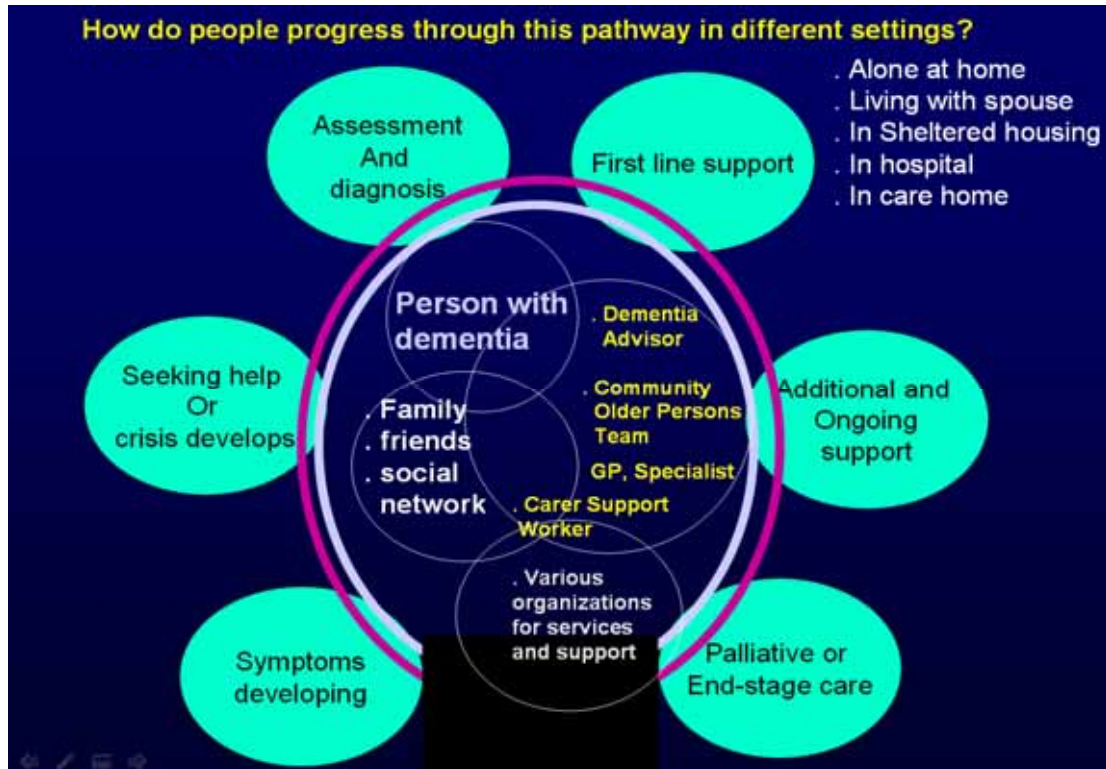


VALUING TIME AND DIGNITY

THE CARPE DEM MODEL (CARE PATHWAY FOR EVERYONE WITH DEMENTIA)  
Towards an 'ideal' dementia care pathway?



BY: DR. GEMMA MM JONES AND DR. WILLIAM J VAN DER EERDEN

**Sept. 2010 - Note for Readers about the context of this work:**

*The CARPE DEM care pathway has been generated and recorded in this form, to contribute to discussions about how to develop the best possible dementia care pathway/s in the U.K. The original Dutch materials we have translated here, were provided courtesy of Prof. Cees Jonker. Since not all terms are readily translatable, we have tried to represent the 'flavour' of the meaning, rather than an unhelpful literal translation.*

*The content and model presented herein are our own thoughts and do not necessarily in any way reflect those of Novartis Pharmaceuticals, UK, who have supported the printing these materials.*

## Endorsement for the CARPE DEM dementia care pathway model

*“Dementia is clearly a huge concern for all societies and is so common as to be now, and by necessity even more so in the future, a general practice issue. Current concerns about the inadequacy of support for carers, lack of resources for patients and their often inappropriate admissions and readmissions to acute hospitals mean that it is very timely that this new look at the care pathway for dementia care, a version of which has been successfully piloted in the Netherlands, is being discussed. Its focus on general practice and the dementia care manager makes great sense and along with the tools for patients and carers to use to help them understand what is happening, will allow memory clinics to develop as real specialist assessment centres, not the secondary registry and drug treatment monitoring centres they have become.”*

*Dr David Wilkinson (OAP, Founder of MARC, Memory and Assessment Research Centre, Southampton)  
June, 2010*

## TABLE OF CONTENTS

An ideal dementia care pathway?	5
Background	5
Assumptions	6
CARPE DEM derived from StIDA –Amsterdam dementia care chain pathway (ADCM)	9
Description of the CARPE DEM model	10
Suggestions for a 3 day course for GPs and Dementia Care Coordinators	16
References	17
<b>Translated sections from the StIDA document</b>	
A) General part	19
. objective and approach	
. what is quality care?	
. number of clients with dementia in Amsterdam	
. family (informal, unpaid) carers: care needs and offers of care	
. summary	
B) Best practice dementia care	28
C) Flow Diagrams for Cases 1, 2 and 3	40
D) Implementation	44
References for both the CARPE DEM and StIDA materials	p 50
Appendix 1 – ideas for assessment and recording tools (unofficial translations)	p 53
UFAR Index – ‘Uncomfortable feeling about a resident (or client) index	54
IDDD - Interview re: Deterioration in Daily Living tasks in Dementia	57
OLD - Observation list for early signs and symptoms of dementia	60
RDIT - Are you forgetful? Recognize dementia in time	61
DEBUC - Duress Experienced by Unpaid Carers [family] Questionnaire	64
TRIADE - Triage in dementia	65
GIP tool - Behaviour assessment in extramural psychogeriatric/dementia settings	67
Appendix 2 – Case study about noticing and supporting people ‘at risk’ in the community	
Mrs. Bundel - variations on possible outcomes	p78

## THE CARPE DEM MODEL, TOWARDS AN 'IDEAL' DEMENTIA CARE PATHWAY?

The purpose of the CARPE DEM model, our concept of an 'ideal dementia care pathway', is to make it available for those involved in discussions in the U.K. information about how existing care pathways could be altered to be more seamless, sustainable, and available to everyone with dementia.

The CARPE DEM model, is available, free of charge, on the website 'thewidespectrum.com', and comprises three items:

- a large (A1) poster, which depicts the whole 'CARPE DEM ideal care pathway'
- a Power-point overview (a series of slides high-lighting specific aspects of the care pathway)
- this explanatory supporting text, for those interested in additional details, and the tools referred to.

### OUR INTEREST IN THIS SUBJECT

Dr. William J van der Eerden studied biology, philosophy and medicine, with specializations in neurorehabilitation, geriatrics and palliative care. He is a 'Nursing Home Medicine' doctor (geriatrician) in the largest care home in the Netherlands (c 530 beds). His longstanding interests are - hippocampal aging effects, motor imagery and neuromechanics. He heads a stroke unit, teaches, and is involved in planning and piloting 'chain-linked care pathways' for people with stroke and dementia in Amsterdam West. He co-authored with Dr Gemma Jones, articles on visuoperceptual-cognitive deficits in Alzheimer's disease to develop and stimulate more evidence-based, well-designed, home-like environments for people with dementia.

