

The President of the Dutch House of Representatives

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Subject		Enclosure(s)	Your letter
Caring for people with dementia			

Introduction

During the budget debate in November 2007 I promised to produce a plan for dementia care by the summer of 2008. The reasons for this plan are twofold. Firstly, the National Dementia Programme (LDP) comes to an end at the end of this year. The interim assessment¹ has already shown that we need to safeguard the results achieved with this programme and enable the improvement processes that have been set in motion to continue. Secondly, last autumn Member of the Lower House Agnes Wolbert (PvdA) presented the Dementia Delta Plan, in which she called for improvements to the care we provide for people with dementia. Your House also adopted a motion to this effect².

In the aforementioned interim assessment of the LPD I had already outlined the factors underlying that programme. The LDP engendered much enthusiasm, energy and forward thinking among care providers and volunteers of Stichting Alzheimer Nederland, the Dutch Alzheimer Association. I want to safeguard the results of the LDP and encourage further improvements in care for people with dementia and their families.

Size of the target group

A person with dementia faces increasing dependency and fewer opportunities to participate in social activities. Slowly but surely they lose touch with the present, and they lose the ability to recognise things, situations and people - even those closest to them. This process is extremely emotional and difficult to cope with, particularly in the early stages when the patient is aware that they are no longer able to do certain things. There are currently 200,000 people diagnosed with dementia in the Netherlands. On average, 3.7 people are involved in providing informal care for an elderly person aged between 75 and 95³. This means that some 740,000 partners, children, other family members and friends are also directly involved in caring for people with dementia. And that excludes the numerous professionals who provide care for people with dementia and

¹ TK 2006-2007, 25 424, no. 66

² TK 2007-2008, 31,200 XVI, no. 51

³ SCP publication 2007/5, 'Verschillen in verzorging' [Differences in care], with calculations by Alzheimer Nederland.

their families. The importance of supporting people with dementia and their families must not be underestimated. A few weeks ago I had the opportunity to speak to some informal carers of people with dementia during a working visit. The commitment of these informal carers and the emotions inherent in the illness process, both for the patient and those around them, made a deep impression on me.

Experience with the National Dementia Programme

The National Dementia Programme (LDP) was launched in 2004 and ends at the end of this year. During the course of the programme, project teams consisting of various care providers and client representatives have been working on improving dementia care in 57 regions (generally two per care administration office region). The regions were launched in five groups. The project team decides what subjects are to be tackled first in a certain region, based on client consultations. During the implementation of the LDP, a clear picture was gained of what good dementia care involves and what we need to do to offer this care in a coordinated way. However, this knowledge is not yet widely known.

Mr Dubbelman says to his son Frans, "Your mother is so forgetful. She'll ask something three, four times over and doesn't remember that I've already answered. And when she makes a cup of coffee she often forgets to put the filter in the coffee machine". Frans doesn't think there is anything wrong. His mother has been forgetful for years, and when she was at his house she seemed to be completely normal. When more and more people start saying that something isn't right, they go to the GP. There, mother insists that there is nothing wrong with her. They return home without resolving anything. The situation gets worse. Mother starts wandering out into the road in her nightie in the middle of the night. Once or twice the whole family has been out looking for her for hours. Her behaviour is becoming more erratic during the day as well. After repeated insistence, the GP refers Mrs Dubbelman to the neurologist at the hospital. She gets an appointment in three months' time. But because she refuses to participate in some of the examinations, it takes another four weeks before the neurologist diagnoses Alzheimer's disease at an advanced stage. He advises the family to look on the internet for more information.

The internet search throws up more questions than answers, and the Dubbelman family actually has no idea how to deal with the illness. Mrs Dubbelman also has great difficulty accepting that she is becoming increasingly dependent on her husband in particular. She can do less and less at home, and even going out with her friend is becoming more and more traumatic. Increasingly she is literally leaning on her husband. Mr Dubbelman is starting to feel the strain of the demands his wife is making on him. He cannot leave her alone for a moment. When he ultimately asks their GP for advice, he suggests organising home care. But the arrival of a person Mrs Dubbelman does not recognise sends her into a total panic, resulting in a crisis admission. The antipsychotic drugs Mrs Dubbelman is given cause her severe side effects. She can no longer return home.

