme Dementia-Friendly Together as a basis for a more structured training course for professionals in various sectors and for private individuals. Youngsters will be involved in this effort by providing information at schools and starting projects focusing on intergenerational collaboration/support.

For some years now, dementia care professionals have been working with the social approach to dementia.

These ideas have found scientific support in the form of the ‘Social Trials Dementia’, carried out in four municipalities<sup>12</sup> under the leadership of prof. A-M The. This will be discussed in more detail in Chapter 5 Support and care.

---

11 RM Droës e.a., Utilization, effect, and benefit of the individualized Meeting Centers Support Program for people with dementia and caregivers; <https://doi.org/10.2147/CIA.S212852>

12 Amsterdam, Amstelveen, Den Bosch, Rotterdam

In the coming years, the Taskforce Home and Care (programme Longer at Home, Action point 3, Home and Care) will organise activities throughout the country: encouraging municipalities, corporations, and care organisations everywhere to enter into agreements with each other with regard to the challenges in the area of residential opportunities, care, well-being, and liveability. In May 2020, the Taskforce Home and Care surveyed municipalities and housing corporations to evaluate to what extent the challenges in the area of “home and care” are in focus and whether a vision has been formulated with regard to home and care (baseline measurement). The goal is to ensure that, no later than the summer of 2021, municipalities and care centres have acquired sufficient insight into the residential needs of older persons and other target groups as well as the demand for care and nursing home capacity. This information then needs to be translated by municipalities, housing corporations, care providers, care centres, healthcare insurers, and real estate investors into implementation timelines and performance-related agreements. In order to guide this process and increase the social urgency involved, we aim to enter into administrative agreements, at the beginning of 2021, with VNG, IPO, Aedes, Actiz, ZN and the Dutch government. The key part of the intended agreements will deal with how the local and regional needs and requirements, individually and collectively, will be translated into local performance-related agreements for residential space, well-being, and care, taking into account the existing agreements in the framework district nursing accord.<sup>13</sup>

Via the task force, we want to encourage the relevant partners to take into account the specific needs of persons with dementia and their families and/or loved ones with regard to residential space, care, well-being, and liveability.

---

<sup>13</sup> Annex to Parliamentary Papers 31 765, no. 494

# Chapter 5 “Tailor-made support when living with dementia”

## 5.1 Problem analysis

Internationally, the Netherlands is known for its high quality of dementia care<sup>14</sup>. We want to maintain that level as a minimum, but there is always room for improvement. Effective care concepts have been developed in recent years, for example in the dementia research programme Memorabel. However, broad practical implementation has been lagging. One of the goals of the 2020-2023 Health and Care Innovation Agenda of the top sector Life Sciences & Health (LSH) is: ‘In 2030, the quality of life of persons with dementia should be improved by 25%.’ In order to realise this goal, the knowledge, insight, and experience from (practical) research must find practical application more quickly, effectively, and easily. Even though various programmes have contributed to enlarging our knowledge of dementia care and support, this knowledge is still finding insufficient application in practice. What is lacking is a methodical and systematic approach within an ongoing framework of knowledge development and application.

The increase in the number of people with dementia and other chronic illnesses and the elderly will lead to more as well as more intensive homecare within the framework of district nursing. What we are seeing is that the fragmentation resulting from the multiplicity of care providers poses an obstacle to the effective management of local care, making it more difficult to provide care and support in an integrated and coherent manner. Efforts are being made to resolve these bottlenecks, but these efforts need to be accelerated.

In recent years, the regional dementia networks have made a substantial contribution to improving the coordination of dementia care in the Netherlands. Improving the care being provided is a continuous process, which also requires a focus on demographic developments. This also applies to the cultural diversity of the persons with care needs as well as the future challenges posed to us by the employment market.

The need for ongoing improvement in the care being provided is also made clear by the completion of the revised dementia care standard. This now has to be implemented on a national level. The structural funding and safeguarding of the networks in the local and regional care structure is also an area that needs to be focused on. New developments, such as the register for dementia care and support, provide the networks with opportunities to customise the care on offer to the wishes and needs of persons with dementia and their family/loved ones. Working with data from the register requires the networks to adapt and learn.

