

Guideline for Integrated Dementia Care [excerpt]

An aid for the development of integrated dementia care

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Introduction to this excerpt

In June 2008 the State Secretary of Health, Welfare and Sport expressed the ambition to improve dementia care in the Netherlands. In her letter to the Dutch House of Representatives she writes:

“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.*
 - a) By 2011 at the latest, some form of case management will form part of the overall range of coordinated dementia care options.”*

To achieve these aims the Ministry of Health, Welfare and Sport, Zorgverzekeraars Nederland (the Health Insurers’ Association), Alzheimer Nederland (the Dutch Alzheimer Association) and ActiZ (the Employers’ Association for Care Providers) joined hands and initiated the Programme on Integrated Dementia Care. They made this guideline as an aid for the development of integrated dementia care. In 2008 16 so called ‘spearhead regions’ made their first action plans. As from 2009 these regions offer integrated dementia care to their clients. In June 2009 a second group of regions joined the programme.

In this excerpt we focused on the parts we think can be helpful for those aiming to improve dementia care in other countries. Therefore we did not include the parts concerning process of purchasing care nor the parts specifically regarding the Dutch circumstances. For further inquiries please contact the department of Long Term Care at the Ministry of Health, Welfare and Sport, tel. +31(0)70 340 6306 or e-mail: dlz22@minvws.nl

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3. People with dementia and their families

3.1 What is dementia and what does it do?

Dementia is not a distinct disease as such, but refers to a combination of symptoms; in other words, to a syndrome. A syndrome is a collection or sequence of related symptoms and conditions. Dementia can be caused by a wide variety of clinical features and is relentless and irreversible.

Symptoms of dementia include memory disorders, such as a reduced capacity to absorb new information and disorientation, and one or more of the following cognitive disorders: aphasia, apraxia, agnosia and loss of ability in terms of planning, organisation and abstract thought. The disorders must be serious enough to constitute clear limitations in daily life (DSM-IV). In addition, one or more psychological or behavioural problems gradually manifest themselves in virtually everyone with dementia. Four clusters can be distinguished in this respect, namely anxiety and depression, restlessness and agitation, apathy, and psychosis (Aalten, 2004; Zuidema, 2007).

The time at which and degree to which symptoms manifest themselves differ for each patient, however. Dementia patients live for an average of eight years with the syndrome and, again on average, live at home for six of those eight years. Furthermore, the course of the syndrome differs greatly from person to person. The specific type of care required therefore depends very much on the individual patient concerned.

For people with dementia, the broader social environment – that is, the respective family and friends of an individual patient – plays a key role in determining well-being and the degree of professional care required. Assistance and information must therefore be directed towards both individual patients and those within their broader environments. Knowledge of dementia and how the patient experiences it, is necessary to optimise the way in which the syndrome is handled. Specific expertise is therefore required on the part of care providers.

In its report on dementia published in 2002 (*Dementie*), the Health Council of the Netherlands stated that ‘The process of decline is slow and has often been underway for years prior to diagnosis. Independent functioning gives way to dependence and participation in social activities becomes difficult’.

Slowly but surely, the patient loses all contact with the present as well as the capacity to recognise objects, situations and people, even those who were closest to him or her. In time, the ability to use or comprehend language is lost entirely. The patient becomes incontinent, at one point loses the ability to walk and ultimately passes away in a completely weakened state. People diagnosed with dementia often continue living for many years, though not as long as peers without the syndrome. Dementia is often accompanied by personality changes and episodes of anxiety, suspicion, depression, anger, restlessness or apathy. Vagrancy and sleep-wake rhythm disturbances also occur. In addition to a biological cause (brain degeneration), the disruption of emotions and behaviour often has a psychosocial dimension (learning to cope with the syndrome). Contrary to popular belief, dementia patients can, disordered thought notwithstanding, experience psychological pain and become depressed, sad or anxious as a result of losing a broad array of abilities. For family and friends, dementia means a long-term mourning process for the loss of a loved one. Caring for a relative or friend with dementia is demanding work and can adversely affect the well-being and health of a carer to a considerable degree. 30%-50% of informal carers of people with dementia have depression-related

complaints. Set against the demanding nature of the work, however, is the satisfaction that informal carers can derive from the assistance they provide.

The emphasis in descriptions of the course of the syndrome tends to be on long-term degeneration. Nevertheless, in a favourable environment and with care based on respect and love, people with dementia can, in spite of their limitations, laugh, dance, sing and cry, mean something special to someone else, care for a fellow resident, and enjoy good food, beautiful music and pleasant smells. They can sometimes look upon their limitations with a great deal of humour and appreciate the care that they are receiving. It is therefore of crucial importance to realise these elements in the care provided and enhance the quality of life of people with dementia.

Alzheimer’s disease, vascular dementia and dementia associated with Parkinson’s disease are the most common forms of dementia. There are dozens of diseases in which dementia can occur.

3.2 People with dementia, their families and numbers

3.2.1 Number of people with dementia in the Netherlands

If the prognoses do not change and curative treatments fail to materialise, the number of people with dementia in the coming years is likely to increase by 65% to more than 380,000 by 2030. The number of people with early onset dementia will remain more or less constant over the next few years (between 10,000 and 12,000).

The relatively strong rise in the number of people with dementia who live alone (widowed, divorced, single) is striking. This distinction is important when it comes to forecasting the need for care, due to the high probability of a lack of informal care. The number of single households is expected to increase by 60% between 2009 and 2030.

Table 1: Prevalence figures, forecast of number of people with dementia (source: Alzheimer NL)

Number of people with dementia	2009	2010	2015	2020	2025	2030
Total	231223	236741	263040	291921	332560	385943
Under 70	16,360	16,768	19,169	19,528	20,435	20,664
From 70 to 80	48,140	48,822	53,461	64,221	77,038	77,084
80 and older	166,723	171,151	190,410	208,171	235,087	288,194
Living alone, under 70	3,166	3,262	3,833	3,900	4,105	4,297
Living alone, 70 to 80	16,782	17,006	18,357	21,418	25,974	25,454
Living alone, 80 and older	84,907	87,929	101,173	111,303	123,231	148,160
Total living alone	104,855	108,197	123,363	136,620	153,310	177,911
Total living with a partner	126,369	128,545	139,677	155,301	179,250	208,031

More figures on dementia in the Netherlands:

- Alzheimer Nederland (the Dutch Alzheimer Association) puts the number of new cases of dementia over the next few years at approximately 30,000 per year.

- The number of patients with early onset dementia (below the age of 65) will remain more or less constant over the next few years (between 10,000 and 12,000).
- Dementia patients live for an average of eight years with the syndrome. Of these eight years, again on average, they live at home for six years and usually spend two years in nursing and care homes. However, a considerable number of people with dementia will continue to live at home until the end.
- Dementia is one of the top three illnesses that cause the most severe loss of quality of life for the patient. Furthermore, dementia is a syndrome that has a major impact on the people in the patient's immediate environment.
- According to the Netherlands Institute for Social Research (Sociaal Cultureel Planbureau, SCP) on average there are three people involved in caring for a dementia sufferer. This means that there are currently more than one million people dealing with dementia in the Netherlands.
- Seventy-eight per cent of informal carers are stressed or are at great risk of suffering from stress (source: NIVEL, 2007) and depression. Because of these excessive stress levels, informal carers need effective and professional help. People suffering from stress will themselves make greater demands on healthcare services.

3.2.2 Numbers for an average LDP region

TNO has calculated what the present figures and forecasts mean for an average National Dementia Programme region (Landelijk Dementie Programma, LDP) with 200,000 inhabitants. The incidence figures provide an indication of the diagnostic capacity in the region. The prevalence figures are estimates based, on the one hand, on a longitudinal study of the occurrence of dementia among older people of different ages and, on the other, the latest demographic data from Statistics Netherlands (Centraal Bureau voor de Statistiek, CBS).

Table 2: TNO calculation for average (fictitious) region with 200,000 inhabitants in 2007

Year	Number of inhabitants	Number of single people	Incidence of dementia	Prevalence of dementia	Number of single people with dementia	Number of people for whom residential care is indicated
2007	200000	31216	425	2680	1198	804
2010	200961	32927	452	2862	1302	858
2015	202954	35284	495	3161	1450	948
2020	204819	36975	549	3506	1579	1052
2025	206466	38177	628	3988	1737	1196
2030	207608	38972	710	4617	1957	1385

3.2.3 Numbers of people with dementia and (working) population

The report by the Health Council of the Netherlands provides predictions of the size of the total population compared with the number of people suffering from dementia. This tells us something about the scope and potential of informal care, but also something about whether it is possible to provide sufficient numbers of professionals to deliver the necessary care. The estimates show that where the number of people with dementia is increasing, the opposite development can be seen in the size of the potential working population (people aged between 15 and 64), which is set to shrink considerably over the next few years. While there were as many as 63 potential workers for every person with dementia in 2000, in 2010 there will be only 55 and in 2050 just 27.

The proportional increase in the number of people with dementia will be much stronger. More and more people will encounter someone with dementia in their immediate social environment. Whereas 1 in 93 people in the Netherlands was estimated to be suffering from dementia in 2000, in 2010 the figure will be 1 in 81, in 2020 1 in 71, and in 2050 1 in 44. See Annex 1 [not included in this excerpt].

When one compares the prevalence figures with the development of informal care and the working population, it can be seen that the pressure placed on the informal care sector for support, help and care of people with dementia will increase considerably. This is an added reason why we should be systematically expanding support for informal carers and changing the care we provide and the way it is organised.

3.2.4 What do we know about the uptake of care?

There are no national records of the uptake of care by people with dementia; indeed there are very few national statistics available on this form of care uptake. However, we do have information available on the living arrangements of dementia sufferers (Health Council of the Netherlands, 2002). In 2000 almost 35% of dementia patients were living in nursing homes or care homes. When one applies this percentage to the situation in 2010, it becomes evident that by then we will need 12,900 more places in nursing and care homes for dementia patients than in 2000. This represents an annual increase of almost 1300 places in institutions or other facilities that offer a similar level of professional care, corresponding to about six nursing homes per year.

Approximately 60% of dementia patients living at home are dependent on daily or constant care, either in the form of support, guidance, treatment, nursing or assistance with daily needs.

