

Ministerie van Volksgezondheid,
Welzijn en Sport

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Appendices
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*Please direct any
correspondence to the return
address, specifying the date
and the reference of this
letter.*

Date 7 July 2015
RE: Shared approaches: integrating dementia in society

Dear chairman,

Over 13,000 people hear from their doctor every year that they have a form of dementia. This diagnosis has a severe impact and marks the start of a process that is often accompanied by a great deal of uncertainty and grief. How do you grapple with a memory that increasingly lets you down? A personality that changes? A world that becomes more and more confusing and threatening? What if you no longer recognise your loved ones? And, perhaps the most difficult question: how can I live a life of dignity despite it all? Dealing with dementia also demands a great deal from people's friends, family and community, from a perspective of caring for their loved one and worrying about them. However, dementia should never be a problem placed solely on people and their communities.

The question of how we deal with people who have dementia is at least as much an issue for society to address. Dementia begins at home, in the yard or at the market. Before the diagnosis is confirmed, there has often been an extended period of doubt and questions. The period of time between when the diagnosis is made and when a person's condition has worsened to the point that they need to be admitted to a nursing home could extend for years (see Appendix 1). The vast majority of people try to deal with this disease in their own homes for as long as possible. In such situations, people with dementia (or the early stages of dementia) still go to the supermarket or the local community centre on their own. Sometimes they function in society without any problems, but sometimes they don't know what to do anymore. It is extremely vital that not only their immediate friends and neighbours, but any other person they happen to have beside them at that time, are aware of the fact that they could be dealing with someone who might have a form of dementia and that they know how to handle this. About 180,000 people, 70% of everyone who has dementia, are still living at home. In an ageing society, in which dementia is unfortunately likely to occur with increasing frequency, I consider it absolutely vital to increase public awareness of this topic, so it can be addressed effectively in society. I also consider it vital to ensure the best possible quality of dementia care, both at home and in an

institution. I would therefore like to take the initiative, in conjunction with all those involved, from carers to family members, neighbours and volunteers, to move towards a dementia-friendly society.

Ambition

The standard of care for people with dementia in the Netherlands is relatively high. This is evident from, for instance, the fact that care concepts developed in the Netherlands are frequently applied abroad. But - as I will also specify below - improvements are both possible and necessary in various areas. We owe that to the people who have dementia and to the carers of tomorrow. As the age demographics of the population shift, families grow smaller and smaller, and the number of single-person households increase, these people will have far fewer people to rely on. On their behalf as well, we cannot be satisfied with what we have now.

On average, people live with dementia for eight years, most of that time spent at home. The symptoms of the disease are dramatic. Even so, people with dementia and their carers can experience quality of life, especially if they feel accepted, acknowledged and supported. I want to contribute to that, by ensuring that they can count on care and support which is aligned to their personal possibilities and preferences.

On 4 April 2013, the Minister and I sent the Delta Plan for Dementia to you. This plan consists of three core areas: research focused on preventing and curing dementia, better dementia care, and a dementia-friendly society. In the end, the point is to improve quality of life for people with dementia and to provide good care for controllable costs. To that end, the Delta Plan for Dementia brings together various groups in society, such as government institutions, the private sector, the scientific research community, patient organisations, care providers and insurers (see Appendix 2). This approach is also in alignment with the National Prevention Programme (NPP). The NPP specifies the Delta Plan for Dementia as a programme-based approach that strengthens the ties between initiatives and societal partners.

Besides the policies in the framework of the Delta Plan, lots of other policies are also instituted that benefit quality of life for people with dementia and their carers. Examples include the National Programme for Geriatric Care, the National Programme for Palliative Care, and the 'Dignity and Pride, loving care for our elderly' plan.