---

<sup>14</sup> Beerens, H.C. (2016): ‘Adding life to years: quality of life of people with dementia receiving long-term care’



The experiments with the social approach to dementia form a specific part of the Longer at Home programme. This approach, developed by prof. Anne-Mei The, is based on the assumption that the focus should not be (primarily) on the condition itself but rather on the living environment of the person with dementia and his family/loved ones. In 2018, experiments over four years were started in four municipalities (Amsterdam, Amstelveen, Den Bosch and Rotterdam). An evaluation of these experiments should make it clear whether this approach leads to an improvement in the quality of life of persons with dementia and their family/loved ones as well as a longer period of independent living before admission to a nursing home becomes necessary.

## 5.2 What are we aiming for?

Important goals are:

- As soon as possible, but in any case no later than 2025, all professionals in every regional dementia network are working in accordance with the dementia care standard, across domains, person-centred, efficiently, proactively, and in a timely fashion.
- From 2025 onwards, every regional dementia network has a strong foundation via defined collaboration agreements and structural funding.

Our aim is to ensure that all regional dementia networks work in accordance with the dementia care standard, across domains, person-centred (including cultural diversity), efficiently, proactively, and in a timely fashion. Within that context, attention is also paid to the coordination with the total package of care and support offered in the region. In addition, we want all the networks to work in a self-learning fashion using data from the register on dementia care and support. Finally, we want every network to have a secure basis in the region and for the collaborative agreements with the parties concerned to be set down on paper, including a structural funding for the network coordination.

It is important, at the local level, to work towards a situation in which more integrated care is offered by recognisable teams. Within that context, it's also important to pay attention to the collaboration with other care partners, such as General Practitioners, VVT institutions, and the social domain. The relevant aspects have been formulated in the Guideline for recognisable and approachable district nursing.<sup>15</sup>

In order to be able to offer good care at the regional and district level, we want to invest, at the national level, in collecting, expanding, maintaining, and sharing knowledge with regard to all aspects of support and care. This applies to the provision of high-quality support and care, with a focus on innovation, as well as the organisation of support and care.

---

<sup>15</sup> <https://www.rijksoverheid.nl/documenten/publicaties/2020/02/28/leidraad-herkenbare-en-aanspreekbare-wijkverpleging>

## 5.3 What are we going to do?

We will work together with the regional dementia care networks and their umbrella organisation, Dementia Network Netherlands, to further improve the care offered and ensure that the networks are future-proof. We will do so in collaboration with the knowledge institutes for care and support operating on a national level. We will evaluate how a national implementation programme can be of assistance in this regard.

We will continue working on the development of the register for dementia care and support. This register collects data from existing registrations about care and support for persons with dementia and any partner they may be living with. With this information, dementia networks, care providers, healthcare insurers, care offices, and municipalities can anticipate the future care needs of persons with dementia. The register also provides insight into the results of learning processes within dementia networks. This assists my efforts aimed at the further development and professionalisation of regional dementia care networks, in coordination with the total package of care and support services in the region.

Should the evaluation make it clear that the social approach towards dementia leads to an improvement in the quality-of-life of people with dementia and their family/loved ones, we aim to collaborate with the relevant parties, including dementia care networks, healthcare insurers, care offices, and municipalities, to consider how we can implement this more broadly via the dementia care networks. This can be part of the care improvement programme for the dementia networks.

Parties in the district nursing sector work to realise increased collaboration. Starting in 2021, every district in the Netherlands will work to implement recognisable and approachable district nursing services. Persons with dementia will also benefit from these efforts.

On 1 January 2020, the Care and Compulsion Act went into effect. Together with the Compulsory Mental Healthcare Act, this piece of legislation replaces the Psychiatric Hospitals (Compulsory Admission) Act and strengthens the legal protection of persons with dementia. The key feature of this new legislation is: 'no, unless'. This means that care must be provided on a voluntary basis insofar as possible. Involuntary care may be implemented only if there are really no other options available. 2020 has been declared a transitional year in which we wish to support care providers in carrying out this legislation. We do so, for example, by providing subsidies for sector-specific parties, organising (digital) information meetings, and working to create a support structure for intramural and extramural involuntary care.

# Chapter 6 Shared themes

## 6.1 Innovation

Ongoing innovation is needed to be able to carry out groundbreaking scientific research as well as to improve the quality-of-life of persons with dementia. In this context, we are thinking of the utilisation and further development of technological tools for research as well as support and care. Non-technological innovation also remains important. For example for the increasing number of persons with dementia, who increasingly wish to remain active in society and are also able to do so. This requires an ongoing and creative process of developing activities. These activities must be meaningful and help persons with dementia retain their dignity as members of society.