Dr. Gemma MM Jones studied biology, gerontology and nursing; her doctorate concerned the cognitive neuropsychopharmacology of Alzheimer's disease. She has taught and written extensively about dementia care, and co-edited four volumes of 'Care-giving in Dementia' with Dr. Bere Miesen, founder of 'the Alzheimer Cafe'. She was a member of the Nuffield Council on Bioethics workgroup which produced "Dementia: ethical issues", a co-founder of the first Alzheimer Café in the UK, and promotes dementia education via The Wide Spectrum.

We are involved in dementia in many ways – in our work, teaching (professionals and family carers), research, with Alzheimer Cafés (and encouraging diagnosticians to refer people to them at the time of diagnosis), and others types support services (including specialist day care services for people with dementia). Inevitably, we have discussions with other professionals - related to their efforts to devise and provide good systems of dementia care. From our different geographical locations, we have been exchanging information about dementia care services for many years. (Dr. van der Eerden was instrumental in assembling and participating in the workgroup, which devised the StIDA dementia chain-care model, described later. He also has experience in developing a care pathway for people with strokes.)

## WHAT IS AN 'IDEAL' DEMENTIA CARE PATHWAY?

For us, it is a configuration of planning, care and support services that:

- . picks up the greatest number of individuals at risk and potentially affected, and their carers, (using information about the local demographics of elderly people, to evaluate outcome)
- . enables people with dementia to be diagnosed in a timely, accurate manner without undue delay
- . enables the provision of support and any required services - to start from the time of diagnosis, and on-goingly so, as part of documented and evaluated care planning
- . is workable in crisis/ non-crisis situations, for rare/complex presentations of illness and injury
- . involves concurrent assessment of family/primary carer needs (including dementia-related education)
- . offers the most seamless (non-fragmented), sustainable package of support possible, throughout the illness process - including any assistance and necessary counselling at the time of palliation and post-bereavement.

This involves a chain of commitment and responsibility, which extends to and includes all those involved in care commissioning, planning and provision.

In June, 2009 we started writing down ideas about what elements were necessary to constitute an 'ideal' dementia care pathway' - in the hope they would be of some assistance to others.

## BACKGROUND

In the absence of a cure for dementia, and with only very limited anti-dementia drug treatments available so far - timely diagnosis, immediate and ongoing good-quality care and support, are the agreed keys for helping provide optimal quality of life for people with dementia and their family or primary carer/s. In the UK, the National Dementia Strategy (2009) has provided the most wide-reaching challenge to date, to find ways to adapt already over-stretched services; efforts to do so continue despite the stressed economic climate.

Also globally, many professionals are trying to devise systems of cooperation between disciplines and services to locate, assess, diagnose and support people with dementia, and to assist their primary carers and paid caregivers. Each existing 'care provision system' has particular challenges, arising from factors such as - existing health and social care infrastructure and protocols, care standards legislation, financial resources, the type and number of professionals with specialist knowledge of dementia, the geography and population density in catchment areas, and the degree of societal stigma attached to having dementia.

The consensus is that most people with dementia wish to remain in their own home as long as possible. Accommodating this desire now, and in the future, will require the utilization of a dementia care model(s) which shows how those involved with care provision (professionals, paid caregivers, and volunteers within institutions, organizations, agencies and charities) can be effectively incorporated and coordinated within it, to meet the wide variety of circumstances that people with dementia and their primary carers experience. This involves devising a care pathway that: enables good oversight and communication between those involved; well defined, non-overlapping work remits, and avoids duplication of assessment, care and support services.

In recent years a number of government, academic and charitable-sector-initiated reports have highlighted findings showing that the majority of 'people with dementia' in the UK are not diagnosed and/or known to their GP. The most recent estimate has been set at 69%, an increase of 9% over previous ones - which translates into about an additional 140,000 people with dementia who have not been diagnosed (Dementia 2010 report). The cracks/gaps that people with dementia remain hidden in are numerous, and include people:

- . who are not aware of support services
- . living on their own without social networks
- . living in Sheltered Housing/ Residential Care settings which they entered without signs of dementia
- . who have undiagnosed dementia and are admitted to hospital for injury or illness
- . who have frail elderly family carers who may not readily notice changes in them
- . with early onset illness whose symptoms are be misdiagnosed
- . with vascular damage/ strokes who develop dementia, but only the strokes, not dementia, are referred to

- . living in more geographically isolated areas
- . with other co-morbidities which can mask dementia (physical illnesses, alcoholism and substance abuse)
- . with learning disabilities who are aging
- . from different cultural/ethnic backgrounds (who may mistrust or reluctantly utilize care services, or, who may not be familiar with dementia).
- . who are socially isolated for (e.g., the homeless, those having histories of poor mental-health, prisoners)

An 'ideal' dementia care pathway will need to address how more people who are 'at risk' and showing 'possible signs' can be identified and helped, soonest.

What did we do?

In coming up with an 'ideal' model, we looked at individual components within existing care pathways, and considered the functional links between the various roles and relationships among those professionals/sectors/providers supplying care. Thereafter, we considered which combination of care pathway components/roles that could best alleviate the sort of gaps, shortcomings or bottlenecks (e.g. those noted in the National Care strategy, 2009).

We started with the experiences and information from our work settings, and also searched the web for 'dementia care pathways'. There was a relative dearth of published information on this subject. Through our work contacts, conferences and meetings such as the Memory Clinic Forum (Basingstoke, 2009), and, we eventually obtained several dozen 'dementia care pathway' diagrams/ flowcharts - local, regional, national and international. (Invariably, the local and regional ones were not published, and most were limited to one or several pages of 'flow diagrams', with little if any supporting documentation.) We studied these various care pathways/systems, in light of frequent concerns expressed by family carers (see Box 1), and the issues mentioned in the report 'Dementia: ethical issues' (2009).

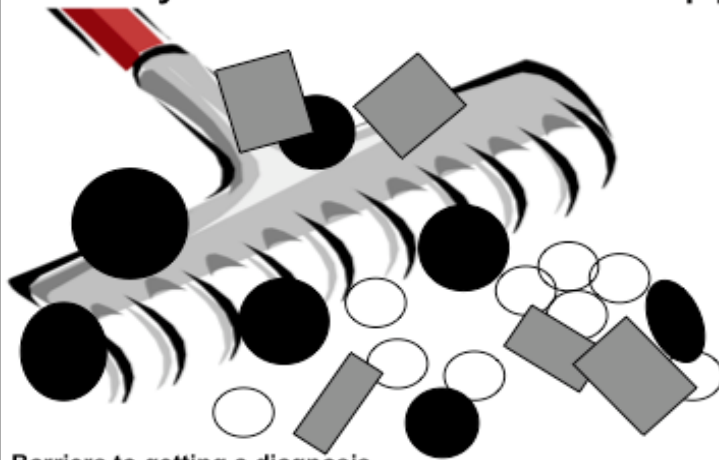
Thereafter, we looked at individual models in more detail to try to determine:

- . the assumptions made
- . the role and ongoing involvement of GPs
- . how people are made known to the service
- . who could be missed being referred into the care system
- . whether people could be lost sight of, once in the care system
- . individual components of the care system (e.g. assessment, diagnosis, referral to care provision services)
- . the linkages between various components
- . definitions of specific types and levels of 'support'
- . definitions of 'memory clinics' or 'memory assessment services' (which vary from: 'memory nurses', single medical specialists, to multi-disciplinary memory clinics including neuropsychologists)
- . types /numbers of professionals involved (and whether they had specific dementia education)
- . types and numbers of agencies/staff involved
- . funding for the service (and any references to case load)
- . how a care pathway worked for normal/ crisis circumstances, for complex/non-complex presentations
- . the presence of tools and protocols for assessment and ongoing evaluation and quality control
- . the presence of potential overall performance indicators to evaluate the service

## **ASSUMPTIONS**

Our assumptions in regard to an 'ideal' care pathway are shown in Table 1.