Mental healthcare is also often involved in the care of people with dementia. Of the total number of referrals a GP makes for people with dementia, 30% are for a mental healthcare institution (Baan et al., 2003). Of the people showing the symptoms of dementia who are referred by a GP, 24% are referred to a geriatrician, 22% to a neurologist and 9% to a psychiatrist.

Figures on the uptake of care at a regional level are also hard to come by. Experience from spearhead regions during the first phase of the programme shows that this often makes it difficult to concretise and quantify plans for dementia care. We would therefore recommend reaching agreement with the chain partners (including municipalities and insurance companies) on how to register figures on care uptake. This could be done via a central registration point or the GP registration system, for instance.

What can you do with this information in your own region?

It is important to ensure that spearhead regions have access to data on the nature and size of the group of people with dementia, both now and in the future. These numbers form the starting point for the facilities that will be needed in your region in the short and longer term. For each spearhead region it is therefore necessary to chart the development of the incidence and prevalence figures per municipality and/or per region and to gear the scope of the desired offering towards this. The numbers of people with dementia differ from one spearhead region to the next, but there will also be different growth percentages within a region - between rural and urban areas, for instance.

Good dementia care in the region not only means having sufficient appropriate facilities available but also ensuring a high level of cohesion between them.

TIP: TNO has documented the number of people with dementia in all LDP regions up to the municipality level in the period up to 2007. Since then it has also obtained the prevalence figures per municipality for 2009-2030 on behalf of Alzheimer Nederland, based on new demographic data from CBS. You can obtain this data from Alzheimer Nederland. An overview of the 57 regions that participated in the National Dementia Programme can be found in Annex 2 [not included in this excerpt].

3.3 People with dementia, their families and their questions

Central message:

In the development of good services and facilities, the demand for care is key. The Landelijk Dementie Programma (National Dementia Programme, LDP) uses the '14 problem areas'. These problems are articulated in the language used by patients and their families. Experience in the LDP shows that this approach helps care providers to look at things through the client's eyes.

Integral dementia care demands a suitable answer to all 14 problem areas that is of sufficient scope and cohesion. At the same time it is important to set priorities. In all LDP regions informal carers were asked which problem areas they feel are the most urgent. The LDP has also compiled a national league table of the top 5 problem areas. A second survey has recently been carried out by Alzheimer Nederland. Alzheimer Nederland made the regional data available to the regions concerned in February 2009. A second national analysis is being published in June 2009. We therefore have a picture of the current regional and national demand from people with dementia and their families. The top 5 therefore plays a crucial role in the development of integrated care in your region.

3.3.1 The LDP's fourteen problem areas

What do care service users want? The National Dementia Programme (LDP) has identified fourteen problem areas which constitute the most important problems and questions raised by people with

dementia and their informal carers¹. The word ‘problem’ was chosen because people with dementia and their informal carers do not express themselves with terms like ‘living areas’, ‘areas of concern’, ‘dimension’, ‘functions’ or ‘care severity categories’.

The LDP’s 14 problem areas are the most important problems experienced by people with dementia and their informal carers, expressed in the words these people use themselves. The 14 problem areas relate to all phases in the care of a person with dementia: from before the diagnosis is made up to admission into a care home. People with dementia and their informal carers will probably have to deal with all of these problem areas in the various stages of the illness process. However, the significance of these problems for the life of the sufferer and their informal carers is determined on an individual basis and depends both on the stage of their illness and their personal circumstances. The 14 problem areas described below embody the most significant problems for the client system. These 14 problem areas are further elaborated upon in Annex 3. The table below provides a non-exhaustive overview of situations that can occur in each of the 14 problem areas. See the LDP Work Book for a more detailed description.

<p>1. Feeling that something is not right:</p> <ul style="list-style-type: none"> - the client suffers from forgetfulness; - the client no longer recognises people; - the client can no longer perform certain actions properly; - the client has difficulty handling the concepts of time and place properly.
<p>2. What is happening and what can be done to help?</p> <ul style="list-style-type: none"> - the client system does not know what help is available; - the client system is unfamiliar with the syndrome, problems and behaviour; - no referral is made after the diagnosis.
<p>3. Frightened, angry and confused:</p> <ul style="list-style-type: none"> - the client feels dejected and is no longer interested in activities and the world around them; - the client refuses to cooperate, does not want to be helped; - the client is quickly irritated and irritable; - the client has difficulty sleeping, confuses day and night.
<p>4. Managing on your own:</p> <ul style="list-style-type: none"> - the client can no longer perform familiar tasks in and around the house; - the client can no longer drive a car; - the informal carer has nobody in their social environment to ask for practical help; - the informal carer is not able to handle day-to-day things because they have never been taught how, have no time or are not physically capable of doing them.

¹ Source: Meerveld, J., Schumacher, J., Krijger, E., Bal, R., Nies, H., *Landelijk Dementieprogramma: werkboek*. Utrecht: NIZW, 2004 (2).

Brochure ‘*Wensen en problemen van mantel-zorgers van mensen met dementie: een vragenlijst*’. Utrecht: NIVEL, 2006.

<p>5. Avoiding contact:</p> <ul style="list-style-type: none"> - the client withdraws; - the client makes demands on the informal carer; - the client displays inappropriate social behaviour; - the informal carer is ashamed of the client's behaviour and tends to avoid meeting other people.
<p>6. Physical care:</p> <ul style="list-style-type: none"> - the client does not look after themselves properly; - the client can no longer dress or undress themselves; - the client is incontinent; - older informal carers can no longer perform care tasks.
<p>7. Dangers:</p> <ul style="list-style-type: none"> - accidents and near-misses in the house (fire, falls); - the client wanders off or gets lost; - neighbours are bothered by the client seeking contact or help.
<p>8. Health problems as well:</p> <ul style="list-style-type: none"> - the client has a medical problem: problems eating or swallowing, constipation; - the client falls or is extremely agitated; - the client has problems caused by the combination of medications they are taking.
<p>9. Loss:</p> <ul style="list-style-type: none"> - the client is saddened, defiant, frightened by their regression; - the client has difficulty accepting their illness; - the informal carer is saddened, defiant, frightened by the regression of their loved one.
<p>10. It's all getting too much for me:</p> <ul style="list-style-type: none"> - the informal carer is stressed by having to care for their loved one; - the informal carer sacrifices a great deal of their own social life; - the informal carer receives little or no support from family or friends; - the informal carer worries about not being able to cope with providing the care.
<p>11. Forfeiting and losing control:</p> <ul style="list-style-type: none"> - the informal carer experiences help as patronising for them or for their partner or parent with dementia; - the informal carer feels threatened by the help; - the informal carer feels dependent on the help.
<p>12. In good and bad times:</p> <ul style="list-style-type: none"> - the informal carer feels it is their duty to care for their partner or parent with dementia; - the informal carer does not acknowledge that they are suffering from stress; - the client has behavioural problems when they attend a day centre or on admission to an institution.
<p>13. Breakdown in communication with professional care providers:</p> <ul style="list-style-type: none"> - the professional care provider and the client or informal carer do not see eye to eye; - there is a lack of communication and coordination between professional care providers; - the professional care providers do not know what dementia care is available in the region; - there is too little contact between the professional care provider and the client or informal carer.
<p>14. Resistance to admission:</p> <ul style="list-style-type: none"> - the client resists admission;

- the partner/family postpones admission or relocation as long as possible;
- the clients/loved ones have a negative perception of the care home or nursing home.

3.3.2 Most urgent problems in each region

A survey of the most urgent problems and needs of people with dementia and their informal carers was produced in each of the 57 LDP regions. Improvement processes were then set in train for these aspects in each region. The survey of the most important problems was produced together with client panels of informal carers and using a special questionnaire based on the 14 problem areas: the LDP Monitor. In the LDP Monitor questions were asked concerning, on the one hand, the importance assigned to a 'problem area' by informal carers and, on the other, whether informal carers also experience problems within a problem area themselves (importance questions and experience questions). Finally, the informal carers were asked what additional care they need.

The client panels (700 members) relatively often identified problem areas 1 (Feeling that something is not right) and 2 (What is happening and what can be done to help?) as the most urgent problem areas. Many close relatives of people with dementia are troubled by the fact that it often takes a long time to obtain the medical diagnosis - often long after the patient or the family themselves start to be concerned. Many families complain that they return home after the diagnosis empty-handed. They want to receive more information, guidance and support right from the time the diagnosis is made.

Importantly, the most urgent problems experienced by people with dementia and their families in each of the LDP regions are therefore known.

National Top 5

The National Top 5 was compiled from the results of the client panels and the NIVEL analyses based on the LDP Monitor. The national analysis of 984 questionnaires and 700 members of client panels revealed that all 14 problem areas were sufficiently important and relevant to informal carers of people with dementia, and that the 14 problem areas do indeed coincide with the problems, obstacles and wishes of informal carers.

The five top problem areas are as follows:

1. Frightened, angry and confused (coping with behavioural and mood problems);
2. It's all getting too much for me (informal carers stressed);
3. Resistance to admission (reluctance and opposition to admission to a nursing home);
4. Feeling that something is not right/What is happening and what can be done to help?
5. Breakdown in communication with professional care providers

It is striking that the first four problem areas in the Top 5 relate to the phase of the illness prior to admission to a residential care facility. The LDP therefore provides a large number of improvement projects that are geared towards providing help and support in the home during the initial years of the illness.

NIVEL has produced a separate analysis of the most common problems experienced by informal carers in caring for their loved ones with dementia. The results of this analysis can be found in Annex 4. A second survey based on the LDP Monitor was conducted at the end of 2008. The regional results of the second survey were published in the regions in February 2009 and the national analyses based on the second survey will be published in June 2009.

3.3.3 Translating problem areas into facilities

There is no direct correlation between a problem area and its solution in terms of a (new) facility. Some problem areas require several different solutions or facilities. And some facilities contribute to the solution of several different problem areas. In the next chapter we take a more detailed look at a desired regional care offer based on the most important problem areas experienced by people with dementia and their families.

What can you do with this information in your own region?

As already mentioned, in the development of good facilities demand for care is key. The demand for care is known for all of the regions that participated in the LDP. Alzheimer Nederland recently carried out another regional survey with the LDP Monitor, including in a number of regions that did not participate in the LDP. There is therefore no need for you to invest any more energy in that area. Alzheimer Nederland is currently organising new panels in many regions to supplement the quantitative results. You can contact the representatives to find out how the organisation of these panels is progressing.