## 6.2 Young persons with dementia

Approximately 20,000 persons with dementia are less than 65 years old, and often much younger. They still have jobs, often still have a family with children living at home, and a partner who also works. But they are also dependent on an income that can disappear, in whole or in part, due to an increasing incapacity for work as a result of the dementia. Due to their relatively young age and, as a result, their different position in society, in combination with their often better state of health and stronger physical condition, their requirements in terms of support and care are different than those of persons who develop dementia at a (much) later age. These younger persons also often have other forms of dementia. They deserve their own separate place in all aspects of this dementia strategy. Although it is structured within the regular programmes, its separate position therein becomes evident in the collaboration with relevant parties such as the Knowledge Centre for Younger Persons with Dementia.

## 6.3 International

The dementia numbers for the Netherlands are worrying. On a global scale, the consequences of dementia can be catastrophic, particularly in low-income and middle-income countries. The figures for people with dementia on a global level are 46.8 million in 2015, 74.7 million in 2030, and 131.5 million in 2050. In 2015, 58% of persons with dementia lived in low-income and middle-income countries. In 2050, that figure is expected to increase to 68%. In 2030, the total cost of dementia care is expected to increase to €2.7 trillion per year<sup>16</sup>. As a rich country, we cannot simply stand by and watch this happen.

Internationally, the Netherlands has a good reputation in the area of dementia care as well as dementia research. We wish to share our knowledge and experience in this regard with other countries so that not only persons in the present who have dementia and their family/loved ones can benefit but also people living in a future world without dementia.

---

<sup>16</sup> Alzheimer Disease International: infographic The Global Impact of Dementia

That is why we wish to focus our efforts on intensifying dementia research and strengthening collaboration in that regard. This relates not only to our participation in the global Joint Programme Neurodegenerative Diseases, especially Alzheimer's (JPND), but also to our efforts at encouraging other countries to participate in JPND.

In addition, we continue to be an advisory member of the World Dementia Council and continue to support the activities of the council. These activities include bringing relevant parties all over the world together in order to tackle the challenges of dementia, encouraging researchers to share their research data, identifying crucial elements of dementia care, and collecting information on effective methods for creating dementia-friendly societies.

Within the EU, we encourage knowledge sharing via the European Group of Governmental Experts on Dementia. In addition, we wish to consider how we can collaborate with the European partners on all aspects of dementia, for example by being involved in projects within the framework of Horizon Europe and EU4Health.

We also remain involved in the dementia activities of international organisations such as the WHO and OECD and the international advocacy organisations Alzheimer Europe and Alzheimer Disease International.

## 6.4 Communication

Communication is an essential element of the strategy and is a common theme in all programmes of the strategy. Not only about the strategy but in particular about the results achieved and sharing the knowledge and experiences acquired, which contribute to realising our goals.

We would like to highlight two topics in particular here.

### 6.4.1 Information about the support and care available for clients and care professionals

Within the framework of strengthening the regional dementia care networks (chapter 5), we wish to help ensure that every network has general information available about dementia with a regional 'who, what, where' for the professional as well as for persons with dementia and their families/loved ones. This information should be easy to access for both target groups. The need for the information to be easily understood by persons with dementia and their families/loved ones is also taken specifically into account.

### 6.4.2 Risk reduction

Via targeted activities, we will provide the general public with information about the possibilities of reducing the risk of dementia, regarding which there is broad scientific consensus. We will start by targeting the high-risk groups, such as persons with diabetes, obesity, and cardiovascular diseases. In doing so, we will collaborate with various third parties including healthcare funds, care professionals, healthcare insurers, and municipalities.

# Chapter 7 Governance

Dementia, and therefore also the strategy discussed here and the underlying programmes, includes a wide range of aspects. A clear and unambiguous management structure is important to ensure that the programmes underlying the strategy are successfully implemented. This 'Governance' serves to ensure a shared and consistent approach towards directing, managing, and supervising the National Dementia Strategy and is focused on an efficient and effective realisation of the goals.

## 7.1 Management group

A management group will be established at the strategic level, under the leadership of the Minister of Health, Welfare and Sport. The members of the management group will be authoritative figures from various sectors of society, each of whom will be able to inspire and motivate their respective sector. This management group provides orders for the necessary activities and has ultimate responsibility for implementing the strategy.