In the letter at hand, I specify the measures that the Cabinet is implementing based on its responsibility to people with dementia and their carers, supplementing existing policy. This letter fulfils my promises to your House of Parliament on various occasions¹, which I have been discussing with you and with

¹ The promises were made in: the general consultation regarding the state of affairs regarding decentralisation of long-term care (11 December 2014), the plenary debate regarding the Long-Term Care Act (Wlz), 10 September 2014 (TZ-VWS-2014-274); the general consultation regarding primary care, 3 July 2014 (TZ_VWS_2014_211); the debate on the Social Support Act (WMO), 23 April 2014 (TZ_VWS_2014_66); the continued general consultation on reforms in long-term care (VAO HLZ), 18 December 2013 (TZ_VWS_2014_74 en TZ_VWS_2014_66); the general consultation regarding the Health

the sector since spring 2013. In preparation for the letter at hand, extensive talks have been conducted with sector parties and experts, Alzheimer's Netherlands and the Delta Plan for Dementia cooperative.

Investing in a dementia-friendly society and personal care and support

In order to realise my ambition – to retain quality of life for as long as possible – I am opting for a wide-ranging approach that targets various aspects of life. I have identified four core areas in which I will be investing a total of €16 million (see page 12) for the supplementary measures through 2020.

The core areas in my policy reinforce the domains in which a person with dementia and his carer will, on average, encounter in sequence: society, the support network, and the care and support systems. My policy identifies two core areas related to care and support: structural improvement and room in laws and regulations. I first introduce these core areas and then describe the measures to be taken in each core area.

1. *Dementia-friendly society*: Dementia plays an ever-increasing role in the daily life of many Dutchmen. Approximately 260,000 people with dementia live in our country. As a consequence of ageing, the number of people with dementia will rise to an estimated 400,000 in 2050². 60% of the people with dementia are female and 70% still live at home. Over 40% of people with dementia are single. An estimated 300,000 carers are ready to assist people with dementia, in addition to all the professionals and volunteers, as shown by research by The Netherlands Institute for Social Research (SCP). On average, people with dementia live over six years at home and over 18 months in an institution. The option to remain in a familiar environment as long as possible is dependent on care and support, the capabilities of the carer, and above all on being enabled to direct their own lives, and being able to count on support to join society on an equal footing.

Society on average sadly often still lacks the necessary knowledge, acceptance and decisive capabilities to make this happen. The torment and desolation of people with dementia and their carer, who often carries the responsibility for their loved one 24/7, will only increase because of this. I am pleased to see that there are several places in the country where municipalities, companies and networks of the dementia care chain are hard at work on improvements. For instance, they train employees how to deal with people with dementia, thus contributing to a dementia-friendly society. The most simple initiatives can have a big impact.

For instance the monthly group tour "Onvergetelijk Centraal" (Unforgettably Central), provided by volunteers in the Central Museum in Utrecht that is organised specifically for people with dementia and their carers. This makes it possible for them to meet in a relaxed and positive atmosphere, and appreciate and discuss art.

Insurance Act, 4 December 2013 (TZ_VWS_2013_304); the budget discussions for Health, Welfare and Sport, 30 October 2013 (TZ_VWS_2013_276) and the general consultation regarding dementia, 22 May 2013 (TZ_VWS_2013_154 and _155).

²These numbers are higher when we – as stated in the opening line – strictly follow the GP registration. The GP is unable to diagnose some of the people with dementia at all, or only late in the onset, and in addition can also sometimes be reluctant to bestow the diagnosis of dementia.