Denial and inadequate information

Both the person with symptoms of dementia and those around them will often deny that they have a problem. Or they do not want to accept it or do not have the courage to face up to it. This subject is - undeservedly - taboo, so people will often keep it to themselves. And yet the more people who are aware that a person has dementia, the more support that person and their family can be given. Furthermore, it is not always easy to get hold of clear, unambiguous information on

the condition. We must make the subject of dementia easier to discuss and we must make it easier for people to get hold of clear information.

Diagnosis/treatment

Often people are only diagnosed with dementia after having struggled with the condition for several years. GPs may suspect that their patient has dementia but they may not inform them as 'there is nothing you can do about it'. Little is as yet known about medication options.

Both those closest to people with dementia and the professionals will often find it difficult to deal with them, particularly if they are displaying 'difficult behaviour'. For example, people in residential care who are in the early stages of dementia and who display anxiety behaviour are sometimes prescribed medication, whilst soothing attention by care workers can be just as effective⁴.

Informal carers can benefit from behavioural advice on how to handle their loved ones.

Caring for people with early onset dementia imposes other demands on care providers than those for the elderly. The illness process usually takes place much more quickly. Because of their age, people with early onset dementia are still playing an active role in society which they will not give up easily. Feelings of powerlessness and frustration are therefore much stronger.

Knowledge of diagnosis and treatment for both groups must be improved, and this knowledge must be disseminated more widely.

Knowledge transfer

The LDP adheres to the principle 'Let 100 flowers bloom'. Each region searches for its own solution to the problem areas that are most urgent in their region. This has brought about a raft of innovative approaches, although many are unknown outside the region to which they apply. The experience gained in dementia care outside the LDP is also largely unshared. In short, we need to improve the transfer of knowledge between professionals.

Informal carers

A study by Nivel⁵ has revealed that twenty per cent of people caring informally for dementia patients are under severe strain. According to earlier research in the context of the LDP, 67% of informal carers receive inadequate help. Informal carers need more information, advice and care coordination, provided by an assigned expert, independent guidance worker. So we need to offer informal carers more and better support in the work they do. During my discussions with informal carers I was able to experience for myself the positive effect good support can have.

Needs assessment

Both clients and care providers perceive the necessary needs assessment to be cumbersome, time-consuming and bureaucratic. The need for reassessment is often not understood. This complaint is not unique to dementia but is also expressed in relation to the care needs of patients with other complaints. There is scope for streamlining the assessment process.

Administrative acceptance, financing

The regions in the first LDP groups are now converting their activities into structural activities for dementia care. Not every region has succeeded in doing so, however. Many regions are having trouble generating sufficient administrative support (both inside their own organisations and

⁴ Neuropsychiatric symptoms in Dutch nursing home patients with dementia, Sytse Zuidema, Nijmegen, 2007

⁵ **LDP Monitor factsheets**, José Peeters, Sandra van Beek, Anneke Francke, NIVEL 2007

among local authorities) for properly coordinated care that meets the client's needs. Structural financing for the organisation of this coordinated care by the (joint) care providers is also not always guaranteed. As a result, the focus on dementia care is being watered down in many regions in the first LPD groups, and the results achieved with the projects are being lost. We therefore need to safeguard them.

Coordinated care

Care providers operate in an organisational context in which they only focus on a particular part of the client's problems with no coordination between the various providers. This gives the client the feeling that they are not getting sufficient help and are being sent from pillar to post. There is too little consideration of what combination of care from the cure, care and social services fields would provide the best outcome for them.