## 7.2 Steering group

An overarching steering group will be formed to ensure consistency and cohesiveness within and between the various (shared) themes. The steering group will consist of representatives of the relevant parties from the field and the government. The steering group is the (delegated) party providing the orders for the various programmes, and is responsible for the implementation of the strategy set out by the management group and for realising the goals as well as for monitoring the progress made in implementing the strategy.

## 7.3 Sounding board group

A sounding board group will be formed in order to ensure that the client and the persons in the field can make themselves heard. Members of this group can include persons with dementia, informal carers, professionals working in dementia care and support, and professionals and volunteers working in sectors where they regularly interact with persons with dementia. The members of the sounding board group participate in a personal capacity and without any mandate or instructions. Individual members of the sounding board group can also function as an ambassador for one of the shared themes in the Strategy. The sounding board group is responsible for translating signals from the field and for providing advice to the Management group and Steering group.

## 7.4 Programmes

The strategy will be implemented in one or more programmes per theme. The following programmes are planned:

- “A world without Dementia”:
  - a 10-year research programme at ZonMw, a follow-up to Memorabel, including JPND
- “Persons with dementia matter”:
  - a programme to encourage participation by persons with dementia (meaningful activities, meeting centres)
  - a follow-up to Dementia Friendly Together
- “Tailor-made support when living with dementia”:
  - one or more programmes as a follow-up to Dementia Care for Each Other

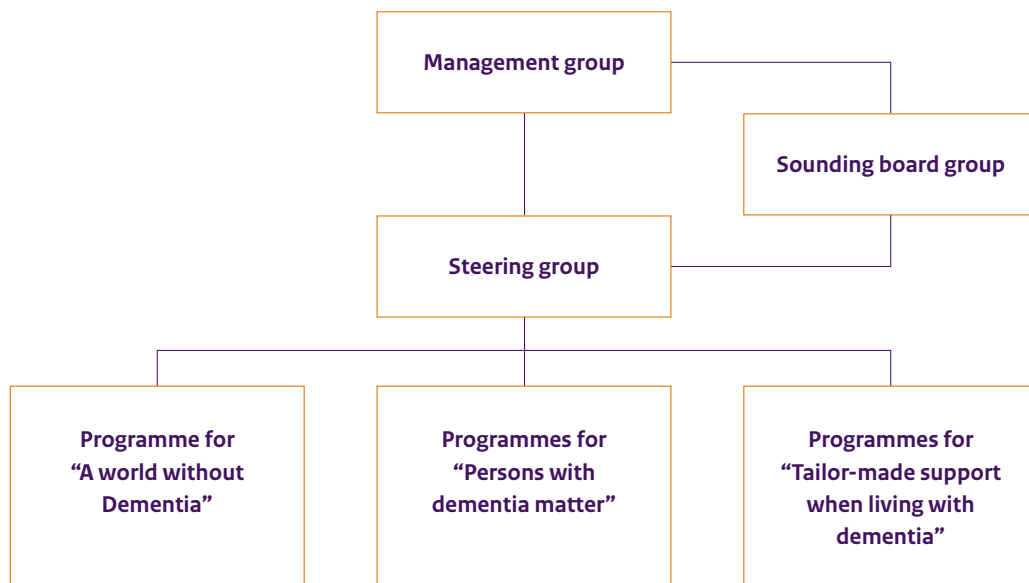
The governance of these programmes will be determined by the management group per programme based on the specific requirements of the programme.

## 7.5 Coordinator

An effective programme secretariat is essential to ensure that the strategy is always kept in focus. The secretariats of the management group, steering group, and sounding board group are taken care of by a coordinator from the Ministry of Health, Welfare and Sport. In addition to these secretariats, the coordinator is responsible for identifying and reporting bottlenecks in the implementation of the strategy and underlying programmes.

## 7.6 Schematic overview

The organisation of the strategy can be summarised schematically as follows:



## Chapter 8 Monitoring

Measurable goals will also be defined when working out this strategy in the form of programmes. The results of the strategy will be measured with the help of these goals. Existing data sources will be used for monitoring the results, including those collected in the register for dementia care and support. We will develop this register further for this purpose as well.

**This is a publication of**  
Ministry of Health, Welfare  
and Sport

**Postal address**  
P.O. Box 20350 | 2500 EJ The Hague  
Telephone +31 70 340 79 11  
[www.rijksoverheid.nl/VWS](http://www.rijksoverheid.nl/VWS)

October 2020