2. *A network surrounding the client and the carer.* Medical care and contribution to quality of life for the person experiencing dementia and their carer go hand in hand. By quality of life, I mean how people perceive their own ability to function in physical, psychological and social dimensions. As their limitations intensify, the emphasis shifts to dignity and contributing to moments of joy. The Netherlands has a solid tradition of medical care. But there is still much room for improvement where it concerns appropriate ways to address and discuss questions involving e.g. acceptance, the ability to make decisions, and human dignity, as well as improving quality of life. Support from close friends and family, for instance, is not an 'added bonus', but an intrinsic part of life and of the support systems for a person suffering from dementia. The carer plays a key role in maintaining the home situation or in transferring the feeling of home to an intramural care situation. For that reason, care and support for people who have dementia themselves is also integrally and intrinsically interlinked with care and support for their carers. Unfortunately, their own community far too often leaves them isolated with their sorrow and their heavy burden. I consider it a matter of grave concern that partners of people who have dementia are currently four times more likely to develop depression compared to people who have a partner who does not have dementia³. In order to put quality of life first for both the client and the carer, an integral approach to the person in relation to their immediate surroundings is vital. This requires cooperation between informal and formal carers surrounding the client and a different perspective on organisation: the network surrounding the person who has dementia and the carer is the primary focus. 4
3. *Structural improvement.* The risk of dementia increases as people grow older. An estimated 1 in 10 people over the age of 65 has dementia; over the age of 80, that number increases to more than 2 and 4 in 10 people over the age of 90 have dementia.⁵There is a parallel increase in the risk of multi-morbidity. A person with dementia may exhibit behaviour that is difficult to understand and deal with, and may also have other care issues, such as pain, pressure ulcers, incontinence, malnutrition and falling incidents. They may also suffer from other age-related conditions, such as heart failure, diabetes and/or arthrosis. The demands placed on the care and support systems continue to increase. Many new interventions are available which are also applied here and there on a project basis. Widespread implementation is not yet available, however. It is high time to make the transition from the phase of funding projects and experiments to the phase of structurally applying targeted interventions.
4. *Room for dementia care.* The dementia care chain moves through and over the partitions between the Social Support Act 2015, the Health Insurance Act and the Long-Term Care Act. The reforms in long-term care assigned responsibility for coherent care in the home to health insurers and

³ Depressie en angst bij partners van dementiepatiënten, Karlijn Jolin et al., *Huisarts & Wetenschap* July 2010.

⁴ 'Naar nieuwe zorg en zorgberoepen: de contouren', by the Committee on Innovation Care Professions & Education Programmes of the National Health Care Institute, April 2015, very justifiably states that a new way of working and other competences are sorely needed for the provision of care and the contribution to the functionality of citizens.

⁵ *Zorgstandaard dementie* [Dementia Care Standard], 2013.

municipalities. Municipalities, health insurers and implementing parties of the Long-Term Care Act work with care providers to resolve inter-related issues, but these parties often still feel compartmentalised. I will be working with these parties to identify and resolve specific, tangible obstacles to cross-domain cooperation created by laws and regulations.

Improvement in a period of transformation

Reforms in long-term care also marked the next step in care and support for people with dementia and their carers. Care is provided in better alignment with the client's experiences and context by placing primary emphasis, especially in the initial phase, on dealing with the disease, handling changes in daily life, and ensuring the low threshold appropriate to accessing support at the local level. Nursing, care, and appropriate medication are closely related to GP care. This has been embedded structurally in the Health Insurance Act.

I am keenly aware that the continued improvement I advocate will have to be achieved within the context of a transformation that is still in full swing.

I have asked Nivel to research procurement of dementia networks and case management in the Health Insurance Act. In my letter of 14 April 2015, I informed your House of Parliament of the results. The Nivel study revealed a number of bottlenecks; chain directors indicated concerns regarding the continued existence of the chain due to the lack of clarity and too-narrow framework regarding the procurement process and future funding. It also revealed that nearly half of the chains cannot fully meet the Dementia Care Standard with the resources at their disposal (see also below).

As I stated during various debates in the Lower House, I consider it important for the dementia chains and dementia case management to be ensured in 2015 and beyond.

To eliminate the lack of clarity regarding the use of the policy measure regarding dementia chain care and procurement of case management, the Dutch Healthcare Authority (NZa) released an extra circular to inform insurers and care providers about its regulations and policies regarding dementia care in the Health Insurance Act. The Dutch Healthcare Authority will also focus extra attention on procurement of dementia care in its public information regarding procurement for 2016.

