

Quality of life

Using the arts to help people living with and affected by dementia



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Forward

Current Strategies for Dementia

Dementia is a major world-wide public health issue. Globally, there are currently 36 million people with dementia, with over 6 million of those living in Europe.¹ In the EU one in every 20 people over the age of 65 has Alzheimer's disease, the most common form of dementia.² It currently costs approximately €130 billion per annum to care for people with dementia across Europe.³

In most European countries the number of people with Dementia being cared for at home is greater than those being cared for in residential homes or hospitals. Many individuals with Dementia are cared for by a wife, husband, son, daughter or other relative who may have given up paid employment to care for their loved one.²

A European-wide strategy aimed at tackling the challenge of neurodegenerative diseases such as Alzheimer's disease launched in February 2012.

The goals of the European strategy are:

- to develop new treatments and preventive strategies;
- to improve health and social care approaches;
- To raise awareness and de-stigmatise Alzheimer's and other neurodegenerative disorders;

- to alleviate the economic and social burden of these diseases.

The EU Joint Programme in Neurodegenerative Disease Research (JPND) is working to implement these goals through:

- building capacity in excellent basic, clinical and healthcare/social research;

- translating research evidence into clinical, social and public health practice;
- co-ordinating and aligning European and national research activities;
- partnering with industry, patient, carer and health service stakeholders, and decision makers.⁴

Working groups are already classifying priorities and it is expected that the first implementation of the initiatives will emerge during 2012.

On a national basis, many European countries have set up their own National Dementia Plan (Table 1), whilst others have identified a need to develop such a plan (such as Belgium, Cyprus, Czech Republic, Finland, Ireland, Malta, Northern Ireland, Portugal, and Switzerland).⁵

Currently the following European countries have a dementia plan in place:

Country	National Plan	Date of Plan
Denmark	Danish National Plan "National Handlingsplan for demensindsatsen"	2010-2013
France	France Alzheimer Plan	2008-2013
Netherlands	Dementia Care Plan	2008
Norway	Demensplanen 2015 "Den gode dagen"	2007-2015
UK (England)	Living well with Dementia: A national Dementia Strategy	2009-2014
UK (Scotland)	Scotland's National Dementia Strategy	2010
UK (Wales)	Dementia Vision for Wales	2011

Table 1⁵

Arts-Based Interventions

It is increasingly being recognised that using non-pharmalogical treatments such as creative arts activities in conjunction with a medical approach can benefit people with Dementia. Across Europe a variety of arts-based interventions are in place including (amongst others):

- Music
- Dance
- Drama
- Storytelling
- Art
- Photography
- Creative Writing
- Live Poetry Reading

Creative arts activities can help a person with dementia to express themselves through non-verbal means. Participation in group creative activities can improve the quality of life of people with Dementia by improving cognitive and verbal skills, social interaction and decreasing behavioural problems. Arts-based interventions should be fun and enjoyable, therefore boosting emotional wellbeing and self-esteem for the participants.

The arts activities need to be of a high-quality and should always be person-centred to allow the activity to be tailored to suit each individual's needs and abilities. There is a need for the creative arts to be more widely available to people with Dementia across Europe and for funding to be secured for such activities to take place on a regular basis. There also needs to be further research into the benefits of the arts for people with Dementia, and for a European Arts and Health 'umbrella organisation' to enable artists to share best practice and to receive training for using the arts to benefit those with Dementia.

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from art to craft

*The pilot project of The Netherlands
Marjolein Baars, Pauline Gerner and Carla Frayman*



Through art and creativity to creative skills

'From Art to Craft', the Dutch contribution (pilot) to the international project Quality of Life, pathways to family learning, consists of a training project from De Stichting Koffer, for staff (careworkers, occupational therapists, team leaders etc), volunteers and family members (partners, siblings, children) of people with dementia who live in a care home.

The project took place on two locations: ASVZ, location Vincentius in Udenhout, a mental health facility, from June 22nd 2010 to January 18th 2011, with staff and family members and Lauwershof (Magentazorg), a nursing home in Oudorp, in a unit for elderly people with dementia, daycare and small scale living units, from October 4th 2010 to April 18th 2011, with staff members and volunteers.

De Stichting Koffer

Since 2005 DSK (The Suitcase Foundation) has developed both socially and creatively innovative and practical training projects in health care. The Artistic board consists of: Marjolein Baars (performer, coach, projects - art & society), Carla Frayman (coach - creative processes and social hygiene, adviser, professional care body) and Pauline Gerner (art therapist, trainer/coach and clown for people with dementia). Beside their own specific individual qualities they are also artist and human development counselors. In the past years they have built up considerable expertise in the field of wellbeing of people with dementia.

The training From Art to Craft is a next step in the development and fine tuning of the approach and elaborates on previous projects. (www.destichtingkoffer.nl)

Central in the contact with people with dementia is listening to and moving along with them in the moment; and to develop flexibility in

dealing with changing mood and behavior. The emphasis here is not on a cognitive and strongly verbal oriented approach ("do you remember?" and "did you enjoy it?" are examples we encounter very often), but to create an (empty) space in which a new experience can take shape, in which memories (exact, changed, partial, colored or formed in the moment) can arise and play a part in the moment. The trap here is the tendency to discover and develop a new form, the challenge lies in creating the experience every time anew.

The different art forms (physical, visual, dramatic, musical) we use in the training contribute in their own way to this challenge. They give different entrances/pathways in making the contact. To an extent they form the material you have at your disposal, the luggage you take with you in your 'suitcase' and can be used in a form that suits the contact and activity between care worker, family member and /or volunteer with the person with dementia.

Goal: in this specific project the artists of DSK do not work directly with the clients/residents, they offer a program in which staff, family members and/or volunteers learn tools to find new ways of communicating with people with dementia by **doing creative activities**.

To make and maintain contact, to have enjoyment together (again) and most of all, to have a shared experience by being active together. It enhances the quality of life for all involved.

When a person or the relationship between people changes, there is a tendency to cling to "the old". One tries to prevent the inevitable but necessary **chaos**, and when it surfaces one wants to bring it back to a familiar order. If the chaos could be accepted as material to work with, one would open up to the given uncertainty and deal with the fact that you don't know what will happen in advance. We exchange a familiar way of interacting with one another for a not yet known one.

DSK works with artists because they are pre-eminently capable to work with and in chaos. They are able to create something new out of chaos by "persevering" and "moving along". This insight and experience provides a new perspective on the situation and can be a new starting point for joint activities. The ability of the artist lies in guiding others through the chaos towards new possibilities.