By the end of June 2009 we will know whether there have been any major changes in the National Top 5 problem areas. Until then, the 2007 National Top 5 will apply.

The tricky part will, however, be translating the demand for care into the appropriate facilities and ensuring cohesion between the two. This is dealt with in the next chapter.

4 Integrated dementia care: what are the important aspects?

In the previous chapter we described the background to dementia. In this chapter we discuss the question of what is actually important for good quality integrated dementia care. Among other things, we examine the entire process of the client system and the associated building blocks, the criteria for integrated care management and the implementation of case management.

4.1 What is important for good dementia care in the region?

In this section we look at how to translate the demand from people with dementia and their families into good dementia care in the region, based on the client system which consists of three phases with various building blocks.

4.1.1 What is good dementia care?

By good dementia care we mean the range of services that people with dementia and their families would like to receive, according to the latest insights and from the perspective of clients and their families. This ideal range of services, as everyone will understand, is an aim that cannot be achieved in the short term and may also change over time. Regions are expected to take the first steps towards achieving this ideal range of services in 2009 and to make further major strides forwards in 2010 so that dementia care chains will be under development in all regions by 2011. Good dementia care ideally consists of a combination of care, cure, welfare and living, and follows the process a person with dementia passes through from the very first feelings that something is not right until their death from the illness.

People with dementia live for an average of eight years, of which they spend about six at home and two in a nursing home. The National Dementia Programme (LDP) has identified the problems faced by people who live at home for the first six years. The National Top 5 reveals that the most urgent needs are for more information, advice, support and treatment right from the start of the illness process. Effective facilities or interventions are not automatically available in every region. Facilities of that kind make a significant contribution to the quality of life of the patient and their family during the years in which the dementia sufferer lives at home.

The client system goes through a process consisting of three phases (see figure 1):

1. Identification and acknowledgement:

The initial phase is the period in which people are concerned about forgetfulness or behavioural changes in themselves or in a partner or family member, but dementia has not yet been diagnosed. This period is mainly characterised by the feeling of something not being right. Many people put off getting a diagnosis and do not discuss their symptoms with their GP or attend the memory clinic.

Nevertheless, early diagnosis is important because the symptoms may also be caused by a disease that is treatable. Drugs can also help in the treatment of conditions occurring simultaneously, such as depression, anxiety or sleep disorders.

Furthermore, in the initial phase many important decisions can be made concerning legal, financial and administrative matters and the patient's medical care. Early diagnosis also gives everybody concerned time to prepare for the changes to come. An additional advantage is that care providers and care purchasers will have a better indication of what help will be needed in the future.

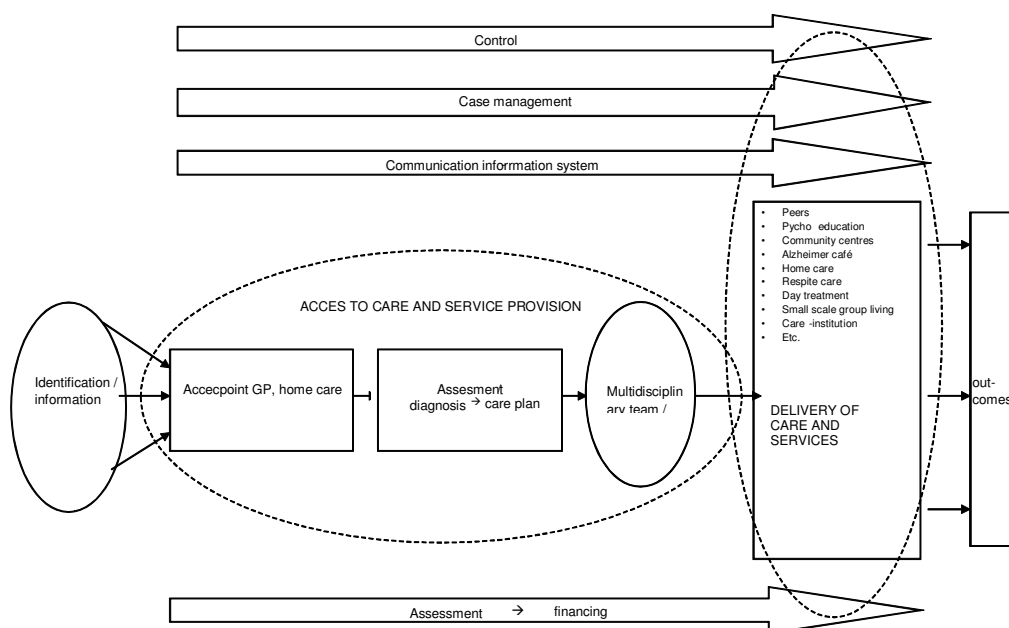
2. Diagnosis and access to support and care

The period in which the diagnosis is made and immediately thereafter is a very intense one for patients and their families, which can last for several months. Patients and those around them do not generally receive sufficient guidance, support and information. This guidance is of fundamental importance in improving their ability to cope and in giving people a chance to prepare for life with this illness. Various effective interventions are not offered. That is the reason why this period should be viewed as a separate phase.

3. Delivering care and services

Most people prefer to remain at home for as long as possible, provided that conditions allow for this and their partner/family/informal carer is able to cope. During this phase too, it is necessary and crucial to provide effective case management in order to be able to monitor the burden on the informal carer on an ongoing basis and to anticipate the patient's future care needs.

Figure 1: The client system process:



4.1.2 The building blocks of good quality dementia care

The basic assumption in the development of good quality dementia care is that facilities have proved their effectiveness either through research, because they have proved their usefulness in practice, or because experts have a positive opinion of the facilities. In many cases it is not yet possible to count on proven effectiveness through research alone, because scientific proof of an effective care method, intervention or treatment is not always available.

The development of the care offer in the region is based on the three phases of the illness process described above. The facilities, activities or interventions required in each phase are then listed. These facilities form the building blocks for the regional care chain and are, in almost all cases, intended both for the person with dementia and their family.

Table 2 shows a summary of the building blocks in each phase. See Annex 5 for a more detailed description of each building block.

An overview of the successful improvement projects in the LDP can be found in Annex 6, along with references to information sources. Annex 7 provides three examples of case management. [both annexes are not included in this excerpt]

Table 2: Building blocks for good quality dementia care in each phase of the illness process

Phase	Building blocks for good quality dementia care	Parties involved
Identification and acknowledgement (prior to diagnosis)	<ol style="list-style-type: none"> 1. Information, advice and support; 2. Identification and active referral. 	Municipality, care service point, registration point, consultation bureaux for the elderly, consultant for the elderly, various professional care providers with whom client is already in contact, e.g. GP, home care provider, etc.
Diagnosis and access to care (during and immediately after diagnosis)	<ol style="list-style-type: none"> 3. Screening and diagnostic examination; 4. Process support/case management; 5. Dealing with patient system; 6. Low-threshold information and support for patient system after diagnosis. 	GP, memory clinic, home care provider, case manager, mental health services (Geestelijke Gezondheidszorg, GGZ), nursing home physician, clinical geriatrician, facilitators/support workers, geriatric research and advice centres (Geriatrisch Onderzoeks en Adviescentrum, GOAC), care assessment centres (Centrum Indicatiestelling Zorg, CIZ)/municipalities
Delivery of care and services (overt phase)	<ol style="list-style-type: none"> 7. Process support/case management; 8. Dealing with the patient system; 9. Information and support for the patient system; 10. Help with ADL and household support; 11. Transport/participation; 12. Services in and around the house; 13. Activities for patients; 14. Respite care/temporary stays to allow informal carer to take a break at night, 	Intra- and extramural care: GP, geriatrician, case manager Home care provider, nursing home, residential care centres, housing corporations Municipality, buddy centre, care hotel

	weekends, holiday; 15. Holiday for people with dementia, with or without partner; 16. A different way of living; 17. Crisis assistance.	
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Below follows a brief explanation of the care offer needed in each phase:

1. Identification and acknowledgement/Care offer prior to diagnosis

First of all, problems have to be identified and acknowledged (the feeling of something not being right), and those affected need to be aware that they can ask for help. What needs to be organised regionally is:

- information that reaches the client and/or their family;
- a point of contact to which those affected can turn for counsel, advice and help;
- good access to primary care that is appropriately qualified to provide dementia care (e.g. GP);
- a person with a knowledge of dementia who can support those affected through the process if desired (case manager, dementia consultant, etc.).

In order to minimise the risk of cognitive deterioration or dementia remaining undetected, arranging preventative home visits to high risk groups such as single people aged 75 and over, can be important. Identification and referrals by professional care providers with whom the client already has a relationship can prevent excessive delays in providing support for the client and their system.

2. Diagnosis and access to support and care

In this phase the patient is introduced to the professional dementia care options for the first time via the GP, a care service point, a memory clinic or a regular care facility. A thorough and prompt diagnosis of the syndrome and the care needs is performed to establish the diagnosis, what the main problems are and what opportunities there are in terms of care and services.

The diagnosis of dementia, established by the GP or at a memory clinic, is the precondition for access to care. It is often automatically assumed that a care diagnosis will be performed at the same time as the diagnosis of the illness, but in practice this is often not the case. Some GPs are not in a position or do not have the time to make a care diagnosis at all, let alone set the implementation of this care in train, monitor it, adapt it if necessary, and evaluate it. Because GPs are so clearly anchored in primary care, they will most likely focus predominantly on healthcare issues, despite the fact that other issues relating to welfare, informal carers and so on arise much more often.

The new National Primary Care Collaboration Agreement (Landelijke Eerstelijns Samenwerkings Afspraak, LESA) which was developed by the National Association of General Practitioners (Landelijke Huisartsen Vereniging, LHV) and the Netherlands Society for Nursing Home Physicians (Nederlandse Vereniging van Verpleeghuis Artsen, NVVA), offers opportunities to also involve nursing home physicians and geriatricians in the illness and care diagnosis. In some places there are also geriatric research and advice centres (GOAC) which could play a role in the diagnosis.