Based on the Nivel report I referred to previously, I engaged in talks with various parties, including health insurers, regarding compliance with the care standard. In doing so, I took action on the motion submitted by Dik-Faber/Bruins Slot (34 104, no. 115) requesting that talks be initiated with health insurance companies and pointing out the importance of the Dementia Care Standard. These talks revealed the following. Talking to the parties showed that the changes in long-term care as of 1 January have led to bottlenecks in a number of chains. Municipalities received a more significant role, because they received responsibility for guidance and coordination of day activities for people with dementia, among others; case management has been assigned to community nursing tasks under the Health Insurance Act, while implementing parties for the Long-Term Care Act saw a decline in some of their tasks related to case management and the dementia care chain. The redistribution of tasks and responsibilities also marked a change in funding.

These changes led to uncertainty for the parties involved, but I now see the gauntlet being picked up within dementia chains. Parties in these chains endorse the importance of the care standard and view the standard as a point of departure

for effective dementia care. That is a good place to start. In the approach I develop below, I do take into account the fact that the sector is still in a transformation phase.

The performance of the dementia care chain, which was placed under the Health Insurance Act in 2015, facilitates funding for the network structures for the dementia care chain. It involves the continuation of an earlier policy intended as a transitional measure to give the dementia chains a chance in 2015 to prepare for 2016 and to reach structural agreements about safeguarding dementia networks. *To give parties more time to design the structure of how the dementia chain is funded, I have decided to continue the Dementia Care Chain policy in 2016. This also creates more time to shape the involvement of municipalities and Long-Term Care Act implementing parties.* *This autumn, I will be talking to municipalities, health insurers, healthcare offices, care providers and professionals to reach agreements regarding the conditions necessary to provide integrated care and support for people with dementia and their carers.*

Wide-ranging approach

The wide-ranging approach that I develop below is closely aligned with the (unshared) social environment of people with dementia and their carers. At the national level, this also requires a coalition in which all those involved form a unified front. The Delta Plan for Dementia was established to facilitate a joint approach. *This summer, I will be continuing talks with the Delta Plan for Dementia cooperative and the organisations which should ideally be more closely involved in the Delta Plan for Dementia in view of my measures. I refer here to representatives from health insurers, municipalities, care organisations and care professionals. Aspects that I want to address include: the connection between medical and social perspectives, an improvement programme to provide care and support for people with dementia and their carers, and safeguarding the public interest.* Explanatory notes on these topics follow below.

Core area 1: Dementia-friendly society

In an open society, acceptance of and respect for people with dementia, their friends and family, their volunteers and for the professionals who support them are important goals. People with dementia should be able to participate in society for as long as possible. Involving people with dementia in endeavours like volunteer work or day activities can make a great deal of difference. A crucial success factor is aligning the options offered with local, social, cultural and individual variation. Sadly, good examples in this area have not yet been widely embraced. The prevailing impression of people with dementia is often still based on the final stage of dementia. The capacity that people with dementia still have to make their own decisions, make choices or express preferences should be more clearly recognised and acknowledged. The exchange of information should be tailored accordingly. It should also be aimed at preparing for the very painful revelation of the diagnosis as well as possible. Being well-informed about dementia and knowing how to deal with people with dementia are preconditions for a dementia-friendly society. In this core area, I make a distinction between two themes:

(1) promoting awareness of and insight into the perspective of people with dementia and their carers, and (2) equipping citizens to more effectively assist people with dementia and their carers.

'From the perspective of dementia' working group

At the end of last year, I established an independent working group: 'From the perspective of dementia'. These fifteen people know all too well, some of them from first-hand experience, what issues arise in situations involving dementia. The first task for the working group is to take stock of what people with dementia encounter in the course of their daily lives, from the initial symptoms until death, viewed from the perspective of the person with dementia and their friends and family. The working group, headed by Ms Ireen van Ditschuyzen, discusses such topics as practical assistance, a feeling of safety, public impressions of dementia, young people with dementia, immigrants, and digital assistance. *The working group is expected to present its recommendations this autumn. At that point, I will sit down with the working group to determine how these recommendations can be expressed in concrete actions. I expect these actions to encompass multiple areas of life, including housing, work, mobility, care and support. The Ministry of Health, Welfare and Sport will coordinate the departments involved.*