## Family carers report falling between the rungs of systems intended to support and help them



### Barriers to getting a diagnosis

- . doctors' uncomfortable / reluctant to diagnose
  - some people are never diagnosed
  - cognitive changes blamed on 'normal aging'
- . doctors' reluctance to relate the diagnosis
  - unaware that a diagnosis is needed to obtain 'Carer Benefits'?
- . lack of sensitivity in relating diagnosis
- . Getting a diagnosis can take a long time
- . incorrect diagnoses before dementia is recognized
- . lack of multidisciplinary Memory Clinics leaves diagnosing up to less skilled practitioners
- . some GPs are uncooperative with desperate carers who use a 'ruse' to get the person in for a check-up
- . GP reluctance to share medical information about the person with dementia with family carers on the grounds of respecting 'patient confidentiality'
- . the (extra) stigma of referral to services in psychiatric / mental health settings can deter fragile people who are afraid of being thought of as 'crazy'
- . lack of emotional support at time of diagnosis
- . lack of ongoing interest in person and family carer

### Lack of timely provision of information

- . to procure finances / support to care at home
- . to understand the illness
- . about the effects of damage to other cognitive abilities besides memory (eg attention, reasoning, visuo-perceptual abilities, and language)
- . about the variety of reasons for changes in behaviour (not all due to dementia)
- . concrete suggestions about care and activities
- . about maintaining carer health and quality of life

### Carers often told they are 'depressed'

- . their a long- term (complex) grieving often goes unacknowledged and thus unsupported
- . the lens with which professionals view carers affects type of care and support they are offered

### Unhelpful vocabulary and models used

- . lack of consistency between professionals
- . old, inaccurate terminology still in use
- . medical/psychiatric terms can be used as a smokescreen for what is not known

### Lip service only to genuine 'Care Partnerships'

- . carers not always included in routine care planning reviews
- . feel like 'token-presence nuisances' versus equal or valued members of the care team, sometimes
- . lack of multi-disciplinary input from some professions (e.g. GPs, OTs, Physios)

### Lack of positive role models and recognition for carers

- . much literature makes caring sound like negative, thankless effort
- . media emphasizes dramatic failures in care, more than positive role model examples
- . this engenders fear of asking for help and using existing services
- . invisibility and lack of appreciation for role as carer

### Hidden encumbrances in care services

- . staff have not had specialist dementia education
- . do not have the skills to assess the subjective needs of carers
- . difficulty finding out what services are available
- . services are fragmented: limited access, geographic inequities
- . inadequate specialist day care (often shared with frail elderly)
- . difficulty accessing emergency respite care
- . services given in people's own homes often overstretched
  - high turnover of staff
  - timing of daily visits can be variable / inconvenient
- . caregivers and professionals who focus on needs of the person with dementia, in isolation of those of the family carer
- . feeling 'lucky to get any help at all', causes reluctance to make complaints about poor quality care

**TABLE 1 ASSUMPTIONS MADE IN THIS 'IDEAL DEMENTIA CARE PATHWAY MODEL'**

- 'support' has physical, psychological, sociological, and cultural components
- the provision of optimal dementia care over the course of the illness requires the input of a well constituted, adequately-resourced, cooperative, multidisciplinary team and ancillary workers
- The organization of dementia care services can help reduce the stigma associated with dementia (e.g. making GPs – rather than old age psychiatrists- key figures in diagnosing dementia) (e.g. removing 'dementia care services' from the umbrella of 'Mental Health Services' which reinforces associations of dementia with 'craziness and mental illness', as opposed to neurodegenerative brain illnesses) could reduce the fear and reluctance of those in need of assessment for signs of dementia. In other countries dementia care comes under the remit of other specialty areas, such as Geriatrics or Neurology, which do not have the associated stigma.]
- If taught, GPs can specifically ask about and observe for signs of early cognitive difficulties in their patients (rather than waiting to be asked), using tools for that purpose (e.g. see later example in text the TRIADE Tool and OLD)
- Providing timely and ongoing support requires that early signs/indicators that people may be at risk, or already experiencing cognitive difficulties, need to be recorded and shared with others involved in 'dementia care system'. This ideally includes the recording and registering of people who experience repeated falls and re/hospitalizations, so early interventions can optimize recovery and functioning (See an example of this in the 'Variations on a Case History' on [page X](#)).
- care-giving staff (e.g. domiciliary workers, personal care assistants, home care workers, in the community, and care-giving assistants in Residential and Nursing homes), are ideally placed to report new concerns about people in their care. Recording tools to assist with this have been developed (e.g. see later in the text, example of the UFAR Index).
- recording behaviour changes accurately, can assist care planning for people with dementia (Professionals such as nurses, psychologists can make use of tools developed for this (e.g. see later example in text of the GIP tool)
- assessing for need, and planning support for family/carers involves taking into account both objective and subjective measures of duress/stress/burden(e.g. see later in text, example of DEBIC)
- ongoing documenting and evaluation of the quality indicators of the care pathway is essential to providing sustainable dementia care that society can be proud of
- avoidance of unnecessary duplication of assessment and information by appropriate sharing of information is possible (between various professionals, state, charitable, voluntary-sector, and other agencies involved in providing services and care). (E.g. Pointon ,2008, had 26 different professionals advise on her husband's care, aside from those privately employed. Each did their own assessment.)
- Those responsible for generating the care plan, are in the ideal position to coordinate, evaluate and adjust care. A 'dementia care coordinator (DCC)', who informs, negotiates, advocates and case-manages care is more likely to help fragile people than someone who only 'advises'.
- the GP is the first, and most frequent and accessible, professional 'port of call' for the majority of the population. GP involvement is central to the assessment, diagnosis and ongoing support of people with dementia, and their carers, and hence in drafting and reviewing care plans with DCCs
- additional education about dementia is required for GPs and Dementia Case Managers to fulfil their roles in the CARPE DEM care pathway model
- additional and ongoing education about dementia and dementia care is required by all involved in care and support provision



In our view, the model that best fulfilled our criteria and assumptions for an 'ideal' dementia care pathway, was the StIDA workgroup's, ADCM model [StIDA = Stedelijke Initiatiefgroep Dementie Amsterdam; ADCM = Amsterdam dementia care chain model]. Despite differences in the Dutch and UK care systems, we considered that the arrangement of services it provided, could be the basis of an 'ideal care pathway' that would aid discussions elsewhere. The StIDA-ADCM model was generated by professionals and academics, in direct response to the Dutch national dementia strategy (LDP = Landelijk Dementie Programma), in 2008. In addition to having been designed to reach as many people as possible, this model also has the benefit of having had two years of pilot studies, ongoing evaluation by measurable criteria, and is undergoing current development and expansion.