For the sake of continuity in the care process, the diagnosis of dementia should be immediately followed by the compilation of a 'care-live plan' in consultation with the client system. The care plan will set out the problems, questions, wishes and options in the client system and what support and/or

care is needed. This care plan needs to meet certain requirements. The wishes of the client system, independent control and autonomy, are clearly set out in the care plan. The care plan can give rise to a multi-dimensional approach of increasing intensity and complexity. In the initial phase of the illness, there is generally a need for information, advice, guidance and support, treatment, and sometimes forms of respite care. Many activities will of course only become available following the assessment by CIZ or municipalities.

3. Delivering care and services

Once the care plan has been established and the financing has been arranged, the required care and services specified in the care plan are delivered; sometimes only a few, sometimes a large number, sometimes for a short period of time, and sometimes for several years. The care and services needed change with the dynamics of the syndrome and the need for care and support. This may mean that a rediagnosis or reassessment will be needed and the indication(s) will need to be reviewed.

Patients in this phase of the illness will need more intensive, more complex arrangements than before: the care is often long-term (at home or in a sheltered setting). In this case a wide variety of professionals will often work together in a team. The care plan may be compiled by a case manager, for example.

The ability of the informal carers to cope is generally of crucial significance in terms of which arrangement is chosen. It is important to look after and consider the informal carers for several reasons: firstly because they are an important source of support, secondly because professional care is supplementary to that support, and thirdly because the informal carers are a risk factor in themselves. Informal carers of people with dementia are at greater risk of mental and physical health problems. It is important to minimise this risk as much as possible.

The care and services that are suitable may be very diverse and may fall within different legal regimes (e.g. the Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten, AWBZ), the Healthcare Insurance Act (Zorgverzekeringswet, ZVW), the Social Support Act (Wet Maatschappelijke Ondersteuning, WMO), housing, social security). This step in the delivery of care and services is also of crucial importance from the client's perspective, because here they need the right care to be delivered at the right time. The quality of the integrated care must prove itself in this context.

4.2 What is important in terms of good quality integrated care?

As described in the previous section, it is extremely important that your region has good quality facilities available in sufficient numbers for people with dementia and their families. But that in itself is not enough. The target group itself complains that it cannot see the wood for the trees. The Health Council of the Netherlands (2002) also observes that there is a lack of cohesion in dementia care. It is therefore not only a question of providing good quality facilities in sufficient numbers, but also ensuring their cohesion and coordination. In other words, the question is: what is important in terms of good quality care chain management? In this section we provide an answer to this question.

4.2.1 The definition of integrated care

The Ministry of Health, Welfare and Sport (VWS) uses the following definition of integrated care:

Integrated multidisciplinary care describes a situation under which a coherent set of care provision is offered by different providers under a recognisable control structure, with the client process at the heart of the system (evidenced by formalised arrangements between the care providers involved concerning the cohesion and continuity of patient care). In the integrated chain there are different degrees from simple and strictly sequential to complex care.

The challenge for providers of dementia care is to create collaboration (a chain) which ensures that the care and services provided meet the clients' and their families' needs and that these facilities are offered at the right time and in a mutual cohesive way.

From the point of view of the client and their family, the most important elements of the process they are going through are coordination and continuity. Assessment and possible re-assessment are important junctures in this process because it is at these junctures that the legal entitlements under the AWBZ and WMO are determined. Indexing and re-indexing are therefore extremely important for clients, but we do not discuss this process further in the context of achieving good quality integrated care. The Care Assessment Centre (CIZ) (in the context of AWBZ) and the municipalities (in the context of WMO) make the running in this case; care providers have no influence over this.

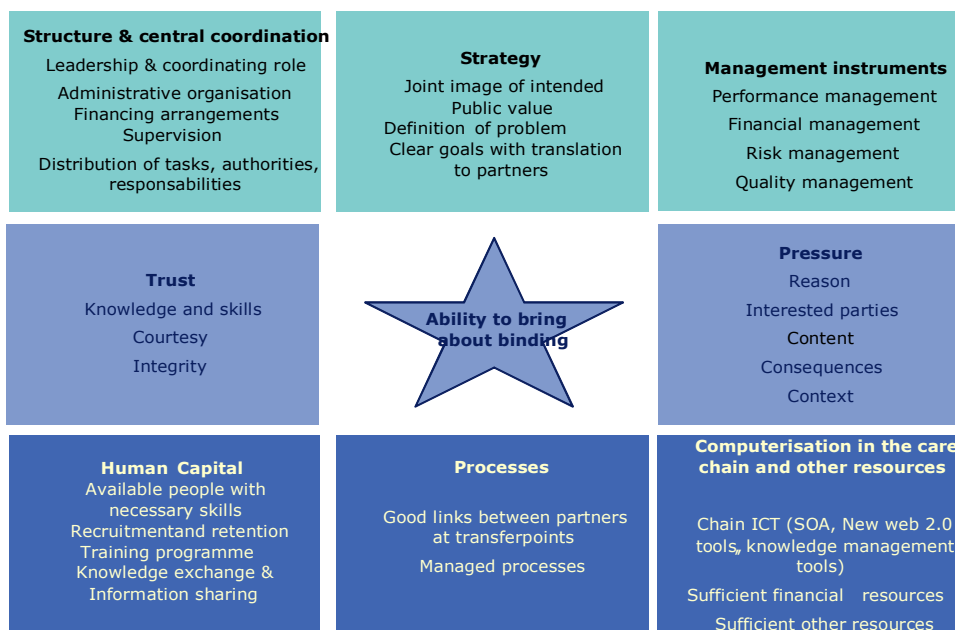
4.2.2 Criteria for good management of integrated care

During the initial phase of the integrated care programme the partners in the care chain in the spearhead regions consult each other with regard to the shape and organisation of the care chain. A structured shape for the care chain is often still being looked for. In order to ensure that the care efforts being delivered by different care providers form a cohesive whole whilst still keeping the client process at central stage, a series of criteria for effective management of integrated care has been drawn up.

Integrated care for dementia is a cohesive network, and characteristic of this type of network of care providers is that proper coordination and exchange of information take place. Thus the network needs to ensure that the integrated care meets a number of criteria.

The criteria listed in Figure 2 are explained in more detail in the following section.

Figure 2: Criteria for effective integrated care management (source: Paul-Jan Linker, Deloitte Consulting: Rules for integrated care, held during the spearhead meeting on 10 September 2008)



Deloitte.

- Structure and central coordination:**
 Structure and central coordination relate to the shaping of an organisational structure for the integrated care chain in which tasks and responsibilities are established structurally and anchored administratively between the partners in the care chain. The lack of a clear chain structure and coordinating function impedes the effectiveness of the care chain.
- Strategy:**
 The partners in the care chain must together identify the gaps in the region (problem definition) and establish both short- and long-term objectives (2012). In addition, the objectives need to be translated into concrete agreements between care providers on aspects such as the range of care services to be delivered.
- Management instruments:**
 Instruments for monitoring the execution, success, deployment of resources and risks of the plans in the region are extremely important for the regions. In some regions, client panels are being developed to monitor quality. Some regions also work with network indicators which can help to crystallize the plans, make them transparent and reveal their quality. The suitability of the network indicators as a management instrument is to a large extent dependent on the maturity of the integrated care network (see the report on the network indicators).

- **Trust:**
Mutual commitment and trust between partners in the care chain is an important success factor for the development of integrated care in a region. The mutual trust between the partners in the care chain can sometimes be experienced as fragile. Mutual competition, in particular, can get in the way of cooperation. This is an important point for consideration in the development of integrated dementia care.
- **Pressure:**
The exercising of pressure between partners in the care chain is a major criterion for the success of integrated dementia care. Concrete arrangements on the performance to be achieved need to be made between partners in the care chain so that all parties involved are motivated to achieve optimal results and judge each other's success. Management instruments and management information are important in this regard.
However, the integrated care chain is wider than the AWBZ alone.
As the financier of the care chain (or much of it), the care office can exert influence on the development of the care chain by imposing purchasing criteria. These criteria can affect both the content of the care and the care process. In their role as the main mouthpiece for people with dementia and their families and carers, interest groups can put pressure on care offices and providers to tie the planning in with the priorities of the client and their social environment.
- **Human capital:**
The aim of the Integrated Dementia Care programme is to arrive at a purchasing model for demand-oriented integrated care. The availability of knowledge and expertise on the purchasing process and costing is an essential part of this. It is therefore important to ensure that the project organisation is made up not only of subject experts but also of project members with administrative decision-making skills and expertise in purchasing.
- **Processes:**
Concrete arrangements and coordination between partners in the care chain in respect of care processes are a key aspect in the shaping of integrated dementia care. Processes need to be mapped out, and in doing so it is necessary to describe what the process should look like, what steps need to be taken (process diagram) and what type of administrator and/or organisation should be implementing each step. It must also be indicated how the processes are to be managed, what activities are being developed for this and who is responsible for them.

4.3 Case manager: a crucial link in the care chain

The subject of 'case management' is an important element in the cohesion of dementia care. The complexity of the problems of dementia is a consequence of the nature of the syndrome, comorbidity and social circumstances. Given that this complexity intensifies as the dementia progresses, it is advisable to allocate a central care provider to the client and their families and carers, who can act as case manager. In the National Dementia Programme consensus has now been reached that implementation of this role is crucial for good quality, integrated dementia care. The lack of cohesion and coordination that characterises dementia care will to a large extent be resolved since case management is by definition intended to bring continuity and cohesion from the client's point of view. It is also important to tackle this role right from the beginning, in other words, as soon as the diagnosis is made. The nature, content and intensity of case management will shift as the illness progresses, and not everyone with dementia will make use of, or want to make use of, a case manager throughout their illness.

4.3.1 Conditions of case management

Case management can be performed in various ways. Different terms are also used in practice: case managers, dementia consultants, care process supervisors, and so on. The term ‘case manager’ is used here. It is important to embed case management in the regional care and support structure so that the case manager can call directly on other care providers (for consultation and coordination). Based on experience in the LDP and research, case management must, according to the LDP core team (Vilans, the Dutch Institute for Healthcare Improvement (Kwaliteitsinstituut voor de Gezondheidszorg, CBO) and Alzheimer Nederland), at least meet the following three conditions:

1. Availability and deployment

The LDP expert team and professional dementia guidelines state that dementia diagnosis and support must always be linked. In practice this means that a permanent care provider should be available the moment the diagnosis is made. Naturally, the client will decide whether they wish to take up this offer (now or later). If need be, the case manager can always be called in at an earlier stage at the GP's request (at the stage when the patient feels that something is not right). The case manager's availability ceases when the patient is admitted to a residential establishment (or dies at home).