Our door to inspiration is **creativity**, in all its manifestations of physical, visual, dramatic and musical arts. We address the creativity in each individual (participants as well as clients) and use the principles of the creative process to enliven the activity and the project as a whole.

The **starting point** in the training is to work from individual qualities and talents of all participants. We train the skills of observation, with the result that new connections can be made

and a new awareness and behavior grows. We work with "what is," in matter, time and space on an individual level. We work with reality and fantasy and the interface between these two worlds, with the unknown, the chaos and uncertainty, and focus on what is possible.

The **methodology** DSK uses is experience-based-learning, to take responsibility for your own learning process, to share observations and insights, and to implement them in your practice. To become active (again), to discover and actively use your own talents and qualities, and to respect and address those of others. To assemble all you have learned and experienced and make the results available for others; Therefore having genuine ownership.

It has been interesting and instructive to work in two different locations with two different target groups. Both the people with dementia and the environment have similarities, but also remarkable differences.

People with a mental health disorder are getting older, due to improved medical care and knowledge, and are now confronted with dementia as well. This is a relatively new phenomenon in this target group. The clients have been living most of their lives in the psychiatric unit. The staff members have been working in the same ward for many years and have a strong personal relationship with the clients. Compared to staff members in care homes for the elderly these staff members are more focused on improving skills of the client and practical solutions, their educational level is often higher. The process of the dementia of the clients develops fast, they are relatively young and it seems harder for staff members to let go of everything that has been built up over the years. It is a process of mourning that has similarities with losing a family member. In this target group the family members are

"What do you experience when interacting with people with dementia?"

sometimes the parents, but mostly siblings. For elderly people with dementia the process and change in behavior is over a longer period of time. Family members are mostly partners and/or children and their spouses. There is a different energy in the work environment, the staff members have less long-lasting relationships with the residents and the emphasis is on physical care. Because of all budget cuts over the last decade the level of education of the staff in care homes for the elderly is lower, and the volunteers play an indispensable role in the day to day care. Most care homes are in transition to small scale living units (with living rooms for 6 residents and 1 staff member). This means that care workers are expected to take care not only of the physical wellbeing of the residents, but also of their mental and emotional wellbeing, for which they have not been trained.

Structure of the project

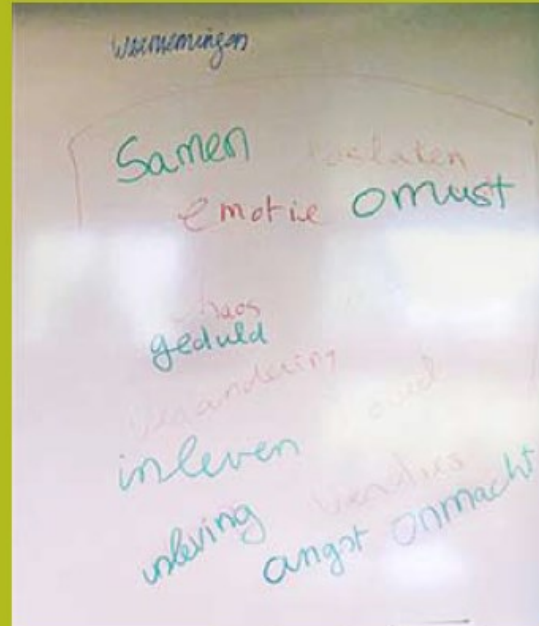
From Art to Craft consists of 20 meetings of

2-3 hours. The program starts with the "kick off", where the participants meet one another and get a taste of the program through doing and experiencing very short examples of the different aspects. At the end of this first meeting everybody receives a suitcase (koffer), in which they find a workbook and materials to work with during the first weeks (massage oil for example). The content of the suitcase will grow during the course of the project, both by contributions of De Stichting Koffer and the participants.

In the second meeting the "field" (the context in which we will research and work) is established. The central question here is: *"what do you experience when interacting with people with dementia?"*

The participants find their answers first through creating (collage for instance), using different materials (rather than thinking about

The suitcase (Koffer) grew throughout the project



the answer), and second, by writing down their observations, sharing them and finding words that express how they feel.

Subsequently everybody creates a personal **learning question** (what do I want to learn in this training?) and a **learning goal** (what do I want to have achieved in the end?). These are written down and signed (commitment).

The next step, in four units of three meetings each, is getting acquainted with the **physical, visual, dramatic and musical arts**. Exploring "the material," emphasising at first to practice and experience it for themselves. This is followed by applying what they have discovered in the working environment. On their own or with a colleague, they facilitate a creative activity with one or a group of clients. After which the participants receive feedback from one of the trainers. In the third meeting there is an opportunity to work with questions arisen from their work and to investigate and refine the subject further.

Physical arts: touching, making contact and staying in contact, to follow your impulse

Participants exploring the physical arts



(indicated by the physical reaction of the client). Massaging and bathing hand and feet, information about the skeleton, nerve, muscle, and lymphatic systems, sensations such as warm and cold (both physical, psychological and social). By practicing on each other, the individual differences are experienced and therefore it is made possible to facilitate for another person to feel comfortable.

Visual arts: Using different materials and techniques (drawing, painting, making collages etc) exploring the impact of a blank piece of paper, complementing each other's work, letting go of the meaning (mind shift) and to work in different dimensions. Old limitations (I can't draw, I'm not creative, I don't like pottering, it is childish) are recurring hindrances.

Participants working with different arts materials and techniques

In St. Vincentius this obstacle was broadly evident, since working with visual arts is no longer within reach for most clients. The emphasis there was on perceiving different materials, hard and soft, warm and cold, rough and smooth.

During the **handbook-meeting** the "field" is formulated anew ("what do you experience when interacting with people with dementia?"). When compared to the first description of the field, the steps in development become visible. A start is made with naming each other's individual talents and qualities and how you can make use of them.