Mr and Mrs de Graaf, both 73, live in Deventer. Mrs de Graaf is worried. Her husband sometimes says incomprehensible things, he has difficulty with everyday tasks and occasionally becomes aggressive. There are some brochures on dementia in the community centre, and after reading one she suspects that he may be developing dementia. Mr de Graaf tells his GP that he feels fine and that there is nothing wrong with him. But the GP picks up on the signs and is able to get Mr de Graaf to agree to speak to the social geriatrician at the same health centre the next day. Following an examination Mr de Graaf is given the diagnosis of dementia. They are immediately put in touch with a geriatric nurse, Maaïke, who will provide them with support when they need it. During her first home visit Maaïke answers the de Graafs' questions that have arisen since the diagnosis. She also observes their home situation. For the moment, the de Graafs have enough information on dementia. Mr de Graaf finds it very hard to accept that he has a problem, but the advice Maaïke gives helps Mrs de Graaf to handle this in a reasonable way. Every few months Maaïke asks Mr and Mrs de Graaf how they are doing. As the sickness progresses, their need for help and Maaïke's input increases. Maaïke and the de Graafs actively keep in regular contact, which enables any changes in the de Graafs' needs to be properly assessed and measures to be put in place promptly. The care provided is based on the de Graafs' wishes. Ultimately there comes a time when Mr de Graaf needs 24 hour care. The various options for this are explained: a residential care home, a small-scale residential unit, sheltered accommodation, or staying in his own home with a full package of services. A solution is agreed that is satisfactory for everyone involved. At 79 Mr de Graaf passes away, surrounded by the people he loves and in familiar surroundings.

Aims of the dementia care plan

Experience with the LDP has shown us that there is scope for improvement in the care we provide for people with dementia. In the LPD regions, for example, cooperation with 'new' partners has been set in motion, collaboration agreements and structures have been put in place and attention is being paid to the client's perspective. I want to ensure that the expertise

accumulated during the LPD is not lost and that everyone with dementia is able to access good quality dementia care.

Main aims

To achieve this I have set myself the key aims of improving the quality of life of people with dementia and their carers and providing professionals with the right tools to enable them to deliver good quality dementia care.

I want to achieve this by:

1. *Creating a coordinated range of care options that meet the client's needs and wishes.*
 - a. I want the range of coordinated dementia care options and the associated purchase of care under the AWBZ to be available in practice throughout the Netherlands by 2011 at the latest.
 - b. By the end of 2009 at the latest, dementia care best practices will be available for all care providers involved, both in book format and online, such as *Zorg voor Beter*.
2. *Delivering sufficient guidance and support for people with dementia and their carers.*

By 2011 at the latest, some form of case management will form part of the overall range of coordinated dementia care options.
3. *Measuring the quality of dementia care annually.*

As an enhancement of the *Kwaliteitskader Verantwoorde Zorg* [Quality framework for responsible care], a set of indicators for coordinated dementia care will be in place nationwide by 2010 at the latest, which will provide care providers with insight into the quality of the dementia care they offer.

Activities for the dementia care plan

To achieve my aims, I will be initiating the following activities.

1. *Coordinated care options that meet the client's needs and wishes*
 - a. Purchase of coordinated care

Zorgverzekeraars Nederland, Alzheimer Nederland and VWS will be working together on the *Ketenzorg Dementie* [Coordinated Dementia Care] programme. The aim of this programme is to produce a purchasing guide for demand-led coordinated care and to start implementing this model in care purchasing in 2009. To achieve this I want to see agreements between care administration offices and care providers in at least ten spearhead regions. Based on these regions' experience with the purchasing guide, it will be amended where necessary and then made available to the other regions. I want the range of coordinated dementia care options and their purchase under the AWBZ to be available in practice throughout the Netherlands by 2011 at the latest. The purchasing guide will also contain an overview of the options for financing dementia care. This subject will remain a key focal point as this guideline is developed further. For the financing of case management, I refer to my comments on this subject below. Purchasers of AWBZ care will ask care providers for coordinated complaint-related options instead of individual elements based on the form of care. Provision of a high quality range of options can be rewarded by purchasers in the form of a higher payment for the contracted care. The demand for coordinated options combined with this financial

incentive should encourage care institution executives to focus more on coordinated dementia care.