On average there will be a period of approximately six years during which the case manager will sometimes be deployed intensively, but there will also be periods during which a telephone call once every three months, for example, will suffice. Furthermore, not every person with dementia will want to make use of the services of a case manager. Research into case management projects in the Netherlands (Ligthart, 2006) shows that a case load of 50 client systems per 1 FTE case manager is considered a reasonable and realistic number.

2. Task package

Case management for dementia sufferers is more than simply an ‘administrative or referral job’, it is also about providing support and guidance for the client system. The case manager's tasks at the very least include care diagnosis, cyclic coordination (identification, arrangement, assessment and adjustment) of care and treatment, providing psychosocial system support (information, psychoeducation, family discussions, coping with grief), offering practical support (e.g. care mediation) and therapeutic treatment (cognitive and behavioural). At the request of the GP, for example, tasks such as early identification, crisis assistance and offering aftercare after admission or death can sometimes form part of the task package.

3. Job requirements

Case management is performed by professional care providers, preferably with higher professional education (HBO), who have ample experience in the care sector and who specialise in psychogeriatrics. More specifically, the job requirements are as follows:

- HBO level education with specific training in case management. The aim is to have every case managed by HBO level care providers;
- Knowledge of and experience in dementia and informal care problems (sociopsychiatric skills, intervention methods to support the client system);
- Familiarity with the various parts of the geriatric network;
- Affinity with the target group and maintaining the right balance between involvement and detachment;

- Ability to deal with conflicts of interest both in the client system and between the client system and third parties;
- Ability to develop a network in the area of work and, within it, to work with other care providers and disciplines;
- Organisational and social skills.

The educational level described above (HBO level) is the one most preferred by experts and current case management providers (Delfi survey).

4.3.2 Good examples of case management

In various regions in the Netherlands different forms of case management operate for longer or shorter periods of time. As already mentioned, the job title varies: dementia consultants, care process workers, case managers, etc. Although there are plenty of good examples to be found in the Netherlands, we present three specific examples here which meet the following criteria²:

- Case management has been operating in this region or town for at least five years;
- Case management at least meets the three conditions mentioned above (availability and deployment, task package and job requirements);
- The results of an evaluation survey by an external organisation are so positive that case management has been continued, possibly with a few adjustments;

The three examples we mention below therefore meet these three criteria, but also illustrate clearly that there is no one single blueprint for case management, since they differ in terms of implementation, organisation and financing. The case studies are:

1. Dementia consultant Tilburg
2. Case management Dementia Leiden
3. Case management DOC-team, Stichting Geriant, North Holland

You will find a description of these examples in Annex 6 [not included in this excerpt]. A summary of the requirements for good case management can be found in Annex 5, building block 4.

4.3.3 Research into the impact of case management

In virtually all the spearhead regions engaged in the development of integrated dementia care, case management is a primary focus. Despite the fact that virtually all regions have identified case management as a primary focus for achieving good quality dementia care, it is not exactly clear what impact it has. Both care providers and care administration offices have therefore expressed their desire to see research done into the impact of case management.

At the request of a number of spearhead regions, the core team responded to this by asking NIVEL and Trimbos to produce a research proposal for a national study of the impact of case management in collaboration with the interested spearhead regions. This proposal was submitted to the National

² The overviews and data presented in the annexes are drawn from the following sources:

- Casemanagement bij Dementie, Ligthart, September 2006
- Samenvatting evaluatie Dementieconsulent Tilburg, Stoop, BOZ, May 2005
- Eindrapportage Casemanagement Dementie, Ravensbergen, May 2006
- Hoofdzaken, factsheet DOC-team en casemanagement dementie, St. Geriant, November 2007

Geriatric Care Programme (Nationaal Programma Ouderenzorg, NPO) and is expected to be defined more clearly during the coming year.

The research in the spearhead regions should provide an insight into the impact of case management, particularly in respect of the burden placed on informal carers and GPs and the problems they experience. This research will also provide a picture of the success and failure factors of case management in practice, and it will investigate how the spearhead regions score in the Dementia Care Network Indicators (Netwerkindicatoren Dementiezorg), where they relate to case management. Finally, this research should give an indication of the costs versus the benefits of case management in dementia care.

If the proposal is accepted by the NPO, the research will be carried out on the basis of two assessment points with the aid of a survey among informal carers in the spearhead regions. In addition, group discussions will be held with informal carers, GPs, case managers and regional project leaders. With regard to the Dementia Care Network Indicators, the research will look at current records. To gain a clearer picture of the costs and benefits, financial information on the introduction of case management will be requested from regional project managers. Information on the uptake of care by people with dementia and their informal carers will also be obtained from care administration offices and GP registration systems. Once the research has been completed, the results will be published. This is not likely to happen before 2011.

What you can do with the information in this chapter:

To ensure good quality integrated dementia care in your region, it is important to know which facilities, activities, arrangements etc. are needed. You can use the information in this chapter to check what is available in your region in terms of integrated dementia care and what is not. You will find relevant information and good examples for each building block. This information will help you to obtain a clear picture of the state of integrated dementia care in your region.

Not included: 5. Using Quality Standards; 6. Responsibilities (care provider, care office, Alzheimer Nederland, municipalities; 7. The Purchasing Process in the AWBZ; 8. Long term prospects

9 Annexes: Additional information and good examples

Not included: Annexes 1. Number of people with dementia compared to the entire population; 2. The 57 LDP-regions;

Annex 3: A brief description of the LDP's fourteen problem areas

1. Feeling that something is not right

In the early stages of the illness, the patient, their family or, for example, their neighbours will often experience a feeling of unease or confusion. They might suspect they have dementia, or they may even be sceptical, but that feeling will be vague. The patient will behave differently, they may feel depressed or they may in fact display excessively upbeat behaviour.

2. What is happening and what can be done to help?

Once dementia has been diagnosed, the pieces of the puzzle fall into place. However, patients and their families often have no idea how they are going to cope with the day-to-day problems that will arise. What is more, the diagnosis is often very distressing and can be coupled with a depressing feeling of worthlessness. Not only in relation to the diagnosis, but also throughout the whole of the illness process, clients and their informal carers will ask: what is happening and what can be done? Who can I turn to with questions or for help?

3. Frightened, angry and confused

People with dementia can suffer from a wide range of behavioural and mood problems. These may be caused by the dementia itself or, for example, by the way in which those close to the client handle the illness. Examples include recalcitrance, anger, mistrust, apathy or loss of inhibitory control. Whether the behaviour is a problem varies and depends very much on the informal carer's ability to cope. To find an appropriate solution, insight is needed into the causes of the behavioural and mood problems.

4. Managing on your own

Having to manage on one's own is a problem for both the client and the informal carer. This problem area relates to practical activities such as driving, managing money, cleaning and gardening. The client is no longer able to perform these tasks and needs someone to do them for them. Managing on one's own becomes a problem as dementia increases.

5. Avoiding contact

The client becomes increasingly focused on the world immediately around them. The people in their social environment do not understand this, and contact with other people becomes difficult. The client no longer goes out and nobody comes to visit any more. The client recognises fewer and fewer people.

The partner is house-bound, which causes social isolation. Children living away from home see the situation differently, which can result in tension between the partner and the children.

6. Physical care

Problems with physical care such as dressing, washing, feeding themselves and handling incontinence. If the home care provider is not present, it is up to the informal carer to shoulder this burden. This can put them under physical and psychological stress. Failure on the part of the patient to acknowledge the problem can cause extreme stress for the informal carer. The patient's home may not always be suitable for delivering the appropriate care: it may be remote, there may be too many stairs, or too little space on the ground floor.

7. Dangers

Clients are forgetful and no longer know how to perform certain tasks. In this case, staying at home without supervision is dangerous (fire, gas, short circuiting). In addition, clients who are on their own at home are

vulnerable. They are generally less stable on their legs and are at greater risk of falling and suffering accidents in the home, particularly if they are restless. Those around them are concerned about aspects such as the house not being kept clean, neglect or absence of the patient, or unsafe situations involving fire or gas.

8. Health problems as well

Besides the dementia, the patient may suffer from chronic or acute health problems which are difficult to treat. Because of the dementia, the client has little understanding of their illness and forgets to take pills or follow treatment advice. On the other hand, the client may be excessively agitated or confused by conditions such as a bladder infection or toothache and is unable to communicate the physical symptoms.

9. Loss

As a result of physical and mental deterioration, the patient loses their sense of self and becomes increasingly dependent on their carers. Informal carers feel that they have lost their original partner and that the illness has turned them into a different person. The expectations and outlook for the future of the relationship and their own lives change radically. Letting go is a process of mourning that is extremely emotional.

10. It's all getting too much for me

The grief surrounding the client's illness combined with the need to organise care is severe. The informal carer has to be available 24 hours a day. This has an adverse effect on the informal carer's ability to take care of themselves, and these problems can lead to exhaustion.

11. Forfeiting and losing control

Informal carers and clients feel patronised by professional care providers. They see their privacy and authority being eroded and do not accept that, or they find that they are not involved sufficiently in the care. Informal carers or clients find it difficult to talk about this problem with the professional care providers because they are dependent on the help they provide.

12. In good and bad times

Informal carers and their families or carers feel under an obligation to care for their partner or parent with dementia because the partner or parent would have done the same for them, or has already done so. Often it is those around the patient who expect them to provide this care. If it turns out that it is not easy or impossible to fulfil this obligation, they are faced with a moral dilemma. They feel guilty about handing over the care to someone else or admitting the patient to an institution.

13. Breakdown in communication with professional care providers

Patients and those around them feel that professional care providers do not take the trouble to gain a true understanding of their experiences and problems. There may also be misunderstandings in communication for language and/or cultural reasons. Clients and informal carers also complain that professional care providers are reluctant to refer them on to other sources of help or cooperate with them to resolve their problems.

14. Resistance to admission

A major fear on the part of clients themselves and their informal carers is the possibility that they may have to be admitted into a nursing or care home. Resistance may continue after they have been admitted to the home.