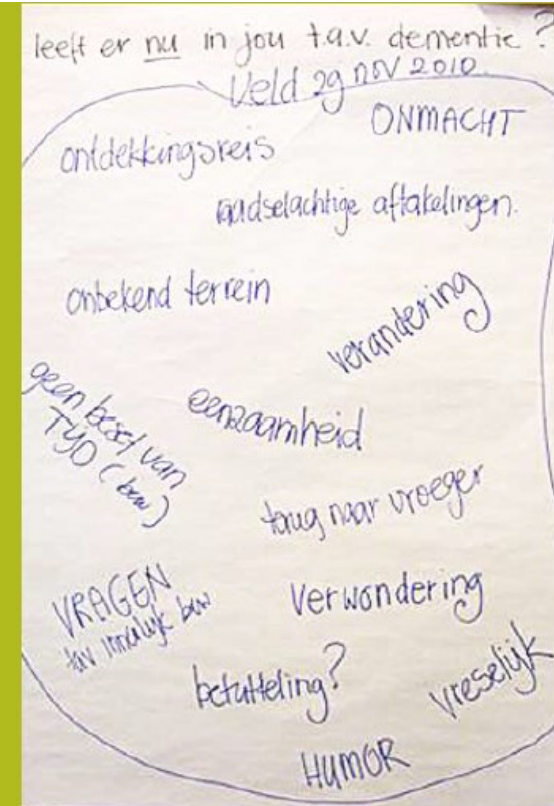


Dramatic arts: moving in synchronization with the person with dementia and the situation (all emotions are welcome, they are not judged as good or bad), to develop flexibility in dealing with the change in mood and behavior. To play and improvise with role, personality and attributes, to tell and write stories. Using fantasy and reality in such a way that the clients/residents can create a new experience (or experience a new creation) out of the contact during that specific moment and in that specific situation.

Musical arts: listening, to the other person, the sounds of the moment, the joint silence. To create "music" by experimenting with rhythm, sound, pace, volume, lyrics, melody and atmosphere. Using music as a language and a joint activity, singing questions and answers, clapping, humming and whistling. To explore your voice as an instrument, to introduce an instrument you can play to make contact and create new events.

"The word activity gets a new, broader meaning; it can happen out of the blue; it doesn't have to last long; it can be done during care; it gives yourself a good feeling too; according to my colleagues we have now the liveliest living room of the unit; I know how I can involve the residents now, let them do what they still can, small things." These are all discoveries made by daring to step in and be active.

The training ends with three meetings. **Insights and obstacles:** looking back on the learning questions and learning goals. Has your learning question been answered and your learning goal been achieved? Which actions did you take to go from question to goal, which obstacles did you encounter and how did you deal with them? The answers in both groups have been positive for everyone, some describe they are still on the way, but (sometimes to their own surprise), a lot has happened and been transformed.



Insights and obstacles

Recognise each other's talents and qualities as well as how best to use them



>
 ASVZ Field 1
 22.6.2010
 >>
 ASVZ Field 2
 28.9.2010
 >>>
 ASVZ Field 3
 30.11.2010

together letting go
 emotion agitation
 chaos
 patience change
 love so much
 empathize loss
 fear impotence
 empathy

take time tranquility
 contact-connection
 response rapid process
 creative thinking
 the meaning we give individual
 start all over everywhere
 adapt to client more with less
 doing nothing can be doing
 something(uncomfortable;
 behave out of the box)
 letting go being there
 I want to make quality of life
 making good observations
 way of rapprochement enjoy
 "short moments"
 client gives the pace

now listening tranquility
 following here and now
 patience
 what I like is not necessarily
 what the other likes
 just act from your gut feeling
 experience-based observation
 acceptance
 awareness insight
 yet fun together/
 yet laugh together
 nothing is a "must" small things

need/affection to give is wonderful
 person falls in black hole-
 doesn't know where he/she is
 -makes the person sad
 impotence
 sad hard/difficult
 to receive their gladness is nice
 golf stream with ups and
 downs/not to get stuck
 to have trust in you respond to
 their capabilities the situation
 process of agony/ what is
 today - is gone tomorrow
 acceptance to touch
 to be active

 journey of discovery
 impotence mysterious decay
 unknown territory
 change
 back to the past isolation
 no awareness of time (client)
 wonderingly
 questions concerning "difficult" clients
 patronizing
 terrible humour

satisfaction humour
 no expectations
 attention
 fun patience
 smile cooperation
 trust
 discovery contentment
 enrichment
 emotion recognition
 warmth
 happiness sense of wonder
 spontaneity
 nearness understanding
 fun

<
 Lauwershof field I
 4-10-2010
 <<
 Lauwershof field II
 29-11-2010
 <<<
 Lauwershof field III
 28-3-2011

Handbook: all the experiences, discoveries, observations and insights of the participants, the things they made with the clients, pictures, anecdotes and dropped pennies are assembled. The form this handbook takes is not preordained, which can turn out to be an obstacle itself: "how are they going to present themselves and their work, who will they invite and how and with whom will they cooperate?"

It is clearly visible that "doing activities together" has not only been beneficial for the cooperation and the social contact between staff/family members and people with dementia, but also between colleagues, family members, volunteers and staff. It has brought understanding and respect for each other's work, which has created a basis for change.

During the final meeting: **"meet, greet, share and continue"** everything that has been collected, learned and discovered is transferred to others: colleagues of their unit, other units, other care homes, family, friends, managers, subsidiaries, fund providers, educational institutes etc. To do so brings genuine **ownership** over what they have learned.

Board Game



Dissemination

There have been many forms in which this "handbook" was presented. In St. Vincentius an impressive board game for staff members was made, with action cards for implementation at work, sensory and cuddly cushions for clients who can experience a whole world of adventure with these cushions (orders were placed on the spot!). In Lauwershof the participants created a "From Art to Craft Fair", with stands, a power point presentation, a play, massages and hand baths, handbooks and "Active Care" (how to combine care and creative activities) got an invitation for a lecture in another home!

For both events many invitations have been sent out, both by Vincentius and Lauwershof as well as by De Stichting Koffer: to colleagues, friends and family, care homes, ASVZ board, Alzheimer's foundation and regional departments, press releases to local, regional and national newspapers, radio/tv the University of Maastricht, participating funds, EVEAN care and many others. The turnout was above expectation.



Meet greet share and continue

The participants of the training have been selected with care. They form the core group of the people that are working this way. They are also the pioneers who will, inside (by being an example) and outside (amongst other aspects of the presentation) the care home, take care of the dissemination of this new approach. It is an organic way of disseminating (like the circles round the stone thrown in a pond), which will find its way through the participants and their enthusiasm. This also means it has its own time path.

The contacts that have been made, for instance with the University of Maastricht and several care homes, give possibilities for new forms of cooperation and new methods of dissemination.

From Art to Craft Fair

Musical and dramatic arts can provide care staff with a new way to interact with people with dementia



Reactions of management ASVZ Vincentius and Lauwerhof:

These will be delivered later.

Publications:

In ASVZ Udenhout a film was made by Matthias de Smit and Joey Bongers from Zoomvliet College in Bergen op Zoom, commissioned by De Stichting Koffer. The **DVD** will be available on the Quality of Life website and was also shown on the international filmfestival Breda (www.filmfestivalbreda.com) in March 2011.