We made a number of small changes and adaptations to the StIDA-ADCM pathway to arrive at the CARPE DEM model

For example:

- . in defining levels of support through to end-stage palliative care
- . adding questions in the form of 'decision points' at each level
- . in supporting the use of Alzheimer Cafés in the UK as a form of support that people can be referred to at the time of diagnosis
- . adding the connection to include monitoring people with falls, hospital re/admissions to the CARP
- . considering how the Expert Team could be constituted in the UK, given some differences in dementia professionals between the Netherlands and UK, and how it overlaps with current OPCMH teams
- . considering options for organising 'dementia case-management' within current services (e.g. who would best fit the DCC role (community nurses, CPNs and Admiral nurses but perhaps also some Carers Support Workers and Outreach workers)

(A translation of details about the development of the StIDA-ADCM model, its implementation, and the tools being used, are provided after the CARPE DEM text. They will provide interested readers with additional clues about how the CARPE DEM model evolved and was developed.

GENERATING AN 'IDEAL DEMENTIA CARE PATHWAY'  
THE CARPE DEM (CARE PATHWAY FOR EVERYONE WITH DEMENTIA)

TERMINOLOGY, COMPONENTS AND ABBREVIATIONS IN THE CARPE DEM MODEL

N.B. once a **'person with dementia'** has been diagnosed, they are referred to here as a **'patient'**, to distinguish them from those who have not been diagnosed, and also to emphasize that they are receiving both medical and psycho-social care interventions.

**Patient and carer/support system** = person with dementia + their [family] carer/s and/or other carer and support network, who function as a unit, although individual members have unique care needs

**DCC** = Dementia Care Coordinator (specialist case manager) who has dementia training and experience and stipulated qualifications and \*\*). They are assigned new cases by the CARP centre after a diagnosis of dementia has been made. They do the 'care assessment and care diagnostics' required to prepare bespoke care plans for the patient and their carer/support system. The DCC evaluates and adjusts the care plan as needed, including monitoring the quality of the care services provided by contracted providers, and is the main point of contact for the patient and carer/support system, ongoingly - throughout the illness.

**CARP** = Community area registry point centre . This is a community area registration point, which is a place/service where any concerns \* about people who are becoming fragile or forgetful are logged, (including those who have been hospitalized and had falls). The CARP informs GPs each week about those who have been reported each week. GPs inform the CARP once a diagnosis has been made. The CARP assigns DCCs to a person with dementia and their carer/support system, after a diagnosis has been made. (\*from members of the public, paid caregivers and health and social care professionals).

**Two types of diagnostics:** 'illness diagnostics' (primarily by GPs), and 'care diagnostics' (by the DCC )

**'Visiting nurses'** attached to all GP practices; they make [at least] 3 monthly visits to those who have been noted as being at risk because of their fragilities and/or lack of support system

**Expert Team** = those professionals who are designated to be available for use by the GP and the CARP centre, as needed. (It includes professionals in, but perhaps even broader than those in 'Older Persons Community Mental Health Teams' and linked to 'memory clinics' - e.g. geriatrician, old age psychiatrist, neurologist, neuropsychologist, clinical psychologist, community psychiatric nurse, Admiral nurse, occupational therapist, physiotherapist, speech and language therapist, family therapist, palliative care physician, incontinence specialist, sensory impairment specialist, wound treatment specialist, dietician, and possible others, such as bereavement counsellors)

**Health and well-being information booths'** to be located visibly/accessibly in communities. (They do not have to be separate entities, but could be part of NHS advisory services, walk-in clinics, dementia enquiry web sites linked to national organizations such as the Alzheimer's Society.) Dementia-related information is displayed openly and freely available there, including self-tests for forgetfulness (such as the RDIT) .

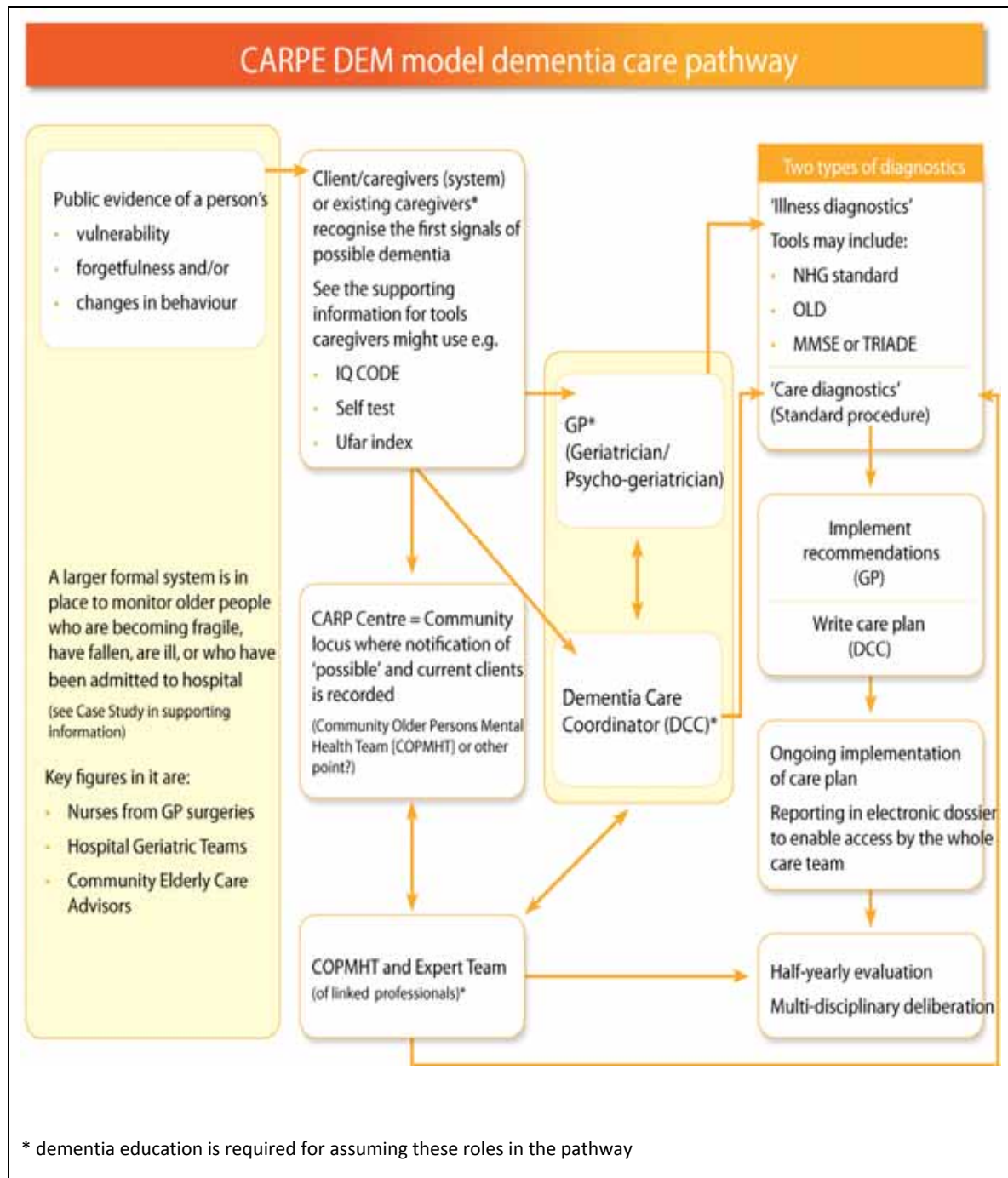
There are a number of central roles/positions, and the working relationships between them, which need to be introduced and consistently maintained to make this 'ideal dementia care pathway' work. These include:

- . reducing stigma and encouraging more societal openness about dementia, by providing information about dementia to the general public in a variety of locations and health centres (e.g. Health and well-being booths)
- . making it 'public knowledge' that 'dementia is everyone's business', and that:
  - it is important to notice cognitive/physical changes in the people they know and/or work with, that these changes can be assessed, and that they may or may not be signs of dementia
  - that their observations can be recorded, so the person they are concerned about can be 'kept an eye on', even if they don't have dementia
  - that various forms of help, including anti-dementia drugs and support services are available early in the course of a dementing illness, not just during crisis times (or when people need admission to a day centre or care home)
- . their concerns can be recorded at a **community area reporting point (CARP)**, a centre, where, once logged, people can be visited, assessed and followed up. Even if someone does not want or need assistance yet, once a concern has been flagged, a person cannot be 'lost' or 'dropped' from the care system. (A designated hospital nurse who is linked to the hospital Geriatric team, also logs information to the CARP centre.)
- . an appointed 'visiting **practice nurse**', (associated with one or more GP surgeries) visits elderly who have been flagged as being 'at risk', and made known to the GP practice directly, or via the CARP
- . GPs are the central figures in this care pathway. GPs are usually the first 'port of call' for people who are unwell, and therefore pivotal in picking up new individuals thought to be at risk, or, those requesting advice for cognitive difficulties. GPs have the responsibility of assessing non-complex presentations of dementia, and developing appropriate care plans in conjunction with another key professional, the Dementia Care Co-ordinator (DCC). (They have taken a course about their role in the care pathway and how they will work with dementia care co-ordinators.)
- . Dementia Care Coordinators (DCC), is a 'hybrid specialist' who assesses care needs (care diagnostics), coordinates and evaluates care, and case-manages individual patient and carers/support system. The DCC's work includes commissioning, regulating and monitoring what is happening to individual people with dementia and their carers, as well as making any necessary adjustments to the services they receive.

**The CARPE DEM model (A1 sized) poster, and slides which accompany this documentation, are not shown in this document but are available on the website: [thewidespectrum.com](http://thewidespectrum.com) on the 'Articles' page.**

Figure 1 below, gives a representation of the model. Figure 2 describes the process and the four levels of support in it.

**FIGURE 1 SCHEMATIC REPRESENTATION OF THE CARPE DEM CARE PATHWAY**



## Figure 2. Steps in the CARPE DEM PATHWAY

### **Recording concerns about people with increasing fragilities at a central location (CARP) to prevent people at risk from being unnoticed or forgotten**

- . People who are concerned about themselves or others, can obtain information about dementia (and 'How forgetful are you' tests) from 'health and well-being information booths' located in communities. Information about how to take concerns with person's GP and/or the CARP is also provided here.
- . Warning signs (falls, fractures and emergency/other hospitalizations) are reported to the CARP and to GPs
- . Domiciliary staff, personal assistants and Care-giving staff in care homes can also log their concerns about their clients or residents (and can be taught to use tools like the UFAR index to record their concerns)

**DECISION POINT: DOES THE PERSON 'AT RISK' REQUIRE REGULAR MONITORING?**

### **Those considered 'at risk' receive regular visits and ongoing monitoring for signs of dementia and any related assistance required**

- . Hospital 'liaison nurses' in hospital-based geriatric teams are linked with dedicated 'visiting nurses' in GP practices
- . People considered at risk of dementia, especially those without (adequate) carer/support systems, are visited at least once every three-months and assessed for changing needs, by a visiting nurse connected to a GP practice
- . Any relevant findings are passed to the CARP so that it can be added to previous information, and from there to the person's GP

**DECISION POINT: DOES THE PERSON 'AT RISK' REQUIRE A DEMENTIA ASSESSMENT?**

## Medical diagnostics: Assess people with signs and symptoms of dementia

- . People may go to the GP directly with their concerns
- . GP may invite a person and carer/support system to an (or another) appointment on the basis of information received from CARP
- . GP follows a specified diagnostic service protocol for dementia
- . GPs (\*) assesses for dementia, (e.g. possibly using new tools, such as the NHG, OLD, TRIADE, in addition to mini-mental state evaluation - MMSE)
- . GPs refer only patients with complex presentations (e.g. unusual symptoms and co-morbidities) for further specialist assessment via members of the Expert Team
- . GPs relate information about new diagnoses to the CARP centre, for DCC to be assigned
- \* GPs and DCCs have completed the required dementia courses (e.g. the three-day course described)

**DECISION POINT: IF DEMENTIA IS EVIDENT, WHAT IS THE BEST WAY TO COMMUNICATE THE DIAGNOSIS – IS A SEPARATE APPOINTMENT REQUIRED?**

## Formal diagnosis of dementia is given to the patient and their carer/support system

### – support and information provision starts now

GPs communicate the diagnosis diagnoses sensitively but openly, to the patient and their care/support system, and answer any immediate questions about it

- . Explain and offer any possible anti-dementia drug treatment options

#### **LEVEL 1 SUPPORT - AT TIME OF DIAGNOSIS**

- . answer immediate questions and concerns
- . discuss the options for ‘anti-dementia’ medications
- . Patients and their care/support system told they will be assigned a personal DCC who will be a ongoing resource for them, and who can be contacted for any concerns or queries
- . Give address and contact details for the CARP /DCC
- . Give details of local Alzheimer’s Café and local Alzheimer’s Society or other carer support groups
- . Give information about national Alzheimer’s Society
- . Inform about any current dementia research studies or drug-trial options for possible future participation
- . Provide written information for the patient and carer/support system to take home (e.g. fact sheets with the above details)

**DECISION POINT: WHAT SPECIFIC CARE AND SUPPORT ARE NEEDED BY THE PATIENT AND THEIR CARER/SUPPORT SYSTEM RIGHT NOW ?**

**Care diagnostics by DCC: assessments and personal care plans done for patient carer/support system. Care and support are agreed, started, evaluated and adjusted ongoingly**

**LEVEL 2 SUPPORT** - FOLLOWS IMMEDIATELY AFTER DIAGNOSIS, WITH THE DRAWING UP AND IMPLEMENTATION OF PERSONALISED CARE PLANS FOR THE PATIENT AND CARER/SUPPORT SYSTEM

- . DCCs assess the patient and carer/support system for their current care needs
- . DCCs confirm the care needs with the patient and their carer/support system
- . DCCs and GPs draw up care plans, which are agreed and signed by the patient and carer/support system
- . DCCs arrange implementation and monitoring of the care plan, including quality control evaluations of specific services and patient/caregiver satisfaction with the care provision

**DECISION POINT: IS CURRENT LEVEL OF CARE AND SUPPORT MEETING THE OBJECTIVE AND SUBJECTIVE NEEDS OF THE PATIENT AND CARER/SUPPORT SYSTEM?**

**LEVEL 3 SUPPORT** - STARTS WHEN THE PATIENT OR CARER'S NEEDS CHANGE

- . The DCC adjusts the care plan in response to the changing needs of the patient or carer
- . As dementia progresses, the DCC can inform people about and organize services such as:
  - . Financial and legal advice, domiciliary care, personal care, befriending services, help with social outings, and sitting services, so carers can attend support groups, etc.
- . Planned and emergency respite care
- . Assistance in planning for admission to residential and/or nursing care home

**DECISION POINT: IF THE PERSON WITH DEMENTIA IS STILL BEING CARED FOR AT HOME, CAN THE CARER/SUPPORT SYSTEM MANAGE, OR IS RESPITE, OR A TEMPORARY OR PERMANENT MOVE TO A CARE FACILITY REQUIRED?**

### **Circum-death care**

**LEVEL 4 SUPPORT** - ORGANIZED BY THE DCC FOR END-STAGE DEMENTIA OR PALLIATIVE CARE IF THE PATIENT REMAINS AT HOME (OTHERWISE IT IS ORGANISED BY THE CARE FACILITY THE PATIENT IS IN)

- care suited to the needs of people in end stages of dementia and/or palliative care
- The DCC can arrange bereavement counseling if needed

The suggested content of a three-day course to provide the additional education required for GPs and DCCs within the CARPE DEM model, is shown in Box A.