Annex 4: Most common problems experienced by informal carers when caring for their loved ones with dementia

<i>Yes/do have a problem</i>	<i>Living at home N=631 (%)</i>	<i>Care institution N=299 (%)</i>	<i>Total N=984 (%)</i>
Has difficulty dealing with changes in loved one's behaviour	80%	72%	77%
Caring for loved one is often too emotionally demanding*	58%	47%	54%
Is apprehensive about loved one being admitted to care institution*	71%	17%	52%
Is concerned about unsafe situations occurring in or around the house as a result of loved one's behaviour*	60%	20%	48%
Does not get satisfactory information about the progress of dementia*	44%	56%	47%
Does not get satisfactory information about dementia and the symptoms that accompany it*	41%	51%	43%
Finds it distressing to have to make decisions for loved one	42%	36%	40%
Onset of health problems because loved one finds it difficult to communicate physical ailments	37%	42%	38%
Finds it difficult to handle the distress of seeing loved one deteriorate	39%	35%	37%
Less social contact with friends and acquaintances in clubs because of loved one's illness	27%	23%	37%
Has the feeling that they are having to cope on their own*	40%	30%	36%
Feels lonely	37%	32%	34%

*Differences between the scores for 'living at home' and 'care institution' are statistically significant ($p < 0.05$)

Annex 5: Development of facilities for people with dementia and their families

17 Building blocks for the regional dementia care chain

The building blocks follow the process of the patient with dementia. The process has three phases:

1. the phase before the diagnosis;
2. the phase during and directly after the diagnosis;
3. the overt phase.

The most important facilities in each phase are described. For each building block we describe (1) the state of the art, (2) any relevant instruments, guidelines or good examples [not included in this excerpt], and (3) a rough indication of the desired scope.

List of the 17 building blocks categorised by phase

<p><i>Phase 1: Care offer before the diagnosis:</i></p> <p>Building blocks:</p> <ol style="list-style-type: none">1. Information, advice and support2. Identification and active referral
<p><i>Phase 2: Care offer during and directly after the diagnosis:</i></p> <p>Building blocks:</p> <ol style="list-style-type: none">3. Screening and diagnostic examination4. Process support/case management5. Dealing with patient system6. Low-threshold information and support for patient system after diagnosis
<p><i>Phase 3: Care offer in the overt phase:</i></p> <p>Building blocks:</p> <ol style="list-style-type: none">7. Process support/case management8. Dealing with the patient system9. Information and support for patient system10. Help with ADL and domestic care11. Transport/participation12. Services in and around the house13. Activities for patients14. Respite care/temporary stays to allow the informal carer to take a break at night, weekends, holidays15. Holiday for people with dementia, with or without partner16. A different way of living17. Crisis assistance

Phase 1: Care offer before the diagnosis (LDP problem area 1: feeling that something is not right)

Building block 1. Information, advice and support specifically for dementia

Important elements:

- Campaign aimed at acknowledging dementia and reducing taboos
- Printed information with folders on dementia at all social and healthcare organisations
- Telephone help desk available 24 hours a day
- Low-threshold information, psychoeducation and peer support about dementia
- Embedding in general information and advice
- Information centre/municipal service point
- Public information in articles, on website and coverage in regional media

State of the art:

- Alzheimer Nederland has been running a campaign aimed at acknowledging dementia and reducing taboos ever since its establishment. Alzheimer Nederland has offered nine LDP regions materials and resources for a regional campaign with financial support from healthcare insurers Menzis and Agis.
- Printed information with folders about dementia. A start has been made on providing information about the regional care offer and about the illness on paper and digitally in 21 LDP regions. A regional website has gone live in six regions (see examples of LDP projects). Alzheimer Nederland offers an extensive range of folders that can be ordered free of charge from Alzheimer Nederland, are available from the Alzheimer cafés during café evenings and can be downloaded via the website.
- Alzheimer Telefoon is available 24 hours a day and is manned by volunteers. It receives about 2500 calls per year.
- 168 Alzheimer cafés offering a combination of low-threshold information, psychoeducation, peer support and advice to visitors are open 10 to 12 times a year. Participation is free of charge and anyone can attend. Opening hours, programmes and addresses are available on the Alzheimer Nederland website and in free local newspapers. Innovative LDP projects such as memory surgeries, memory bus, memory shops and memory support points have been launched. Memory support points are open at set times for queries specifically on memory and dementia. The support points are manned by professionals or volunteers with specific knowledge about dementia. They are free of charge.
- WMO service points or MEE service points. These service points provide low-threshold help for many different groups of people with general requests for help. Once a dementia problem has been identified, early referral to professionals with specific expertise is important.
- Living with dementia and the importance of early diagnosis are receiving increased media coverage, not only as a result of campaigns by Alzheimer Nederland. Increasing numbers of care providers and healthcare insurers have their own magazines and websites in which information is provided about dementia.

Estimate of the target group size:

The target group is large: in fact it includes anyone who is concerned about their own memory and changing behaviour or that of a loved one. The SCP puts the number of potential carers of 65- to 95-year-olds at 3.7. These will mainly be their children, neighbours or other family members. A rough estimate of the size of the target group which needs to be provided with general and specific information is twice the incidence, i.e. there will be twice as many people with concerns. This figure must include both actual and potential dementia sufferers and their potential carers. For a region with 200,000 inhabitants, this means that the target group to be reached will consist of approximately 4000 people (see incidence figures in section 2).

<p>Building block 2. Identification and active referral</p>
<p>Important facilities:</p> <ul style="list-style-type: none"> - Preventative home visits by volunteers or professional consultants of the elderly - Identification and referral by professional care providers with whom the person already has a relationship - Consultation bureau for the elderly - Identification by GP during regular consultation - Case-finding by case manager, consultant of the elderly, district nurse, GP
<p>State of the art:</p> <ul style="list-style-type: none"> - Preventative home visit: it is not known in which or in how many municipalities in the Netherlands preventative home visits take place. - Consultation bureau for the elderly: consultation bureaux offering medical examinations, sickness prevention and health advice for elderly people are available in various places in the Netherlands. A list of the consultation bureaux for elderly people in the Netherlands can be found at www.kennniscentrum-ouderen.nl. This is a new facility. Its effectiveness has not yet been assessed. - Identification by GPs and other primary care providers. GPs are increasingly making more in-depth diagnoses when patients present with problems or when there are indications of cognitive impairments (such as forgetfulness, slowing down, poor comprehension), but also in case of general deterioration in functions and mood changes. 80-90% of elderly people visit their GPs at least once a year; identification by GPs takes place using the OLD (observation list for early symptoms of dementia) developed specifically for this purpose. There is absolutely no evidence of any added benefit of annual screening. - Case-finding: this takes place at the client's home and involves practical solutions for problems organised by a case manager, a consultant for the elderly, a district home care nurse or a GP. - Among the tasks performed by these professional care providers are identification of dementia and of stress in informal carers. There are also some other specific facilities; see Relevant Instruments and Guidelines.
<p>Estimate of the target group size:</p> <p>The size of the target group for identification and case-finding is determined by the difference between the expected and known prevalence of dementia. The bigger the difference, the greater the efforts there will need to be in a region to identify unknown people with dementia.</p>

Phase 2: Care offer during and directly after the diagnosis

<p>Building block 3: Screening and diagnostic examination</p>
<p>Important elements:</p> <ul style="list-style-type: none"> - GP - Mental health services for elderly people/diagnostic centre/memory clinic - Geriatric department - Process support/case management
<p>State of the art:</p> <ul style="list-style-type: none"> - In accordance with the guidelines, the GP can perform the diagnosis himself, possibly with the assistance of a nurse practitioner. The GP can also refer the patient on for diagnosis. If dementia is suspected, the first step is to perform an orientation test using the observation list for early symptoms of dementia (OLD) or the Standardised Mini Mental State Examination (S-MMSE). - The following general conditions are crucial for the proper implementation of GP policy: <ul style="list-style-type: none"> ○ The GP must be aware of signals that may point to dementia. ○ The GP can perform the diagnosis of dementia himself or refer the patient to a specialist. ○ The diagnosis of dementia is geared towards establishing memory impairments, other cognitive impairments and reduced ability to perform daily tasks. ○ If dementia is diagnosed, the GP provides advice and information; medical treatment plays a very

- minor role in dementia.
 - The GP discusses the patient's care aspects and the ability of the carers to cope.
 - Behavioural impairments in dementia require additional attention because of the severe strain they put on the carers.
 - Support for the patient with dementia requires coordination and collaboration with different disciplines.
 - The GP monitors the informal carers for signs of stress and communicates this to the case manager.
- What happens in practice differs from what is laid down in the guidelines. GPs see a limited number of new people with dementia every year. In a district with a large ageing population, a GP may see three new people with dementia a year at most. In an average district a GP will have 21 people with dementia living at home on his books. People with symptoms and their families have high expectations of their GP and often feel disappointed with the speed with which the diagnosis is made, referrals are organised and advice is provided (this was also revealed in the LDP client consultation).
 - The Dutch College of General Practitioners (Nederlands Huisartsengenootschap, NHG), Alzheimer Nederland and the Nijmegen Alzheimer's Centre have developed training courses on dementia for GPs and their nurse practitioners which are being actively offered in LDP regions. The first (roughly 80) GPs and medical assistants have completed the EASYcare course. In March 2007 the NHG also introduced a two-year NHG management training course in geriatrics for GPs who wish to focus on care for the elderly.
 - There are currently about 75 memory clinics which perform diagnosis for memory complaints in the Netherlands. These healthcare centres have developed a series of quality criteria. A list of all clinics can be found at www.geheugenpoli.com. The LDP panels have revealed that post-diagnosis support for the patient and their families is not organised everywhere, even though this follow-up is part of the actual quality indicators.
 - For more complex co-morbidity, a referral to one of the 57 geriatric departments or clinical geriatricians in the Netherlands will be necessary. There is a problem insofar as the approach, physical environment and knowledge of dementia in other departments in many hospitals do not meet the needs of people with dementia.

Rough estimate of size:

The size of the target group for diagnosis will be bigger than the incidence of dementia in a region. In fact it includes anyone who is concerned about their own memory and behaviour. For a region with 200,000 inhabitants, this means that the size of the target group for diagnosis will be at least 850 people. These figures depend very much on the structure of the population. In areas with a rapidly ageing population, the incidence will be much higher than in 'young' areas.