De Aanzet: article about the project From Art to Craft and Quality of Life, March 2011, edition of ASVZ, region Brabant

Magenta zorg:

This pilot would not have been possible without the support and cooperation of many people. We would like to thank in particular:

ASVZ Vincentius: Sectormanager Wonen Johan Remmers, members of the Board, Mr. Wim Kos and Mr. Peter Mertens, Mr. W. Baars, team leaders Connie Klijn and Babs van Laarhoven and all participating staff members, family members and clients.

Magentazorg Lauwershof: Head Care team Lia Rienks, the residents, the funds who participated financially (RCOAK and Sluyterman van Loo), Mr. Kees de Winter (De Waarden) and of course, last but not least all the volunteers and care staff who followed the training.



Pilot Project	Goals	Activities	Methodological Approach	Forms of Interaction/ Communication	Reactions of the Participants	Participation	Forms of Learning
<p>Stichting Koffer</p> <p>“From Art to Craft,”</p> <p>Nursing home Lauwershof/ Alkmaar; ASVZ Vincentius/ Udenhout</p>	<p>Enhancement of the communication between <i>patients</i>, nursing staff, volunteers and relatives via body, musical, visual and dramatic arts (and movements)</p> <p>Sensitization of nursing staff, relatives and volunteers towards the employment of creative methods for the stimulation of dementia patients</p> <p>Imparting creative skills and competences for the employment of creative methods in working with dementia patients</p> <p>Facilitate individually based new perspectives and social behaviour</p> <p>Create a tailor-made creative guidebook</p>	<p>Kick-off - Getting to know (“de Stichting Koffer”) “From Art to Craft”</p> <p>Getting acquainted with and working with different materials</p> <p>Physiological (and tactile) methods</p> <p>Working with different techniques and materials of fine arts</p> <p>Visual, Drama - and music based training</p>	<p>Learning by doing</p> <p>Learning by action</p> <p>Sharing individual observations to plough the work field and the subject</p> <p>Applying insights and implementing in practice</p> <p>Enhancing ownership</p>	<p>Group work</p> <p>Partner work</p> <p>Individual work</p> <p>Expansion of the commonly used media of communication (language, facial expression, tactility) through different artistic/ aesthetic expressivity</p>	<p>Sensitization of the nursing staff</p> <p>Change of perspective</p> <p>More awareness</p> <p>More activities</p> <p>More fun</p>	<p>Nursing staff</p> <p>Volunteers</p> <p>Relatives</p>	<p>Organised and systematic learning</p> <p>Learning by doing</p>

Table 1b:
Overview of the results

mapping of formal care facilities

Mapping of care and support in The Netherlands
Simona Thiel



netherlands



Epidemiology

Introduction

Dementia is a syndrome that causes a disturbance in the processing of information in the brain. This is the cause of memory impairment, with varying combinations the following disorders:

- *Aphasia (not being able to understand or express oneself coherently through speech or writing)*
- *Apraxia (not being able to execute deliberate actions)*
- *Agnosia (no longer being able to recognise objects)*
- *Disorder in executive functions (not being able to extract information, to produce logical conclusions, to organise, to make plans, to act with purpose)*

The most specific type of dementia is Alzheimer's disease (70%), followed by vascular dementia (16%).

People with dementia on average live for 8 years with the disease. During the process the number as well as the severity of the symptoms of the disease increases. Dementia cannot be cured. Eventually the patient will die as a result of the dementia.

*Source: Alzheimer Nederland (NL).
Fact and figures about dementia, 02-11-2011.*

Figures

According to Alzheimer Nederland over 243,000 people in the Netherlands have dementia.

- *Out of this number 12,000 are diagnosed with dementia at early age (< 65 years).*
- *Out of this number over 60,000 live in*

nursing and care homes.

- *Out of this number over 100,000 are still without diagnosis.*

Age is the most important risk factor for dementia. The risk of dementia increases with age:

- *Over 10% of the people above the age of 65 have dementia.*
- *Over 20% of the people above the age of 80 have dementia.*
- *Over 40% of the people above the age of 90 have dementia.*

*Source: Alzheimer Nederland (NL).
Fact and figures about dementia, 02-11-2011.*

The National Institute for Public Health and Environment in the Netherlands only counts those people in its database who are diagnosed with dementia. The figures they published are as follows:

On the 1st of January 2007 50,500 people were diagnosed with dementia (point prevalence). This came down to 1.9 per 1000 men and 4.3 per 1000 women. In 2007 there were about 19,100 new patients with dementia (incidence). This brings the total number of people diagnosed with dementia to 69,500.

In 2007 7,271 people (1,974 men and 5,297 women) died with dementia as the primary cause of death (24.4 per 100,000 men and 64.0 per 100,000 women).