Database of dementia stories

These initiatives should obviously seek to connect to the perspectives of people with dementia. In this context, I support the database of stories (the 'Verhalenbank') collected by Professor Anne-Mei The. Researchers at the University of Amsterdam analyse the stories of people with dementia and their friends and family to identify patterns and use this information to come up with ways to improve quality of life for people with dementia and the people around them. The initiators are working to develop a 'social approach' to dementia that does justice to the things that people with dementia encounter in the course of their daily lives. The approach is being put into practice in the dementia pilot project in Friesland, in conjunction with the Kwadrant group. The initiators are pursuing a structural financial foundation for the database of stories. I am supporting this initiative.

Dementia Friends

In the framework of the Delta Plan for Dementia, a programme entitled Dementia Friends has been launched, based on Japanese and English examples. The essence of the initiative is for people to learn more about dementia and learn to deploy that newly acquired knowledge to help people with dementia. Various tools are used for that purpose, including an online forum, a service desk, and modules for informing people, equipping them with the right skills, and training them to use those skills. The programme is tailored to the target group (for instance hairdressers, bank tellers, policemen or neighbours).

The aim is for 1 million people to be more aware of dementia within five years and for some of them to become actively engaged friends. The friends become the pivotal point in a movement. Working from the bottom and from within, they can make society more dementia-friendly.

I am supporting this five-year programme. After a year of development, it will be rolled out throughout the Netherlands in 3-4 sections.

Core area 2: A network surrounding the client and the carer

The connection between the lives of the client and the carer requires a major organisational capacity and solid agreements about optimal care and support, inter-professional cooperation, chain management, logistics, and a results-based approach to working and learning. For a person who has memory problems, it is important to have carers and other friends and family continue to play a permanent role and to establish a network with a fixed team of professionals who provide care and support – which requires a specific form of professional competence.

The focus on carers is a fundamental aspect of dementia care. Based on the Social Support Act 2015, the municipality takes an integrated look at the client's situation as well as the carer's situation when assessing a reported need for support - in consultation with the client and the carer. This promotes the provision of tailored support for both clients and carers. By providing appropriate activities, day activities and respite services for people with dementia, the carer's tasks can be alleviated in such a way that they remain bearable, allowing the carer to continue as well as possible.

In my progress update on informal care of 11 November 2014, I notified your House of Parliament regarding the state of affairs on my policies targeting informal care. On 24 June 2015, your House of Parliament received a progress update again regarding the latest developments concerning the Future Agenda for Informal Care and Support, drawn up last year with formal and informal authorities. Improving the interaction between formal and informal care and support provided to carers is top priority here. The participants recently saw which forms of additional support can be offered to older carers. It is important – for this category of carers as well – for municipalities and professionals to invest in network support so more helpers become active, 'spreading around' the care otherwise provided by the older partner.

To improve the interaction between formal and informal care in the workplace and at institutions and organisations, I launched the InVoorMantelzorg programme at the end of last year. In the context of this programme, projects by 18 institutions focused (partly or fully) on people with dementia.

The letter from the Minister of Health, Welfare and Sport on 6 May 2015 presented the strategic outlook on preventing depression conducted by the Trimbos Institute to your House of Parliament. In the strategic outlook, the broad group of carers is one of the six high-risk groups selected for consideration. Based on talks conducted with many professionals in the field, the report offers indications of how effective interventions can be achieved. Progress reports will be released via the National Prevention Programme.

A useful way to spend the day

A useful way to spend the day is essential for people with dementia, so they can continue participating in society for as long as possible. Not only does it promote social participation among people with dementia, it also provides a key support function for people caring for someone with dementia. In the motion submitted by MP Dik-Faber (Parliamentary Papers 2013-2014, 30597, no. 406), your House of Parliament asks the government to advise municipalities on structuring day activities, including ways for people with dementia to spend the day. In the context of the introduction of the Social Support Act 2015, municipalities were

notified of the specific needs and items for attention related to people with dementia and their carer(s). The website at www.invoeringwmo.nl offers practical examples and guides (in Dutch). Relevant information is also available on the site at www.pakdehandschoenop.nl and in the step-by-step plan for municipalities to improve dementia care, introduced by Alzheimer's Netherlands. This is my action in response to the aforementioned motion.