Building block 4: Process support/case management

Organisation

- Case management is embedded in the regional care and support structure so that the case manager can call directly on other professional care providers.
- The case manager is independent and where necessary can arrange care outside of the interagency collaboration.
- The case manager is generally assigned permanently to the client.

Availability

- The case manager is available for the client and their family from the time of the dementia diagnosis to the client's death or admission to a care home.
- There is an arrangement for case management availability in acute situations.

Tasks/knowledge

- Care diagnosis.
- Cyclic coordination (identification, arrangement, assessment and adjustment) of care and treatment.
- Provision of psychosocial system support (information, psychoeducation, family therapy, grief management).
- Offering practical support (e.g. care mediation).
- Therapeutic treatment, both cognitive and behavioural.
- Case managers have an in-depth knowledge of the problems of dementia and informal care and of the

social services map.

Rough estimate of size:

- One case manager for every person with dementia

Building block 5: Dealing with the patient system

Important elements:

- GP services
- Specialist medical help
- Case management
- Deployability of multidisciplinary team
- KOP group

State of the art:

- GP and medical specialist prescribe medication that slows down the progress of the illness and medication for behavioural problems.
- Case management (see Part 2, Chapter 2 of this guideline): the case manager is not a clinician themselves but can play a key role in early identification of problems and coordinating the help.
- Deployability of multidisciplinary team. Deployment of a multidisciplinary team is possible in a number of LDP regions (see LDP practical examples). This team is often deployed in the event of behavioural and processing problems and for comorbidity. Recent doctoral research shows that the deployment of a multidisciplinary team in the first year after diagnosis is also cost effective at the memory clinic (Wolfs, C. An integrated approach to dementia, a clinical and economic evaluation. Maastricht, 2007).
- The KOP group is a therapeutic discussion group for people with dementia, led by an experienced clinician using an established method (sometimes including exercise). There are currently 30 KOP groups in the Netherlands. Gelderse Roos, Alzheimer Nederland and ZonMw, the Netherlands organisation for health research and development, are promoting the setting up of more of these groups via workshops, a manual and a course for group leaders.

Rough estimate of size: N/A

Building block 6: Low-threshold information and support for patient system after diagnosis

Important elements:

- Case management (see Part 2, Chapter 2)
- Telephone and other support
- Dementia course
- Peer support group, discussion group for families and informal carers
- Low-threshold information, psychoeducation and peer support on dementia (e.g. Alzheimer café and meeting centres)

State of the art:

- Case manager (see Part 2, Chapter 2)
- Alzheimer Telefoon is available 24 hours a day and is manned by volunteers. It receives about 2500 calls a year. In addition, the Amersfoort region has launched the 'Telefonische coach' ([telephone coach] project in which trained care home staff provide coaching for people with dementia who live at home, and for their families, in a small number of telephone calls. The initial review of this service was positive.
- Dementia courses are run right across the country by many different institutions such as mental health institutions, home care organisations, informal care support centres, MEE (an organisation that assists disabled or chronically sick people) etc. Research (2006, Annals of Internal Medicine) into the support available solely for informal carers revealed that participants on these courses suffered much less depression, for example: one in eight compared with almost one in four in a control group. The course trains the carers

how to solve problems, teaches them skills for dealing with dementia, general coping skills and handling stress.

- Peer support group or family therapy group: Often much of the care of a person with dementia who lives at home falls on the shoulders of their immediate family: their partners and children. In the peer support group informal carers can share experiences about their situations and get information on the illness process. As the illness progresses and forgetfulness and character changes increase, it becomes increasingly difficult for the informal carer to care for the sufferer. Support with this care helps maintain care at home for longer and helps them look after their own health. The discussion group is intended to allow the people who bear direct responsibility for caring for an elderly person with dementia to share their experiences with other people. In this way they are able to support each other. Information is also provided on the illness itself, how to deal with difficult behaviour, what help is available and where to get it.
Home care institutions, welfare organisations, informal carer support centres and healthcare centres organise discussion groups for dementia sufferers' family members. The groups are generally closed, with a maximum of eight participants.
- An Alzheimer Café is a monthly event for people with dementia, partners, family members, care providers and other interested parties. After an introduction by an expert, visitors can exchange ideas, information and experiences. There are currently 168 Alzheimer Cafés.
- There are 47 meeting centres across the Netherlands and another 27 currently being set up. Evaluation studies have shown positive effects for both the patient and the informal carer.

Rough estimate of size:

- Sufficient number of volunteers for the Alzheimer Telefoon;
- Alzheimer Café: at least one 'bar manager' who has successfully completed the training course for Alzheimer Café discussion leaders. Each Alzheimer Café receives between 20 and 60 visitors per session.
- Ideally, everyone should have easy access to a meeting centre in their vicinity (see the manual for meeting centres at www.ontmoetingscentradementie.nl).

Phase 3: Care offer in the overt phase

Building block 7: Process support/case management

Organisation

- Case management is embedded in the regional care and support structure so that the case manager can call directly on other professional care providers.
- The case manager is independent and where necessary can arrange care outside of the interagency collaboration.
- The case manager is generally assigned permanently to the client.

Availability

- The case manager is available for the client and their family from the time of the dementia diagnosis to the client's death or admission to a care home.
- There is an arrangement for case management availability in acute situations.

Tasks/knowledge

- Care diagnosis.
- Cyclic coordination (identification, arrangement, assessment and adjustment) of care and treatment.
- Providing psychosocial system support (information, psychoeducation, family therapy, grief management).
- Offering practical support (e.g. care mediation).
- Therapeutic treatment, both cognitive and behavioural.
- Case managers have an in-depth knowledge of the problems of dementia and informal care and of the social services map.

Rough estimate of size:

- **One case manager for every person with dementia (caseload app. 50 persons)**

<p>Building block 8: Dealing with the patient system</p>
<p>Important elements:</p> <ul style="list-style-type: none"> - GP - Specialist medical help - Psychological help - Multidisciplinary team - Case management - Individual counselling (psychotherapy) - Occupational therapy at home - Structured family therapy
<p>State of the art:</p> <p>See treatment shortly after diagnosis. The difference between the post-diagnosis treatment and this treatment is that the content of the problem shifts. The LDP survey in 2007 revealed that emotional support for the informal carer and concrete advice on how to deal with the dementia sufferer's changes in behaviour provided by a trusted and qualified professional are needed by 75% of informal carers. In the LDP the results of this need have been translated into case management and process guidance projects (in 51 regions) and into training projects for professionals.</p> <p>Inaugural speech by Myrra Vernooij Dassen: 'half of all informal carers of people with dementia suffer from clinical depression. Only one in five obtain treatment for this condition. Support for patient and informal carer helps if the wishes of the patient and the informal carer are taken into account. Sadly, support programmes are hardly ever used', Vernooij-Dassen says (22 May 2008).</p> <p>Ten sessions of occupational therapy at home improve the self-reliance and quality of life of people with dementia and their families at home. Occupational therapy at home is in principle paid for (Graff, 2007). Self-reliance and self-confidence improve so dramatically that less help is needed. In their article the researchers conclude: 'We believe that occupational therapy reduces the need for professional care in the long term, resulting in less need for institutionalisation.' Olde Rikkert: 'If informal carers learn to train a person with dementia to do tasks such as go shopping or take their own medicine, they lose their perception that "there is nothing I can do about the dementia".'</p> <p>Research shows that psychoeducation, working on a coping strategy, group discussions, individual counselling and structured family therapy have had positive results for informal carers of people with dementia. This is help that helps.</p>
<p>Rough estimate of size:</p> <p>Research shows evidence of widespread underconsumption: uptake of existing facilities and help is low. Informal carers see a therapist too late and too infrequently about their depressive or other symptoms.</p>

<p>Building block 9: Information and support for the patient system</p>
<p>Important elements:</p> <ul style="list-style-type: none"> - Case management/process support - Peer support group, group discussions for families and informal carers <p>See also Building Block 6.</p>
<p>State of the art:</p> <p>The need for information is shifting increasingly from the patient to their informal carers and those around them. Participation in a KOP group is only appropriate at the beginning of the illness.</p> <p>See also Building Block 6.</p>
<p>Rough estimate of size:</p>

See Building Blocks 4, 6 and 7.

Building block 10: Help with ADL and domestic care
Important elements: <ul style="list-style-type: none">- Domestic care (also to relieve those around the patient)- Personal care at home- Nursing care at home
State of the art: <ul style="list-style-type: none">- Many people who provide domestic, personal and nursing care at home often have inadequate knowledge of how to deal with people with dementia (fact sheet 2, Nivel, 2007). Family members want more concrete guidance and advice about how to deal with their loved one's changing behaviour. In and around the LDP various types of training have been developed and used with a view to improving practical knowledge on how to deal with and communicate with people with dementia and their loved ones.- In 2007 the WMO made municipalities responsible for providing domestic care. The municipality determines its own assessment criteria and system, or it outsources the assessment to the CIZ. With the introduction of the WMO there has been a clear shift from HV II (help for which the professional care provider assesses the need) to HV I (help which the applicant is able to request themselves). AN is of the opinion that where there is evidence of dementia, HV II should be indicated and implemented automatically. Option to obtain the care in kind (ZIN) or arrange it oneself with a personal budget (PGB).- Personal care (PV) is a function that is paid for under the AWBZ and for which an assessment from the CIZ is needed. This function includes washing, hair care, dressing, administration of eye drops and toilet assistance. Option to obtain the care in kind (ZIN) or arrange it oneself with a personal budget (PGB).- Nursing care is a function that is paid for under the AWBZ and for which an assessment from the CIZ is needed. Tasks include: wound dressing, injections or teaching self-injection.
Rough estimate of size: <p>No research available for size of current and potential target groups.</p>