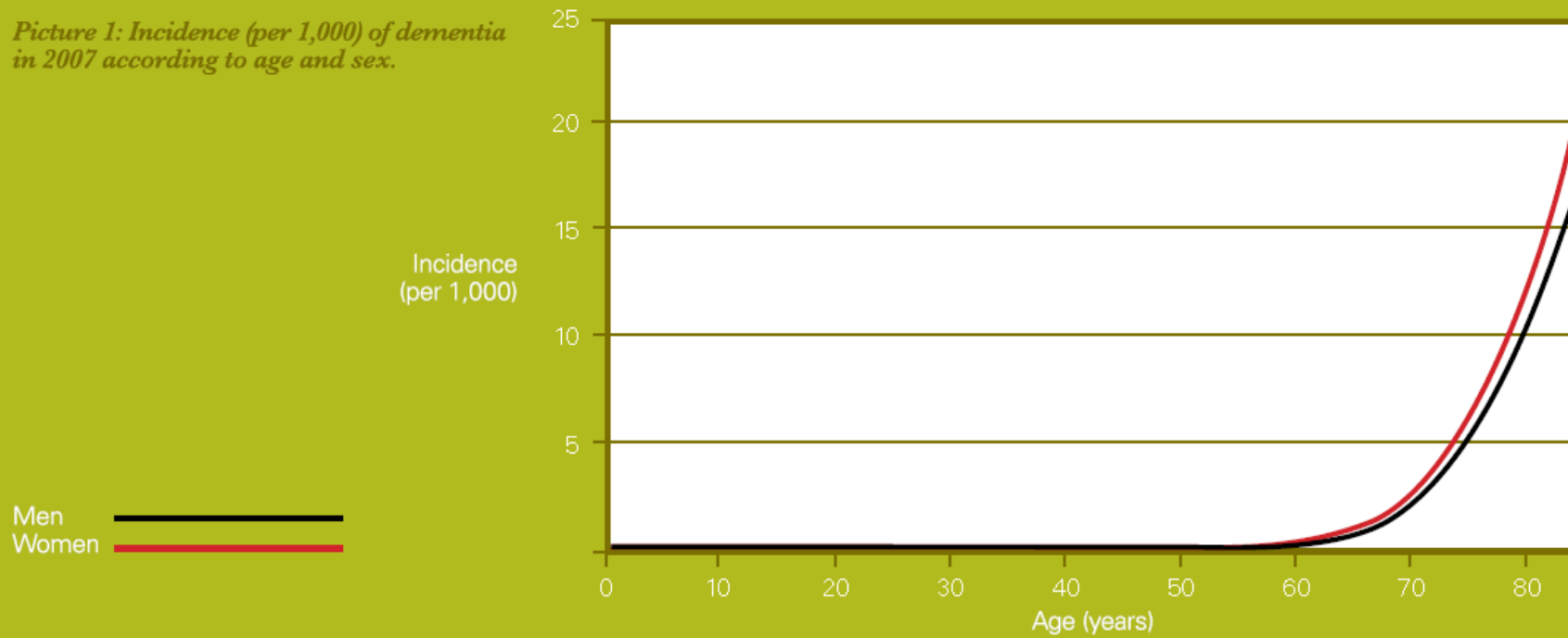


Notes to the figures presented

The figures presented here are calculated in the framework of VTV 2010 (Hoeymans et al., 2010). The estimates of incidence (number of new cases) and prevalence (overall number of patients) are based on the analysis of 5 registrations made by general practitioners. In the tables below reliability intervals are also presented.

In the pictures and in the tables on the following page the figures are presented according to age and sex.

Picture 1: Incidence (per 1,000) of dementia in 2007 according to age and sex.



Picture 2: Point prevalence (per 1,000) of dementia on January, 1, 2007 according to age and sex

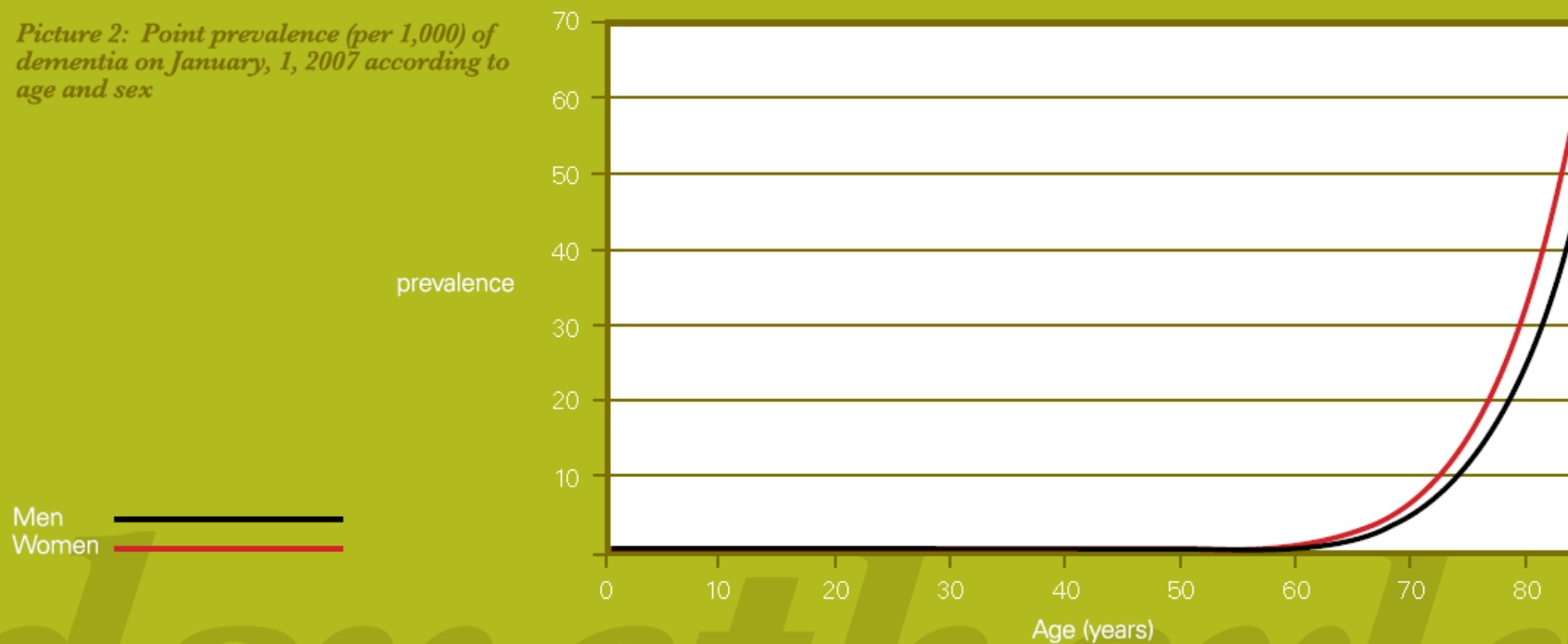


Table 1: Incidence of dementia (absolute and per 1000) according to age and sex in 2007

Age category	Incidence per 1,000		Incidence absolute	
	Men	Women	Men	Women
0-4	0.03	0.03	15	16
5-9	0.01	0.01	4	5
10-14	0.00	0.00	2	2
15-19	0.00	0.00	1	1
20-24	0.00	0.00	1	1
25-29	0.00	0.00	1	1
30-34	0.00	0.00	2	2
35-39	0.01	0.01	3	4
40-44	0.01	0.01	7	8
45-49	0.03	0.03	17	19
50-54	0.07	0.08	40	47
55-59	0.20	0.23	109	125
60-64	0.51	0.60	247	287
65-69	1.38	1.63	484	594
70-74	3.35	3.96	913	1,245
75-79	7.18	8.52	1,462	2,354
80-84	13.24	15.71	1,646	3,396
85+	19.78	23.38	1,462	4,529
Total	0.79	1.53	6,415	12,637
Lower 95%-reliability	0.48	0.94	3,850	7,776
Upper 95%-reliability	1.37	2.53	11,078	20,979
Total 65+	5,82	8,87	5,967	12,117

Table 2. Point prevalence of dementia (total and per 1000) according to age and sex on January, 1, 2007

Age category	Point prevalence per 1,000		Point prevalence total	
	Men	Women	Men	Women
0-4	0.04	0.05	20	26
5-9	0.02	0.02	8	11
10-14	0.01	0.01	4	6
15-19	0.01	0.01	3	4
20-24	0.01	0.01	3	4
25-29	0.01	0.01	4	5
30-34	0.01	0.01	6	8
35-39	0.02	0.02	12	16
40-44	0.04	0.05	24	31
45-49	0.08	0.11	49	65
50-54	0.19	0.26	109	144
55-59	0.49	0.65	272	358
60-64	1.19	1.59	551	732
65-69	3.05	4.10	1,055	1,482
70-74	7.36	9.91	1,993	3,112
75-79	16.26	21.89	3,261	6,010
80-84	32.47	43.55	3,995	9,411
85+	54.57	72.54	3,918	13,774
Total	1.89	4.26	15,287	35,197
Lower 95%-reliability	1,18	2,72	9.521	22.487
Upper 95%-reliability	3,08	6,69	24.920	55.284
Total 65+	14,05	24,91	14.21	33.790

Table 3: Death due to dementia (total and per 100,000) according to age and sex in 2007 (Source: CBS Statistics on cause of death).