b. Dissemination of practical examples

Experiences in the LDP regions are being bundled to produce practical examples which will be made available to care providers, at least via the internet, in the second half of 2008. The final evaluation of the LDP, which will be published in the second quarter of 2009, will be used to produce a set of best practices. Ways of incorporating other practical examples in these will also be examined. Besides the book format, the *Zorg voor Beter* knowledge bank is another way of disseminating these practical examples.

c. Streamlining needs assessments

The policy for the AWBZ is geared towards extensively streamlining the needs assessment process. Reducing bureaucracy will benefit the client, the care professional, the care provider and even the assessors themselves. On my request the Care Assessment Centre (CIZ) launched a number of pilots aimed at simplifying and improving needs assessments in the autumn of 2007. I informed you about this in my letter of 12 October 2007 (Parliamentary documents II, 2007/08, 26631, no. 227). I will inform you of the outcomes of the pilots along with my policy perspective shortly.

This phase centres around the following pilots:

- transfer points (secondment of CIZ staff) in major health centres;
- needs assessment by GPs and nurse practitioners;
- increasing the flexibility of the work processes (FWP) at the CIZ.

These pilots are not geared specifically towards the situation of elderly people at the onset of dementia, but they can also entail a simplification of the administrative process for these people. The other pilots - development of risk and client profiles and development of self-assessment for clients - have a longer time span and will be launched in the autumn. The client profiles pilot in particular can be used to establish whether a tailor-made assessment process would be a possibility for the target group of people at the onset of dementia.

2. *Sufficient guidance and support for people with dementia and their carers.*

a. Information

Having to face up to dementia and its consequences is extremely traumatic both for the patient and for their families. There will be many different emotions at play. Research⁶ has shown that the client and their family need a great deal of information and support, not only when the dementia diagnosis is made, but also before the diagnosis when they begin to suspect that there might be something wrong. At the beginning of the illness process the predominant emotion experienced by the client and their family will be one of unease and uncertainty about what is wrong. They may suspect dementia, or they may be in doubt. Furthermore, it is sometimes difficult to tell certain signals apart from the common signs of ageing. The client will not always realise what is going on. Targeted information can help to eliminate doubts. This information needs to be easily accessible for everyone. Alzheimer Nederland plays a role in disseminating general information on dementia in its various manifestations. The municipalities also have a key role to play: under the *Wet maatschappelijke ondersteuning* [Social Support Act] they are responsible

⁶ *LDP Monitor factsheets*, José Peeters, Sandra van Beek, Anneke Francke, NIVEL 2007

for policy on supporting informal carers. In my policy letter *Voor Elkaar* [For Each Other]⁷ I announced that I would be offering municipalities an orientational framework which would set out a number of basic functions for the range of support services they offer, centred around preserving the balance between the burden and the capacity of the informal carer. This demands a tailor-made solution so that the informal carer can choose the support they require, such as information and advice, financial support, respite care, practical support etc., from a total package of functions.

b. Case management

The LDP defines case management as follows: 'the systematic provision of coordinated care and necessary support in the area of treatment, care and welfare by one assigned professional forming part of a local interagency collaboration aimed at people with dementia living at home and their carers throughout the entire process of becoming aware of the existence of a problem or diagnosis up to their admission to residential care or death'.

During a recent working visit to an institution offering case management for people with dementia, I discovered exactly what the support of a case manager can mean for these people. A visit such as this tells you more than the thickest report. Being diagnosed with dementia raises a lot of questions for the client. The doctor who makes the diagnosis has an initial role in this process. During the consultation at which he informs the patient of the diagnosis, it can be expected that he will answer any questions the patient may have. He will also provide information on dementia. This is also the point at which the doctor can put the client in touch with someone who can answer questions at a later stage and who can help the client and their family come to terms with the diagnosis. As the illness progresses, the need for help and support will increase.