#### **BOX A SUGGESTED CONTENT FOR THREE-DAY DEMENTIA COURSE FOR GPs AND DCCS**

##### **Pre-test**

- Definition of dementia: what it is and is not
- the 'dementia process' in the most commonly occurring dementing illnesses
- 'Medical diagnostics': standard assessment and diagnostic procedures for dementia (physical, cognitive, mental/emotional)
- 'Care diagnostics' for assessing ongoing patient/carer(system) needs (subjective & objective)
  
- how to use new tools/questionnaires
- information about services, interventions and support
- consider a variety of case histories: normal, crisis, complex, paradoxical presentations
  
- ethical issues in dementia care and ethical decision making (also information from the Nuffield Council on Bioethics, 2009 report: 'Dementia: ethical issues')
- liaisons with related care professionals and caregivers
- circum-death care (end-stage and palliative care considerations, including bereavement counselling)
- dementia-management – coordinating documentation for the care process

##### **Post test**

#### **Final note:**

Designing care systems is complex work. There are new opportunities to improve services, but doing so will require much cooperation and commitment to investment in the form of providing education, developing good liaisons between stake-holders, and utilizing care services and care environments efficiently.

Neither of us are economists, and so cannot analyze our supposition - that good, pro-active, co-ordinated dementia care (keeping people with dementia/carers supported and contented in their own homes as long as possible, and thereafter providing specialist residential care), would be more cost-effective in the long-term, than any particular existing care system. Anyone undertaking such a cost analysis would need to take account of savings made, and qualitative benefits of minimizing/eliminating:

- . emergency admissions for crisis circumstances that could have been prevented
- . repeat hospital admissions of fragile and 'at risk' people, who are not 'in the system'
- . bed-blocking of people with dementia in acute hospital beds
- . the costs involved in caring for over-stressed, ill family/carers (carer hasn't had respite breaks)
- . redundancies in professional assessments
- . inefficiencies in service provision
- . the cost of delayed assessment and provision of support (and loss of carer employment time)
- . the cost of investigating complaints about inadequate care of (undiagnosed) people with dementia in hospital, and
- . the cost of ongoing societal fear and denial of dementia, with the associated wariness of using existing services.



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## EXCERPTS FROM THE StIDA MODEL

### ABOUT THE RELATED AND MATERIAL, REFERENCES AND APPENDICES THAT FOLLOW

Permission to translate the following material, has been given by Prof. Cees Jonker, Chairman of the StIDA workgroup.

The following translations are our own (to reflect the flavour of the meaning, where literal translation was not helpful.) The 'tools' that have been translated hereafter, are not 'official translations', but provided with the permission of Prof. Jonker, to give readers an idea of the protocol being developed and used in the Netherlands.

Dr. William van der Eerden, along with Prof. Cees Jonker and Dr. Rinze Merkus, were the initiators of this project. Eventually, with the input of twenty-nine professionals, for more than a year, the StIDA document was produced. The professionals included specialists in geriatric medicine [hospital and community based specialties], 'Nursing Home Medicine' physicians, a community nurse specialist, a Home Care Innovations Manager, a Director of Care for a Care Foundation, an old age psychiatrist, a regional 'Elderly Well-being Manager', directors of large Residential/Nursing Care Homes, a professor in dementia, psychologist, family carer consultant, researcher from the Free Univ. of Amsterdam [VU] Alzheimer Centre, and the Coordinator of the Amsterdam 'Meeting Place' Centre.

This StIDA model has been tested in two regions of Amsterdam (A'dam-West and A'dam Zuid-Oost) for the past two years, and continues to be evaluated. This initial, measureable success, since the release of the original document in 2007, has prompted further development of the ICT system to assist in its development.

For more information about the **StIDA-A** model, and ICT development currently underway to progress this model - please contact Dr. William van der Eerden at : [wvandereerden@osiragroep.nl](mailto:wvandereerden@osiragroep.nl)

Note: In the Netherlands, there is a professional 'medical specialism' that does not have a direct equivalent in the UK. It is that of a 'Nursing Home Medicine Specialist'. These doctors take three years post-medical specialization, and although they are geriatricians, they are different from 'hospital-based geriatricians'.

[Translated sections from the StIDA document about the Amsterdam dementia care-chain model]

## TERMINOLOGY AND ABBREVIATIONS FOR THE TRANSLATED PARTS OF STIDA DOCUMENT

- **Client (system)** = person with dementia client + their carer +/- other care/support network
- DCM, Dementia Case Manager = case manager [dementie case manager]
- CARP, community area registry point [wijkmeldpunt]
- Dementia care-chain [dementie ketenzorg]
- Care plan review meetings [MDO]
- ECD electronic client dossier [elektronisch client dossier]

## A. GENERAL PART

### 1 INTRODUCTION, BACKGROUND

Dementia has dramatic implications for the person with dementia and those closest to them. (1) The disease is characterized by progressive intellectual deterioration, often with memory impairment as an early feature. In the course of the disease problems can develop with the understanding and use of language, restrictions in performance of actions/operations, problems in recognizing people and objects and an inability to plan, organize and abstract. The disease process, and coping with the consequences of it, frequently leads to an [apparent] loss of personality, behaviour problems (eg aggression), and psychotic-like symptoms such as suspiciousness, and emotional disorders such as depression - which means that people with dementia are no longer able to function independently and become increasingly dependent on the care of others. The main types of dementia are: Alzheimer's disease (56%), vascular dementia (14%), Parkinson-dementia/Lewy-body dementia (10%) and fronto-temporal dementia (8%). In the 'Directives in the diagnosis and pharmacological treatment of dementia' (CBO, 2005), the causes of dementia are discussed in detail (1). The number of people with dementia in the Netherlands is approximately 180,000. The Dept. of Health expected this will increase to approximately 400,000 in 2050 (2).