Age category	Death rate per 100,000		Death rate total	
	Men	Women	Men	Women
0	0.00	0.00	0.00	0.00
0-4	0.00	0.00	0.00	0.00
5-9	0.00	0.00	0.00	0.00
10-14	0.00	0.00	0.00	0.00
15-19	0.00	0.00	0.00	0.00
20-24	0.00	0.00	0.00	0.00
25-29	0.00	0.00	0.00	0.00
30-34	0.00	0.00	0.00	0.00
35-39	0.00	0.00	0.00	0.00
40-44	0.00	0.00	0.00	0.00
45-49	0.32	0.00	2	0.00
50-54	0.35	0.88	2	5
55-59	2.34	1.28	13	7
60-64	3.53	4.18	17	20
65-69	14.82	10,67	52	39
70-74	46.94	46.13	128	145
75-79	163.59	161.36	333	446
80-84	420.49	502.36	523	1,086
85+	1,222.63	1,832.52	904	3,549
Total	24.37	63.96	1,974	5,297
Total 65+	189	385,41	1,940	5,265

Prognosis

Dementia is a growing problem.

The number of new patients with dementia has strongly increased in the period 1976-2003. The number of new intakes in nursing homes is also still growing. Death caused by dementia has increased between 1998 and 2005 with men as well as women. Based on the demographic developments only, the number of people with dementia will increase by 46% in the period 2005-2025

Increase through ageing and early recognition.

The increase of the number of new cases is partly due to ageing; but also when the age and size of the population is taken into account, increase is visible. This is also related to an earlier diagnosis, due to the fact that

carers and relatives have an earlier recognition of the symptoms. Also in some cases the development of Alzheimer's disease can be delayed with medication.

Source: Lange J de (Trimbos-instituut). Dementia summarised. In: In: Health, Future, Exploration, National Health Compass. Bilthoven: RIVM, <<http://www.nationaalkompas.nl>> National Health Compass\Health and illness\diseases and disorders\Psyhic disorders\Dementia, 25 September 2007.

The increase of the number of people with dementia in the Netherlands differs from province to province as there are differences in age structure. According to Alzheimer Nederland the number of people in the Netherlands with dementia will increase by 117% in the period 2010-2040. The increase per province is as follows:

Source: Alzheimer Nederland (NL). Facts and figures on dementia, 02-11-2011.

Prognosis

- Dutch Association for Clinical Geriatrics: *Directive Diagnostics and treatment through medicine of dementia (2005)*
- Van Eijken, M; Peijnenburg, R; van Achterberg, T., *Guideline for dealing with behavioural problems with dementia patients (non- medication orientated recommendations). 2008. Scientific Institute for Quality of Healthcare, UMC St Radboud. 102 p.*

Examples of Specific Projects

- **The national dementia program (2005-2008)** is focussed on improving the consistency of the care for people with dementia and their caregivers. *The client*

	2010	2011	2020	2030	2040
Groningen	8836	9008 (+2%)	10626 (+20%)	14053 (+59%)	17169 (+94%)
Drenthe	8166	8409 (+3%)	10569 (+29%)	14291 (+75%)	18079 (+121%)
Friesland	10058	10341 (+3%)	12915 (+28%)	17069 (+70%)	20822 (+107%)
Flevoland	3258	3377 (+4%)	4605 (+41%)	7387 (+127%)	10969 (+237%)
Noord-Holland	37381	38179 (+2%)	46115 (+23%)	63071 (+69%)	79776 (+113%)
Overijssel	15787	16245 (+3%)	20052 (+27%)	26479 (+68%)	33198 (+110%)
Zuid-Holland	51010	52019 (+2%)	61434 (+20%)	81673 (+60%)	103201 (+102%)
Utrecht	15705	16087 (+2%)	20069 (+28%)	28029 (+78%)	37067 (+136%)
Gelderland	28738	29560 (+3%)	37282 (+30%)	50484 (+76%)	63899 (+122%)
Zeeland	7052	7225 (+2%)	8696 (+23%)	11613 (+65%)	14163 (+101%)
Noord-Brabant	33040	34314 (+4%)	45660 (+38%)	62016 (+88%)	77504 (+135%)
Limburg	17778	18375 (+3%)	23689 (+33%)	31141 (+75%)	37887 (+113%)

has a structural leading role in this program. (look at: [http://www.zonmw.nl/nl/publicaties/?no_cache=1&tx_vipublicaties_pi1\[action\]=details&tx_vipublicaties_pi1\[id\]=568&cHash=73b68b7751e8ffafd853b126ffa602d6](http://www.zonmw.nl/nl/publicaties/?no_cache=1&tx_vipublicaties_pi1[action]=details&tx_vipublicaties_pi1[id]=568&cHash=73b68b7751e8ffafd853b126ffa602d6)) In this program several national organisations have worked together such as Alzheimer Nederland (NL) Foundation, Vilans, national independent knowledge centre for long-term care, TNO, innovation for life, independent research organisation. They produced a report and recommendations. The report is only available in the Dutch language their carers.

- In 2008 the **Chain of Dementia Care** program started as a follow-up of the national dementia program (2005-2008). In this program "building blocks" have been collected for each of the developed problem areas. The provision of care and support together make a chain of care. Each of the building blocks is again translated in terms of possible provisions and indicators which can help to determine the result of this specific offer. In the stage preceding the actual diagnosis, advice and information campaigns are important building blocks regarding for instance "the feeling that there is something wrong," both for people and their environment as well as for general practitioners this can be of help to make the link to dementia when certain complaints occur. In this way a model for a "chain of dementia care program" has been developed. (<http://www.vng.nl/Documenten/Extranet/Wmo/02-Dementiezorg.pdf>) This document is a description of a mini toolkit for local governments and care offices (32 in NL) how they can work together in an integral approach for dementia care. This document is only available in the Dutch language.
- **Dementia standard of care** (<http://www.vilans.nl/Pub/Home/Over-Vilans/Opdrachten/Zorgstandaard-dementie.html?highlight=dementie&search=1>)

Alzheimer Nederland (NL) and Vilans, national knowledge centre for long-term care, are developing a standard for care that will be published in the spring of 2012. The aim is to achieve set standards for dementia care. The development and implementation of a standard for care will be a lead for the regions and will support the regional chain of care approach which is directly connected to the needs and wishes of people with dementia and their caregivers. This standard is developed for professionals working in the long term care. Document only in the Dutch language.