In my letter of 29 April 2015 (Parliamentary Papers 2014-2015 34104 no. 55), I notified your House of Parliament regarding the realisation of innovations in care and support close to home. One of the themes where continued development and innovation are vital is 'suitable care and support close to home'. Suitable care and support close to home means that there is a good-quality array of options that meet people's demand for support. In continuing to shape this theme in interaction with the professional field, I will have a specific focus on people with dementia. To provide input for the talks with the professional field, I will commission a study in the coming period to identify good examples and the areas for attention that accompany them. I will disseminate the examples for innovative forms of day activities among municipalities.

Housing and dementia: monitor on residential approaches to dementia

Most people suffering from dementia eventually reach a point where they can no longer live at home. The transition to an institution requires careful guidance and personal transfer of tasks. I advocate ensuring that the array of intramural services should be provided in the neighbourhood familiar to the person with dementia as much as possible, in view of maintaining connections to the client's social network.

Appended to this letter, please find enclosed the Monitor on Residential Approaches to Dementia, trends and success factors in nursing home care for people with dementia, 2008-2014, Trimbos Institute, 2015. The research report is based on assessments conducted in 2008-2009, 2010-2011, and 2013-2014. 54 institutions took part in the latest round of assessments. Various methods are used to collect data on organisation of care, staff complement, use of psychopharmaceuticals and measures that restrict freedom of movement, quality of life and intensity of care for residents, working conditions and employee well-being, multi-disciplinary cooperation, and the engagement and efforts of family and volunteers in care. The monitor shows e.g. that residents are more involved in activities and experience a higher quality of life due primarily to a vision based on personal experiences, tailored to individually appropriate care and strengthening the social network in ways that mitigate the measures that restrict the freedom of movement. One of the outcomes is a continued high level of psychopharmaceutical treatment. I outlined how this trend should be redirected in the Psychopharmaceuticals Action Plan I sent to you on 26 June 2015. In many cases, the institutions that participated in the monitor will be addressing their specific areas for improvement. I have decided to co-fund the next and fourth assessment round for the monitor, as an important contribution to the continued development of dementia care.

Core area 3: structural improvement

The Dementia Care Standard is – as its name states – the definitive standard in the Netherlands for the entire care process for people who have dementia: from

early identification and prevention to diagnosis, case management, treatment, guidance, support and supply of care and services. The standard provides general, functional descriptions of the support and care that should be provided to both clients and carers, as well as when and how.

Case management, advance care planning and network care are intrinsic parts of the standard. The standard does not dictate who must provide care or exactly how it should happen, leaving room to adapt the specific activities and division of tasks to the local situation in a neighbourhood, district or region. Obviously, there is also room to adapt the standard to the local, individual situation. I applaud this pioneering work, initiated by Alzheimer's Netherlands, with support from Vilans knowledge institute and widespread efforts by regional parties operating in the professional field.

Network care

With great enthusiasm and ingenuity, professionals from various organisations, each of which supplies some aspect of dementia care in a region, have been working since 2008 to achieve coherent care and support for people with dementia in the framework of the Dementia Care Chain Programme. There are now 86 of these networks in total in the Netherlands, consisting of representatives from home care organisations (district nurses), municipalities, GPs, organisations that provide care in nursing homes, mental healthcare institutions, outpatient clinics for memory disorders, and/or geriatrics outpatient clinics in hospitals.

The 'Strong Together' programme, which will run until the end of 2016, contributes to further professionalisation of the networks. Quality assessments of these aspects show that the dementia networks achieve better scores in nearly all areas. The nationwide Dementia Network is now focusing on areas for improvement for dementia care networks. The added value of cooperation with networks in the National Programme of Care for the Elderly is also being explored, with the aim of pursuing active knowledge-sharing and cooperation.