Research⁸ has shown that many people - both clients and informal carers - benefit from a form of case management. An advisory report published during the LDP shows that based on an analysis of model projects, evaluations and client research, case management can be expected to have the following effects:

- it will increase the client's and their carers' satisfaction with the care and support they receive,
- informal carers become less burdened, stressed or depressed,
- informal carers are better able to cope with problem behaviour of the person with dementia,
- support by the case manager relieves the burden on GPs,
- fewer crisis admissions,
- delayed admission to residential care,
- more efficient deployment of resources.

Various forms of case management have been developed over time in the Netherlands. Within the LDP, 52 of the 57 regions have decided to implement a case management

⁷ TK, 2007–2008, 30 169, no. 11

⁸ 'Casemanagement bij Dementie', S. Ligthart, National Dementia Programme, 2006;

'Evaluatieonderzoek van de pilot casemanagement Dementie in de regio Delft Westland Oostland', H. Groenewoud *et al*, Rotterdam University, *Kenniskring Transitie in de Zorg*, 2008

improvement project. There are regional differences in the implementation of this function. These differences can take account of the specific features of the region (urban or rural, population composition). The people taking on the role of case manager can also differ: a nurse practitioner attached to the GP's surgery, for example, a district nurse, a geriatric nurse, a socio-psychiatric nurse or a specialist in case management for people with dementia. For these reasons I do not want to define the function of case management too rigidly, nor do I believe it makes sense to incorporate case management as a separate function in the AWBZ. To be effective, however, case management must meet certain minimum requirements.

These are:

- The function must be a natural point of contact in the regional care and support structure that incorporates welfare and cure as well as care.
- The case manager must have knowledge of dementia and informal care problems and must be familiar with the social map.
- The case manager must be independent to the extent that where there is a demand or need, they must be able to arrange care for the client outside the interagency collaboration.
- The case manager must in principle be one assigned person.
- Case management must be available for the client in their home setting from the time of diagnosis to the person's admission to residential care or death.

The client and their carers should be able to obtain support from a case manager who meets these minimum requirements. It is important that the supply chain network in the region responds to this. In the period before and around the diagnosis, the client will often not be entitled to AWBZ care. Some municipalities have shown a willingness to finance case management under the Social Support Act (WMO). At that point it may also be more appropriate to claim under the Healthcare Insurance Act (ZVW). In the ZVW it depends who has the most frequent contact with the client and the people around them. This could be the GP or the GP's nurse practitioner, or it could be someone from the mental healthcare sector, with case management provided via the DBC-GGZ. Within AWBZ financing, a point for attention for care providers is that at least some of the activities in the case management function are paid for as part of regular financing. Where coordinated dementia care is purchased, the care administration offices should make the purchase contingent upon the provision of case management. The care administration offices are given the opportunity to grant an additional payment to care providers offering high-quality dementia care including case management in accordance with the coordinated dementia care purchasing guide (AWBZ), which provides additional financial scope for care providers. In those areas in which the care administration office is not authorised to arrange matters themselves, they can ask the AWBZ care providers for assistance, for example for communicating with primary care providers or arranging WMO facilities if the client is dependent on them.

3. *Measuring quality with dementia care indicators*

The *Verantwoorde Zorg, Verpleging, Verzorging en Zorg Thuis (langdurige en/of complexe zorg)* [Responsible Care, Nursing, Daily Living Assistance and Home Care (long-term and/or complex care)] quality framework was established by the Responsible Care steering committee. This steering committee consists of client organisations, professional organisations, industry organisations, the IGZ, Zorgverzekeraars Nederland and VWS. The

steering committee's aim is to make high quality information on care institutions in the nursing, daily living assistance and home care (VV&T) sector available. The provision of transparent information is intended to help clients to make choices, support insurers in their contracting activities, support the IGZ in its supervisory role and encourage internal quality improvements. The information is gathered on the basis of a set of 35 indicators subdivided into ten themes⁹. Much of the information measured is generic (i.e. not illness-specific). Coordinated care is one of the ten themes listed, but this is still under development. The aim is to put effective agreements in place between the care organisation and other care organisations or providers so that the client is not affected by boundaries in care and related sectors.