- **Dementia care program** (<http://www5.vilans.nl/smartsite.dws?id=113127>) The Dementia care program is a digital information system. In this information system, data and practical tools can be found to improve and maintain care, living and wellbeing of people with dementia and their loved ones. This program is primarily directed towards care providers, but it also contains important information for clients and their families. Bartimeus (www.bartimeus.nl) is investigating dementia and cerebral visual impairment. Cerebral visual impairment can be part of dementia. Visual observation disorder can directly be caused by damage/deterioration of the brain in the visual (association) areas or can indirectly be caused by other disorders (such as decreased attention span) which impede visual observation in a secondary way. It is important to note that many people working with visual arts in dementia do not realise that people with dementia often have difficulty with their sight. For instance with Alzheimer's disease the yellow-blue colour sight disorder occurs; blue small cones are broken down by the same process affecting the brain.
- 'Utrecht, 9 June 2011- in Belgium, Germany and the Netherlands this the first ROSETTA domotic-systems have been installed in

houses of people with dementia. ROSETTA is meant to improve the quality of life of people with dementia in order to postpone the unavoidable intake in a nursing home. Vilans, national knowledge centre for long-term care, is monitoring the 3 pilots which will finish at the end of April 2012. Earlier research has shown that ROSETTA-software can postpone the intake into a nursing home on average within a period of three months. (<http://www.vilans.nl/Pub/Home/about-Vilans/about-Vilans-News/Pressreleased/Pressrelease-Advanced-software-for-living-at-home-people-with-dementia-in-use.html?highlight=dementie&search=1>) This information is taken from a news article on the Vilans website. It is only available in the Dutch language.

Infrastructure: care-facilities

Care mostly consists of support at home.

Care mostly consists of support at home. The care for people with dementia in most cases takes place at home. Over 65% of people with dementia live at home (Factsheet Homecare and dementia, NIZW 2005). The general practitioner, together with the caregiver that might be present, are important caregivers. Together they determine the need for care of the patient. Care gets more complex as the illness progresses. In the course of the illness therefore the strain for the caregiver and the general practitioner to give support, to supervise and to give care to the person with dementia increases. The general practitioner, knowing the progressive nature of the disease, will frequently keep track of how the care situation is, and will if needed propose adaptations. This can for instance be done by involving home care to help and support the caregiver when the care is becoming too much of a burden or is too technical and needs to be seen from a medical perspective. Intake into a care or – nursing home can be necessary if the caregiver is no longer able to carry the burden or when no caregiver is available to take care of the patient.

General practitioner refers many people with Dementia to the GGZ (Organisation for Mental Health Care)

The mental health care is very often involved with the care of people with dementia. Out of the total number of referrals which a general practitioner writes for people with dementia, 30% goes to a facility for mental care (Baan et al., 2003). Of those people who show the symptoms of dementia, 24 % is referred to a geriatrician, 22% receives a referral to a neurologist and 9% to a psychiatrist.

High need for care for the majority

More than three quarters of people with dementia have a high need for care. This care can be support, supervision or direct care. In the course of the process of dementia it is possible that there is a need for personal care, toileting and feeding until 24/7 care or monitoring. 23% need incidental care or care every few days. Of the persons with dementia who live at home 60 % is dependent on 24/7 care, in care and nursing homes this percentage increases to 90% or more. (Factsheet Caregivers Care and dementia, NIZW 2005.)

Sources: Hoekstra J (RIVM), Poos MJJC (RIVM). Which care do patients use and which are the costs? In: Health, Future, Exploration, National Health Compass. Bilthoven: RIVM, <<http://www.nationaalkompas.nl>> National Health Compass\Health and illness\diseases and disorders\Psychic disorders \Dementia, 19 August 2008.

Baan CA, Hutten JH, Rijken PM. Coordination of care. A background study about care for people with a chronic disease. RIVM-rapport nr. 282701005. Bilthoven: RIVM/NIVEL, 2003.

9. Contacts

Interesting links related to dementia care

Infrastructure

<http://ldp.socard.nl/default.aspx>
On this website you can find all organisations related to dementia care

[http://www.zorgbelang-nederland.nl/index.php?p=114:](http://www.zorgbelang-nederland.nl/index.php?p=114)
Overview of most of the nursing homes in the Netherlands

<http://www.activite.nl/home/care-at-home/care-and-help/meeting-place-dementia>

<http://www.zorgvoorbeter.nl/subjects/about/dementia/examples/meeting-places/>

<http://www.uvitzorgkantoren.nl>
Care offices

<http://www.zorgkaartnederland.nl/zorgkantoor>
Care offices

Information

<http://verpleeghuis.startpagina.nl/>
All about the nursing home

<http://dementie.startpagina.nl>
Portal about dementia

<http://dementie.startkabel.nl>
Another portal about dementia

[http://www.mee.nl:](http://www.mee.nl)
A lot of information about the social mapping. The organisation Mee supports people with a disability (for instance case management)

<http://www.overdementie.nl/>
Website about dementia

[http://www.dementierijnmond.nl/viewpage.asp?pag_id=100643:](http://www.dementierijnmond.nl/viewpage.asp?pag_id=100643)
Useful publications and links

<http://www.dementia.nl/>
Website about dementia

<http://www.ggzcentraal.nl/diseases/dementia/causes-of-dementia>

<http://www.loketgezondleven.nl/>
website about living in a healthy way
<http://www.nationaalprogrammaouderenzorg.nl/>
Website national program for older people

<http://www.bigregister.nl/>
Website about reserved interventions in health care

www.alzheimer-nederland.nl
Advocacy organisation for everything concerning dementia

www.opnieuwgeleerdoudgedaan.nl
Website about the learning ability of people with dementia

www.herkendementie.nu
Online test if in doubt about having dementia

www.modernezorg.tv
Website filled with short films about innovative care

www.dementie.be
Informative Belgium website in the Dutch language

www.pick.nl
Website about people with Pick's disease and their caregivers with lots of information about this disease as well as a forum about Frontotemporal Dementia

www.korsakovsyndroom.nl
Informative website of the national Korsakov platform and the Korsakov knowledge centre

www.lewybody.nl
Website with information and a forum about Lewy Body Dementia.