Compliance with Dementia Care Standard

The Health Inspectorate report entitled 'Organisation of network care for people with dementia living at home is highly promising, aspects of care still involve risks', dating from July 2013, analysed the status of the networks. The key areas for improvement identified in this report were:

- the strength of the networks, e.g. through guidance and intensified expertise;
- early identification of clients who avoid care, e.g. among people with dementia who are not part of a social network;
- clarity on exactly how the case management function is defined in the network;
- further development of care plans, e.g. with an updated medication passport and access granted to every care provider.

A number of dementia care chain networks are already working on these areas. In my view, these areas for improvement should be addressed proactively and intensively throughout the country.

I consider encouraging compliance with the Dementia Care Standard to be an important tool for taking a structured approach to this, thus improving coherence and continuity of care and support for people with dementia.

In the talk with the Delta Plan for Dementia cooperative and other stakeholders referred to above, I want to partner with the National Health Care Institute to make agreements about an improvement process along the lines of the Dementia

Care Standard. The aim of this process is to raise care and support in the Netherlands to a level that will allow people with dementia and their friends and family to tangibly experience that care and support are suitable, timely, coherent and continuous.

Adapting to changing circumstances

The improvement process will also need to incorporate new insights, e.g. regarding prevention, risk factors and interventions, and changing circumstances, such as rapid developments in technology and ICT (such as domotics, GPS, more effective information and communication traffic). The wide range of new options for self-reliance, support and care that these circumstances offer demand extra attention for the process of implementation and for the development of care and support professions. Training for care and support professionals and related scientific research are vital links in this process.

In conjunction with the National Health Care Institute, the necessary revisions/updates to the care standard will be addressed, as well as improving information on quality in 2016. By ensuring that the set of chain indicators complies with conditions for content-based validity, comparability and statistical reliability, it becomes possible for these indicators to be used more effectively for the procurement of care and support. There is always an option to include agreements regarding aspects of care or the care standard on the long-term agenda for the National Health Care Institute in order to emphasise their importance to society and to initiate actual improvements linked to milestones and a timeline. It must also be established which of the professional groups involved here are willing to bear partial or full responsibility for revising/updating the Dementia Care Standard.

A great deal of research is being conducted on improving knowledge and methods for people with dementia, for example in the Memorabel research programme, the first core area of the Delta Plan for Dementia. The Cabinet has made a total of €32.5 million available for the implementation of that programme for the 2013-2016 period. *During the course of 2016, the Cabinet will decide how to continue funding for this programme.*

International cooperation

The Netherlands is seen as a role model for many other countries, both in terms of the dementia care offer and the quality of research on dementia. However, we can learn from other countries as well, e.g. in developing a dementia-friendly society and in reintroducing community care and helping people live at home for longer. The Netherlands is actively involved in the EU Joint Programme on Neurodegenerative Diseases Research (JPND), an alliance of 26 EU and associated countries and two non-European countries (Canada and Australia). The Memorabel research programme is the national implementation of the JPND strategic research agenda.

A group of 20 prominent figures from the business community and the scientific research community in the G7 countries visited our country in early June 2015 to learn more about Dutch dementia policy and dementia care. On that occasion, I was pleased to accept an invitation to contribute to a G7 strategic working group focused on global action in response to dementia.

A two-day conference on dementia will be organised in the framework of the Dutch EU presidency in the first half of 2016. During that conference, there will be

a focus on the importance of solid scientific research, effective care and support, promotion of a dementia-friendly society, and support for national and international cooperation in that context.