In recent years a trend towards 'extramuralization' of care for people with dementia has started. This is partly a result of public desire, but also that of clients and carers. This means that - with an increasing number of people with dementia - there will be an increasingly heavy emphasis on this target group in the focus of the primary care and ambulatory care system [components]. According to data from Alzheimer Netherlands about two thirds of all people with dementia are cared for at home, and a third receive care in formal care setting [institution]. (3) Care for people with dementia is far from optimal (4). According to the report of the Dept. of Health (report: Dementia Health, 2002), often there is a lack of integration and consistency of care, 'crisis centres' are poorly regulated, the training of professional caregivers shows great variations, and Regional referral agencies (RIO, now CIZ) tend to hint at shortages. The quality of home care and care in institutions is not optimal everywhere. The organizations would be able to achieve improvements through increased cooperation and exchange of knowledge and experience about the content and organization of care. Consensus on a comprehensive package of care for people with dementia is missing. Also the changes in health care are forcing a clear definition of roles and responsibilities of the various disciplines involved in the dementia-care.

### THE LDP - THE DUTCH NATIONAL DEMENTIA PROGRAMME

Therefore, the Dept. of Health gave the public the advice to take the lead to develop a National Dementia Program (LDP = Landelijk Dementie Programma), with quality-requirements for the content of care and support of people with dementia. The roles and responsibilities of the organizations, institutions and disciplines involved, would therein be clearly defined.

Via the LDP, the government wants to offer/achieve more and better solutions for the questions and problems of people with dementia and their carers. The LDP is based on the perceived bottleneck [problems] of the people who are most involved: people with dementia and their families. The questions and issues faced by this group were translated into fourteen problem areas [bottlenecks] (see Table 2), formulated in the language of people with dementia and their families. The LDP is primarily a tool to gather all regional providers of care and services 'around the table' in order to agree upon and align with each other, their services/activities for people

with dementia. Using these fourteen problem areas, at local/regional levels, the gaps in care for people with dementia can be identified and, if any, solutions are proposed, can be implemented wherever possible.

**TABLE 2 THE FOURTEEN PROBLEM AREAS IDENTIFIED BY FAMILY/CARERS, THAT THE DUTCH NATIONAL DEMENTIA PROGRAMME [LDP] AIMS TO ADDRESS**

1. Something doesn't feel quite right	8. Additional health problems
2. What's the matter and what/who can help?	9. Losses
3. Frightened, angry and confused	10. It's becoming to be too much
4. Standing alone in providing care	11. Continual losses and the eventual loss of one's 'right of say' in one's own affairs
5. Diminishing contacts	12. In good times and in bad
6. Physical care	13. Miscommunication with caregivers
7. Danger	14. Resisting entry into care settings

#### CHANGES IN MENTAL HEALTH, 'SOCIAL GERIATRICS' AND NURSING HOME CARE

In 2003, the three 'mental health care institutions' [MHC = GGZ] in Amsterdam developed a plan 'urban care for those with cognitive impairment in Amsterdam'. The ensuing report 'Dementia' (2002) by the Dept. of Health was not the only reason for this initiative. Developments in neurology and geriatrics, which are increasingly profiling them as experts in the field of dementia, and systematic changes, necessitated the mental health care institutions in Amsterdam to reconsider the role of MHC institutions, in the care of the person with dementia. In the "urban care programme" it has been indicated that, in future, the MHC institutions in Amsterdam, will be limited - only to the care of people with dementia with behavioural problems, psychiatric symptoms and / or 'complex system problems'. To date, long-term-care has been provided to all people with dementia who are referred to them. In the future, this change-of-course, will mean that the MHC will be involved with approximately 80% of people with dementia at some time temporarily, but not continuously. The decision that the MHC institutions in Amsterdam will, with regards to dementia, be limited to only core tasks and the provision of specific expertise, means that those aspects of the current primary care for dementia, which have been delivered by the MHC institutions must be organized differently.

The role of 'social geriatrician (community-based)' [versus the 'acute hospital-based geriatrician'], who now works in the 'outpatient elderly care' of MHC institutions will change in the coming years, in the light of this trend. The extramuralization of nursing home care, rebuilding of homes to 'living/care centres', small 'clustered' living [residential] projects and the additional development towards full care packages at home (this is complete nursing care on the site where the client continues to live), coincides with the development of the delivery of 'complex care' in the so called 'living-service [Woonservice] neighbourhoods'. This will call for a dynamic in which the 'social geriatricians' and 'nursing home medicine specialist physicians', (who have recently re-grouped in one professional association and one educational curriculum), to occupy other positions in the first and second line: as co-therapists, treatment-experts, or consultants. This change means that:

. 'social geriatricians' shall no longer, with respect the usual 'basic dementia care-related work', work exclusively for the MHC institutions

. 'nursing home medicine specialist doctors', along with their patients, will increasingly be located in the community/district.

#### PRELUDE TO DEVELOPING A BEST PRACTICE FOR DEMENTIA

Simultaneous with the development of the 'urban care programme for cognitive disorders', the three MHC institutions commissioned 'Sigra Services Agency' to investigate, at city level, whether there is sufficient support for the establishment of a well-developed quality care programme for clients with cognitive disorders. Therewith, it is important that continuity of care is guaranteed [maintained/sustained] (hence the so-called 'integrated care-chain'). The results of the 'feasibility study about quality care for cognitive

impairments' (October 2004), showed that in forming 'care-chains' [interlinked chains of care], is important that all stakeholders support the ideas behind the care system and act accordingly. Good arrangements must be made well in advance about who does what tasks and when tasks are transferred. Further it was shown that there was an incoherent circuit between the fields of diagnostics, treatment and dementia care. There appears to be a need for 'integrated care' that is clearly coordinated and has 'signaling' [alerting to possible dangers] functions. A major point of concern mentioned was that it must be a sole-purpose program for the whole city, one must have broad support, and that it must be constructed/constituted by all concerned parties together. Good communication is necessary.

At the first 'invitational conference' (2005), with representatives of all institutions and providers in Amsterdam involved in dementia, the findings of the survey Sibra were confirmed and arrangements made for a pilot studies in two districts of Amsterdam, namely 'South' and 'Central'. The purpose of the two pilot studies was to determine whether 'the workplace' was a suitable place for develop an 'integrated dementia care chain' from. 'Project South' has joined the National Dementia Program (LDP) and is developing comprehensive care from the perspective of the client. It has recently started implementing the results. In the 'Project Central', based on existing cooperation at district level, known as PG teams, an initiative has been set up to work with GPs.

At the second "invitational conference" (2006), it was proposed, as the basis for a care chain serving clients with dementia and the client system, to start from a 'best practice model for dementia', such as that which already exists for clients with diabetes. The development of an integrated care chain via such a model must ensure quality care for dementia, which on the basis of negotiations with health insurers, is possible to fund.

## 2 OBJECTIVE AND APPROACH

### 2.1 OBJECTIVE

Developing a chain of care for dementia involves:

- Description of the disease process, which identifies the actions which point in the care of clients with dementia are needed and by whom these actions are carried out (best practice)
- Developing quality indicators
- Identifying an indication of the time required [to be taken] for different activities
- The formulation of the preconditions required for the development of integrated care.

This should result in:

- A gold standard for caring for clients with dementia in Amsterdam
- High quality care for client and caregiver
- Integration of the care offered by the sectors of health care [V&V], the mental health service, GPs, home care and well-being
- Prevention of overlap in the care provided by having an efficient work-methodology
- Achieving efficient and secure information exchange with regard to fulfilling jointly-achieved care plans
- Cost savings through more efficient use of resources

### 2.2 METHOD

#### 2.2.1 WORKING GROUP

To achieve this, a working group called the Urban Initiative Dementia Amsterdam, in short 'StIDA'. The Working Group is composed of representatives of workers and health institutions from the Amsterdam healthcare network around clients with dementia, so the widest possible public support, and optimal information exchange between the various parties could be promoted.