Building block 11: Transport/participation
Important elements: <ul style="list-style-type: none">- Taxi centre- Local transport service
State of the art: <ul style="list-style-type: none">- There are various transport options available which differ from one municipality to the next: a volunteer bus service, a demand-responsive taxi service, a season ticket or a senior citizens' bus service. On a national level there is a system called Regiotaxi. Regiotaxi is a type of door-to-door public transport available to everyone in the region. A public transport pass is not needed for the Regiotaxi. When someone has been assessed as requiring a transport facility under the Health Services Act (Wet Voorzieningen Gezondheidszorg, WVG) (under the WMO), they can apply for a free transport pass for the Regiotaxi. If the municipality decides that someone qualifies for travel with a companion or if the elderly person with dementia has an NS companion's card, the companion travels with them free. Supra-regional transport is provided by the Valys system. Use of this system is contingent on an assessment and entitles the person for transport and accompaniment to and from public transport facilities. A low or high PKB (Personal Kilometre Budget) is also available, which can be used for one of the taxi facilities. In some cases the care insurer reimburses taxi costs, when there are medical grounds.
Rough estimate of size: <p>No research available for size of current and potential target groups.</p>

Building block 12: Services in and around the house
<p>Important elements:</p> <ul style="list-style-type: none"> - Odd job service - Administrative support
<p>State of the art:</p> <p>Services in and around the house:</p> <ul style="list-style-type: none"> - provided by the municipality: odd job service for senior citizens (55+), meals on wheels or senior citizens' restaurant, volunteer home help (for a visit, a chat, a walk, etc.), shopping with volunteers, day centre, Steunpunt Mantelzorg (informal carers' support centre), Bezoek en Oppasservice (BOS) (volunteer home visit and sit-in service); - various services such as different aids, personal alarms etc. can also be provided via the home care service; - some companies also offer services such as home optician visits, supermarket delivery services, laundry and ironing services; - the internet can be used for a whole range of services such as booking a holiday, buying clothes, ordering books and CDs, etc.
<p>Rough estimate of size:</p> <p>No data available</p>

Building block 13: Activities for patients
<p>Important elements:</p> <ul style="list-style-type: none"> - Individual support for activities (e.g. volunteer visitor, buddy) - Day patient treatment - Day care - Day centre - Sports clubs - Senior citizens' exercise classes (Meer bewegen voor ouderen, MBVO) - Swimming for senior citizens
<p>State of the art:</p> <ul style="list-style-type: none"> - Individual support for activities There are various voluntary organisations which organise support for individual activities, such as Mezzo, Stichting Welzijn Ouderen (foundation for welfare of the elderly) and Alzheimer Nederland. These types of individual support vary from a 'buddy' to voluntary home care. There are currently about 120 volunteer home visiting services, 90 of which are voluntary home care organisations in the Netherlands with about 700 volunteers and 20 'buddies' for young people with dementia run by Alzheimer Nederland. This is not enough. The demand is greater than the supply and it is expected to increase further over the next few years. - Day patient treatment, day care and day centre. In the Netherlands the following types of day care and day treatment are available: care farms or low-threshold 'meeting centres', volunteer home visiting services, care ship, in residential care home, meeting centres. The method, approach and criteria applicable to meeting centres have been described in detail. There are no quality criteria available for psycho-geriatric day patient treatment in nursing homes. There are currently 150,000 people with dementia living at home in the Netherlands. Day patient treatment and day care are only taken up by 10% of the people with dementia who are known to GPs and who live at home. There are 3688 places for psychogeriatric day treatment in the Netherlands for about 150,000 people with dementia who live at home. This means that there are 2.5 places per 100 people with dementia who live at home. - Sports and exercise clubs Exercise is an important way of reducing the risk of or slowing down dementia. The little research available shows an improvement in the frontal part of the brain - the part that plays an important role in our ability to lead independent lives - in subjects who exercise regularly. Thus research involving middle-aged people show

that they are at significantly lower risk of developing Alzheimer's Disease if they have been physically active (Scherder, 2007).

Prof. Scherder: Every person with dementia should exercise for at least 30 minutes a day, a minimum of five times a week. This must be done with above-average physical effort (e.g. fast walking).

Rough estimate of size:

The current number of facilities has been identified. Research reveals that activities relating to patients' wishes contribute to a better quality of life (de Lange) and possible stabilisation of the deterioration (Scherder). A bigger and more varied offer is therefore desirable.

Building block 14: Respite care/temporary stays to allow the informal carer to take a break at night, weekends, holidays

Important elements:

- Buddies (see Building Block 13)
- Nursing home
- Care home
- Care hotel
- Voluntary home visiting service

State of the art:

- Nursing home/care home:

With an assessment from the CIZ, the 'temporary stay' function can be spent in a nursing or care home. This falls under the heading of 'respite care' and is designed to give the informal carer a break. There are several options for temporary stays which differ depending on the care or nursing home. It is possible to stay for a continuous period, e.g. a week, but also a shorter period such as one weekend per month or a number of nights per week. Admission is also possible if the informal carer has to undergo an operation, for example.

- Care hotel:

The first care hotels were designed for patients who were not yet able to return home after spending time in hospital. More recently, care hotels have opened which offer services to a much wider target group. These include a boarding function (e.g. during holidays) for people with dementia who are usually cared for at home by their partner. These are financed under the Healthcare Insurance Act (ZVW).

There are two types of care hotels:

those affiliated with hospitals or other care institutions (physically or at some distance);
independent care hotels not affiliated with a hospital or other care institution.

- Voluntary home visiting service:

Bezoek- en oppasservice (BOS): usually organised by Stichting Welzijn Ouderen in the municipality, financed by the WMO. A trained volunteer comes to the home so that the informal carer can go out for a short time, such as to the hairdresser, shopping, to visit a friend, or to the theatre.

Rough estimate of size:

No figures available.

<p>Building block 15: Holiday for people with dementia, with or without a partner</p>
<p>Important elements:</p> <ul style="list-style-type: none"> - Care hotel - Holidays organised by Alzheimer Nederland, the Dutch Red Cross, Stichting Mens en Samenleving, Het Vakantiebureau.
<p>State of the art:</p> <p>The name ‘care hotel’ (see Building Block 14) includes the following three variants: a care hotel connected to a hospital, a care hotel connected to a care and treatment centre, and an independent care hotel. The features of a care hotel are as follows:</p> <ul style="list-style-type: none"> - the client stays for a short time and then returns home - there are 24 hour care and services available - the hotel is service-oriented, has comfortable accommodation and is equipped with various facilities. <p>The advent of care hotels ties in with the developments in care. Clients are demanding more in terms of the quality of the residency and care. Because of a shift from residential care to extramural care people live independently at home for longer and return to their home situation more quickly after admission. Care hotels can also act as a bridge in integrated care and reinforce the links between the elements in the care chain. There are currently 45 care hotels in the Netherlands. Residencies vary from a few days to a few months.</p> <p>Toch Uit is a holiday programme run by Alzheimer Nederland which organises holidays for people with dementia and their partners. A holiday with Toch Uit combines relaxation with information, tips and personal advice. An impact analysis of Toch Uit holiday weeks delivered the following results:</p> <p>42% of patients experienced Toch Uit as a relaxing week’s holiday; 77% of carers went along for some relaxation themselves, 73% were accompanying the patient, and 65% went along so that they could ask the in-house expert questions.</p> <p>Participation in Toch Uit had no specific consequences for 72% of the patients, while 71% of the carers felt better after a week’s holiday.</p>
<p>Rough estimate of size:</p> <p>No figures available.</p>

<p>Building block 16: A different way of living</p>
<p>Important elements:</p> <ul style="list-style-type: none"> - Adapted living - Physical adaptation of the house - Domotics - Sheltered housing in a small-scale form of accommodation - Admission into a nursing or care home
<p>State of the art:</p> <p>The housing service zone and cluster housing for people with dementia are examples of adapted living. Home adaptations are not often used for people with dementia. But there are examples of housing adaptation per housing complex and adaptations and Woningplus adapted housing projects.</p> <p>More and more care institutions and housing corporations are using domotics. Domotics are electronic applications in the home that enable people to remain independent in their homes for longer. For dementia sufferers, these are mainly applications in small-scale group homes and for people who live at home with a partner. The aim is to improve the quality of the residents’ lives and support the care personnel or informal carers, rather than to enable people to live at home for longer. This is not insignificant to the 70% of people with dementia who live at home. Examples that help to increase safety: magnetic locks, socket protectors, oven button protectors, smart hob burners, thermostatically controlled taps. Examples of remote supervision: a</p>

combination of sensors and cameras. Examples of identification and detection: GPS and GSM equipment, movement sensors, magnetic contacts on the front door. The suitability for and effects on dementia sufferers are currently being assessed

Small-scale care can be delivered in various ways: as an independent district facility, as a facility alongside a care organisation or as clustered group accommodation in a large-scale facility. Of the total range of facilities offering 24-hour care for dementia sufferers in 2008, only 12% were organised on a small scale.

A safe, recognisable and homely environment is not only created by residents playing an active role in domestic activities. It also comes about as a result of the look, smell and atmosphere that are created, and is therefore important for people in all stages of dementia. Alzheimer Nederland therefore emphatically regards small scale accommodation not as an interim facility but as a fully-fledged alternative to residential care. Regrettably, among the 12% of nursing home facilities organised as small-scale accommodation are some at which people with dementia are unable to stay for the rest of their lives. They have to move house again at some stage.

Admission into a nursing or care home

The 2007 LDP survey revealed that there is fierce opposition to admission into a residential home among families. LDP problem area 13, Miscommunication, was also rated as one of the most urgent improvement priorities in the LDP. The informal carers' main desires are to see qualified staff, individual and systematic attention to the patient and the family that meets their wishes and requirements, and effective, respectful communication.

The weak points in nursing home care are already known, however. The sector and the inspectorate are working on improving the quality of the care they offer by way of the standards for responsible care.

Rough estimate of size:

Alzheimer Nederland is of the opinion that at least 50% of nursing home capacity should be small-scale by 2010. An important point for consideration is the fact that not all small-scale forms of accommodation are suitable for people with dementia until the end of their illness. Moving house means additional upheaval and stress and is therefore undesirable.

Building block 17: Crisis assistance

Important elements:

- Crisis support by case manager/process supervisor
- Crisis admission into a separate unit or in the nursing home as an undesirable but necessary element.

State of the art:

In many regions crisis arrangements may be acceptable on paper, but suffer major problems in practice. Family members complain about a lack of crisis support at home and that crisis admission is not available, or only at a distant location. Process supervisors in the LDP note that crises can be eliminated or postponed through better support for the patient and their family, but that crisis admissions are still necessary. Process supervision 'can also help you see the crisis coming'.

Rough estimate of size:

The nursing home fees include a payment for crisis beds.