Core area 4: Room for dementia care

As of 1 January 2015, municipalities and health insurers are responsible for the majority of home care and support. Before that point, it often involved three parties. The municipality plays a key role in supporting people with dementia who are living at home, as well as their carers, especially in the initial phase of the dementia chain. Information, identification, referral, support for the carer and guidance (including day activities and short-term residential care) are tasks that have been assigned to the municipality. Since 2011, municipalities have been tasked with designing preventive geriatric healthcare pursuant to Article 5a of the Public Health Act. Activities in this area can provide a foundation for the aforementioned municipal tasks. Case management done by a skilled, equipped professional is part of the district nursing service covered by the Health Insurance Act (Zwv). Case management can be implemented under the Health Insurance Act if the client's need for care is related to the need for medical care or an elevated risk of developing that need.

Dementia chains and case management in dementia

The extent to which effective care and support can be achieved for people with dementia and their carers, as described in the care standard, depends in part on procurement policy, implementation, and (mutual) cooperation.

This will also play a role in the improvement process referred to above. I will be talking to the Delta Plan for Dementia cooperative and other stakeholders about this topic this summer. Key building blocks in this process are that the dementia chain provides coherence and continuity in care and support and that the professional handling case management in that chain is well-equipped for the task.

Encouraging experimentation

Cooperation to provide dementia care is not restricted to specific domains. Talks with stakeholders following the Dik-Faber/Bruins Slot motion revealed that this can lead to bottlenecks in some situations, since the partitions between the domains are not always viewed as clear or consecutive. Due to the interwoven complexity, providers and procuring parties can benefit greatly from tried-and-tested partnership concepts. Based on the experimentation article in the Long-Term Care Act (Article 10.1.2), experiments involving cross-domain funding and accountability will be possible as of 2016. I have asked the Dutch Healthcare Authority (NZa) to advise me on how this article from the Long-Term Care Act can be used in 2016, for instance to arrive at a coherent spectrum of care and welfare services for people with dementia and their carers. Obviously, this also requires a focus on coherent regulations governing healthcare infrastructure, such as screen-based care. *I am also talking to professionals in the field about their ideas for experimentation. In the framework of promoting compliance with the care standard, I am providing budget for coordination and research related to these experiments.* If it becomes apparent after 2016 that the intended experiments are running into legal restrictions, the application of experimentation articles can create room for such endeavours.

It goes without saying that it is initially up to providers, health insurers, healthcare offices and municipalities to make structural agreements for funding the chain care organisation based on experiences gained from the experiments, with a view to achieving a coherent spectrum of care and support. The agreements should create room and mandate for humane solutions suggested by experts. *The dissemination of good examples of funding should be part of the aforementioned improvement process which is on the agenda for the talks with the Delta Plan for Dementia cooperative and other stakeholders.*

Budget

For the supplementary measures announced in this letter, I am providing a total budget of €16 million for the 2015-2020 period. I am awarding a budget of €2 million annually for the Dementia Friends programme for a period of five years. For the other measures, in the framework of the 'From the perspective of dementia' working group, compliance with the care standard and coordination of experiments, I am providing a total budget of €6 million for the 2015-2020 period. I will be awarding a subsidy of €150,000 to the Verhalenbank database of dementia stories from this latter budget for one year (page 6).

In conclusion

The unflagging efforts of many people to improve quality of life for people with dementia and their carers has been impressive. In this letter, I state that there is due cause to institute supplementary measures. In doing so, I aim to improve quality of life for people with dementia and their carers and lay the foundations for adaptation to future demographic developments. The measures on behalf of a dementia-friendly society (core area 1) are intended to ensure that people with dementia are able to participate in society for as long as possible. The measures for networks surroundings clients and carers (core area 2), structural improvements (core area 3) and room for dementia care (core area 4) aim to ensure that care and support are aligned more effectively with the personal possibilities and preferences of people with dementia and their carers. Key conditions to make that possible include strong networks for the dementia care chain, effective implementation of the case management function, and funding that effectively facilitates integrated care and support.

I have emphasised that the measures require united cooperative effort. Today and in future, the needs and preferences of people with dementia and their carers demand no less. *I will periodically update your House of Parliament regarding the state of affairs and the progress achieved on the actions specified in this letter.*

Respectfully,

the state secretary of Health,
Welfare and Sport,

M.J. van Rijn