A limited set of indicators is being developed specifically for coordinated dementia care; these can be regarded as a supplement to the indicators in the quality framework. This set gathers information on aspects such as clients' experience with the care and life plan. The coordinated dementia care indicators will then address the content of the care plan in more depth. The initial draft version of the dementia care indicators is expected to be completed soon. The care providers in the regions spearheading the purchase of coordinated dementia care can then be asked to be the first to carry out a practical test with these indicators. Once the indicators have been finalised, the care providers can measure and deliver proof of the quality of the dementia care they offer.

Additional activities

Sufficient knowledge to enable diagnosis to be made promptly; sufficient knowledge on treatment options including in relation to possible multimorbidity

Dementia is one of the geriatric giants in the National Geriatric Care Programme¹⁰. Research and experiments in the area of dementia are increasing our knowledge of its diagnosis and treatment. This programme also covers the dissemination of the knowledge gained. Interagency collaborations can make use of the opportunities offered by this programme to perform experiments and research projects in the area of dementia.

A patient presenting to their GP with suspected dementia or dementia-like symptoms can expect the GP to have enough knowledge to be able to recognise the symptoms. This means that the GP needs to know when to refer the patient to secondary care (outpatient memory clinic etc.) and what support can be offered. To do so he will use the available professional standards (such as the NHG Dementia Standard, the LESA Dementia and the guideline on the diagnosis and medication options for the treatment of dementia) and the Regional Support Structure (ROS). Responsibility for this rests with the GP's surgery or the interagency collaboration.

Further professionalisation

9 Themes for responsible care

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|-----------------------------------|---|
| 1. Care (treatment) and life plan | 6. Participation and ability to cope socially |
| 2. Communication and information | 7. Mental wellbeing |
| 3. Physical wellbeing | 8. Safety at home and in residential care |
| 4. Care-related safety | 9. Sufficient and skilled staff |
| 5. Living and life circumstances | 10. Coordinated care |

Offering coordinated care based on the client's needs and wishes requires a change of attitude among care providers. In the first instance it is up to the professional organisations to pay attention to this.

Living environment

A good living environment is essential for people with dementia. In the memorandum I therefore return to the subject of small-scale living, which I expect to be able to send you in a few months' time.

Consultation bureau for the elderly

The Vilans Knowledge Centre's vision document sets out five different functions for the consultation bureau for the elderly. When I debated the policy for the elderly with you in January this year and when I took receipt of the vision document in April, I specified the value-added of these functions, such as for prevention and for the necessary link between welfare and care. I believe that the consultation bureau's functions must be embedded in existing initiatives. The functions of 'early identification and case-finding' and 'connecting link' may be relevant in the context of dementia. However, these functions would then need to form part of an organised network in a particular area. In this network it is important to put these two functions into practice adequately and to reach precise agreements on the connections and referrals.

Finance

No additional funds have been budgeted for the implementation of this plan. It will be financed from existing budgets such as the National Elderly Care Programme (2008-2011: total budget approximately €80 million), the rules on building and small-scale living (2009-2011: total budget €80 million), the budget for development of indicators for dementia care (2008: €40,000) and the care innovation fund (2009: total budget €15 million). When spending the money in the innovation fund, particular attention will be paid to dementia. To back up the care administration offices' preparations for purchasing coordinated dementia care, support will be available for both the care providers and the care administration offices in the form of process management.

With the implementation of this plan I am taking a major step towards achieving client-oriented, coordinated dementia care which can impact on the entire care sector.

The State Secretary of Health,
Welfare and Sports,

Dr. J. Bussemaker