www.parkinson-vereniging.nl
Website of the association of Parkinson's disease

www.handy-wijzer.nl
Information about technology and regulations

www.geheugenwebsite.nl
Website about how the memory works with tips to train and maintain the memory

www.DOTMidden-brabant.nl
Website of the centre for support and training in case of dementia with the aid of interactive video supervision

www.jong-dement.nl
Website for people who develop dementia at a young age with initiatives in the province of Limburg both the Dutch as well as the Belgium province.

www.hersenstichting.nl
Website about the brain and research into brain disorders such as dementia

www.alzheimer.startpagina.nl
Portal about dementia and all sites that refer to this subject

www.reminiscentie.nl
Website about reminiscence, with lots of information, articles and links

www.lichtvoorlater.nl
Website about the influence of light on people above the age of 50, also contains information about light and dementia

www.alzheimerexperience.nl
On this site people can experience how it feels to have dementia, looking through the eyes of a person with dementia

Knowledge and Research

<http://www.vilans.nl/>
Knowledge centre for long-term care; it supports scientific research

<http://www.zonmw.nl>
ZonMw stimulates research into health and innovative care

<http://www.nivel.nl>
Dutch Institute for research in the field of healthcare

<http://www.emgo.nl/home>
Research centre of the Free University in Amsterdam

www.ideon-dementie.nl
Knowledge Centre for Dementia Care

www.innovatiekringdementie.nl
Knowledge Centre committed to the improvement of the quality of dementia care

www.trimbos.nl
Website of the knowledge Centre for mental healthcare

www.solg.nl
Website of the Foundation investigating the function of light in healthcare

www.dementieinbeweging.nl
Website of the Free University in Amsterdam and information about some of their research programs around movement and dementia

Caregiving

<http://www.expertisecentrummantelzorg.nl/>
Knowledge centre for caregiving

www.mezzo.nl
National association for caregivers

www.pasaan.nl
This is the website of the company that has developed and can deliver a portable care home and a readymade build on rooms for care

www.bmzm.nl
Website of the national association of agents in care who take over the administrative work of caregivers

www.dementiedebaas.nl
Internet course and information for family members of people with dementia

www.dementelcoach.nl
Website about coaching by telephone for caregivers of people with dementia

www.mantelzorgerbenjenietalleen.nl
On line newspaper for caregivers

Incompetence of will

http://www.dwangindezorg.nl/laws-and-rules/Incompetence_of_will

http://www.kiesbeter.nl/patientsinformatie/Decisions_made_by_someone_else/at_which_moment_will_a_person_be_declared_as_someone_incompetent_of_will/default.aspx

<http://www.rijksoverheid.nl/onderwerpen/kwaliteit-van-de-zorg/vraag-en-antwoord/hoe-zijn-de-rechten-en-plichten-van-de-arts-en-de-Patient-geregeld.html>

<http://www.rijksoverheid.nl/subjects/coercion-in-healthcare>

www.clientenrechten.nl
Website about the rights of clients receiving care

Living with dementia

www.geheugenwinkeltilburg.nl
The website of a shop situated in a care facility which has a lot of practical tools and games for application with dementia

www.thuiswonenmetdementie.nl
Website about in home adaptations for living with dementia

www.wonenmetdementie.nl
Website about small-scale living with dementia. The website contains a survey of all such locations in the Netherlands

www.slimwonenmetdementie.nl
Website with information about innovative technical solutions for living at home

www.domoticawonenzorg.nl
Website about the use of domotics

Dementia care other

<http://www.zorginstellingen.nl/>
Platform for managers working in healthcare and elderly care

www.hadikhetmaargeweten.nl
Website linked to the book: If only I had known- about modern dementia care

www.alzheimercentrum.nl
Website of a research and treatment centre for dementia at the Free University in Amsterdam

www.alzheimercentrumlimburg.nl
Website of a research and treatment centre for dementia in the province of Limburg

www.alzheimercentrumnijmegen.nl
Website of a research and treatment centre for dementia in the city of Nijmegen

www.ontmoetingscentradementie.nl
Website about day-care centres and support for family members

www.geheugenpoli.com
Website of Centres for diagnosis and treatment, often linked to local hospitals
www.anderszorgen.nl
Website of DAZ, a private organisation dealing with innovation of care. The website contains a lot of information about innovative tools and technology, self-reliance and communication

www.kiesbeter.nl
A website comparing the health care institutions managed by the government

www.igz.nl
Website of the health care inspection

www.loc.nl
Website of the national organisation of client

councils of home care facilities and nursing and care homes and GGZ

www.ciz.nl
Website of the organisation responsible for giving an indication for the need for care

www.pregoplus.nl
Website with hundreds of tips to decrease the physical burden of caregiving

www.consumentendezorg.nl
Website where users report their experience with care institutions

www.pgb.nl
Website of the organisation Per Saldo about person related budgets

www.devpg.nl
Website of the Psychogeriatric Association

www.ademtherapie-aos.org
Website about breath and relaxation therapy for people with dementia as well as their caregivers

www.zorgleefplanwijzer.nl
website for care staff about the design of the care

contact details of the partners



Uni-T

Verin Furkulture an der Karl-Franzens
Universität Graz
Zinzendorfsgasse
8010 Graz
Austria

T: +43 (0)3163807490
E: culture2000@uni-T.org
W: www.uni-T.org

Universität Klagenfurt

Universität Sstrasse
A-9020 Klagenfurt
Austria

T: +43 4632700
E: uni@uni-klu.ac.at
W: www.uni-klu.ac.at

Peter's Dance Centre

Koulutus- ja kehittämispäällPetr Veleta
Peters Dance Centre Prague

E: petrveleta@centrum.cz

Theatre Academy of Finland

Koulutus- ja kehittämispäällikkö
Kokos-palvelut
Teatterikorkeakoulu
Haapaniemenkatu 6, PL 163
FI-00531 Helsinki

T: 050 439 0517
E: etunimi.sukunimi@kokos.fi
W: http://www.kokos.fi

De Stichting Koffer

3E Egelantiersdwarstraat
1015 SE
Amsterdam
Netherlands
0031206255091

T: +31 206255091
E: info@destichtingkoffer.nl
W: www.destichtingkoffer.nl

Cultuur- Ondernemen

Nieuwe herengracht 119
Post bus 2617
1000 CP Amsterdam
Netherlands

T: +31 205352500
E: info@cultuur-ondernemen.nl
W: www.cultuurondernemen.nl

Live Music Now

Music Base
Kings Place
90 York Way
London
N1 9AG

T: +44 (0)1653 668551
E: contact@livemusicnow.org
W: www.livemusicnow.org