#### 2.2.2 METHOD

Data were collected on the health needs of clients and carers, based on the results of a recent survey. The definition of what constitutes "quality care" was considered sufficient. Moreover, data on the size of

the target and the forecast for Amsterdam were compiled. In subsequent monthly meetings, the care needs in the various stages of dementia was discussed using case studies, to explore a sound division of labour between the various care providers.

### 3 WHAT IS QUALITY CARE?

An important question for the development of integrated care is what quality care for a client means. A description of what this care should reflect the desire of, that is - by the norms and value systems of - clients with dementia and the client-system. In the 'Care Institutions Quality Act' (1996), quality is interpreted as 'Responsible Care'. This is, care of a good level, which in each instance is, effective, efficient, safe and patient-oriented and is granted based on the actual needs of the client. The care delivered fulfils field-of-work and professional standards.(5,6) A major focus of Responsible Care is that an integrated care-chain is achieved. Settings and institutions, including care given by GPs, ensure a clear goal – and distribute responsibility and / or coordination with other community organizations, in the areas of care, housing and well-being, to arrange and provide a care package appropriate to the care needs of the client-system. The joint responsibility of these organizations to adopt responsible care and to provide continuity of care lies in making agreements.(7) For people with dementia that means that a proactive and professional attitude at the earliest signs of cognitive decline is a primary condition for responsible care. Moreover, responsible care, for this group - perhaps even more than for those with somatic disorders – is associated with respect for the autonomy of the person concerned. That means a commitment to preservation of identity, dignity, self-esteem and involving the client with dementia and his/her 'care/system' to make decisions about the deployment of 'care input'.

For a high quality integrated care-chain, we therefore used the following definition: a care package/arrangement that is effective, efficient, safe and offered in a client focused way and is tailored to the needs of people with dementia, while respecting their autonomy. The care package/arrangement is provided by institutions and organizations that have agreed a clear division of responsibilities and duties in the areas of well-being, care and housing, and guarantee continuity of the care given.

### 4 NUMBER OF CLIENTS WITH DEMENTIA IN AMSTERDAM

An estimate of the number of clients with dementia in Amsterdam on the basis of epidemiological data is given in Table 3, which includes the size of the population based on data from CBS in 2006. Assuming a prevalence of dementia of 6.3%, there are over 5500 elderly people with dementia in Amsterdam, and the number of clients with dementia will increase by an average of 900 new cases annually. Based on estimated incidence rates, the group of those aged 65-75 years will increase by 129 new clients with dementia. The expected increases in the group of those over 75 years is substantially higher: 793 per year. According to the latest figures, Amsterdam has 1853 dementia [PG] beds. That means that over 33% of clients with dementia reside in a nursing home. If we assume that - according to the estimates of Alzheimer Netherlands – an additional 17% of older people with dementia reside in a 'greater care needs' units in residential care homes, then in Amsterdam reside (= 935 clients with dementia), making the number of people with dementia who live in the community only half of the total number of those with dementia (over 2700), aside from the more than 900 new clients with dementia every year. In 2030, the numbers aged 65+ in Amsterdam is expected to be 121,036 (14.7% of 823,374). Compared to 2007 is an increase of about 37,450 elderly people. The number of elderly with dementia in Amsterdam by 2030 will have increased by 2000, rising to 7,625.

**TABLE 3 PREVALENCE / INCIDENCE OF DEMENTIA IN AMSTERDAM**

<b>Prevalence</b>			
Age	Population	Percentage	Estimate
65+	83,589	6.3%	5.526
<b>Incidence</b>			
Age (years)	Population	Total	Annual estimate
65-74	43,141	2.3-3.6 per1000/yr	99-155
75+	40,448	16.1-22.7 per1000/yr	651-918
<b>Total</b>	<b>83.589</b>		<b>750-1073</b>

#### 4.1 PREVALENCE / INCIDENCE OF DEMENTIA IN AMSTERDAM BY DISTRICT

Table 4. The figures presented for each district are only an estimate based on prevalence / incidence data. Such estimates can be very different from the actual numbers, because retirement and nursing homes are not evenly distributed over the districts. That affects at the district or district level, the percentage of clients with dementia who are living at home. Moreover, the tables do not take into account GPs working part-time. Note: The actual number of clients with dementia living at home should be determined on the basis of data from the data from primary care, once the size and scale for care-chain regions are established.

**TABLE 4 NUMBER OF PEOPLE WITH DEMENTIA PER DISTRICT IN AMSTERDAM**

Prevalence of dementia is 6.3%						
City region	65+	GPs	Number dementia	with	Number dementia clients /GP	of
A. Central	7030	41	443		11	
C. Westerpark	2532	16	159		10	
D. Old-West	2392	22	151		7	
G. Zeeburg	2492	18	157		9	
H. Bos en Lommer	2267	14	143		10	
J. De Baarsjes	2763	11	175		16	
N. A'dam-North	13811	41	870		21	
P. Geuzenveld-Slotermeer	5511	16	347		22	
Q. Osdorp	7373	22	465		21	
R. Slotervaart	6130	16	386		24	
T. Southeast	6757	44	426		10	
U. East/Watergraafsmeer	6371	32	401		13	
V. Old-South	8716	44	549		12	
W.Zuideramstel	9709	32	612		19	



Most older people with dementia live in the city areas of Amsterdam-north, Old South, and Zuideramstel, respectively, 870, 549 and 612. The numbers are significantly less in the areas of Westerpark, Old-West, Zeeburg, Bos en Lommer, and Baarsjes is only between 150 to 175.

In the strongly greying regions (Amsterdam North, Old-South Zuideramstel) a GP annually sees (in addition to his/her existing clients with dementia, which he obviously does not always know!) maximally three new clients. In regions with a younger population base (Westerpark Old-West, Zeeburg, Bos en Lommer the Baarsjes) that is maximally 'one' per year. (Table 5).

**TABLE 5 NUMBER OF PEOPLE WITH DEMENTIA PER DISTRICT IN AMSTERDAM**

City region	65-74	GPs	New per year, 75+ per area		New per year, per area	
A. Central	3988	41	9-14	(12)	30	49-69 (59)
C. Westerpark	1363	16	3-5	(4)	11	19-26 (22)
D. Old-West	1413	22	3-5	(4)	97	16-22 (19)
G. Zeeburg	1516	18	4-5	(5)	97	16-22 (19)
H. Bos en Lommer	1249	14	3-5	(4)	10	16-23 (19)
J. De Baarsjes	1637	11	4-6	(5)	11	18-26 (22)
N. A'dam-North	7176	41	16-26	(21)	66	107-150 (128)
P. Geuzenveld-Slotermeer	2450	16	6-9	(8)	30	49-69 (59)
Q. Osdorp	3622	22	8-13	(11)	37	60-85 (72)
R. Slotervaart	2886	16	7-10	(9)	32	52-74 (63)
T. Southeast	3424	44	8-12	(10)	33	54-76 (65)
U. East/Watergraafsmeer	3278	32	7-12	(10)	30	50-70 (60)
V. Old-South	4691	44	11-17	(14)	40	65-95 (78)
W.Zuideramstel	4140	32	9-15	(12)	55	90-126 (108)

The group people 65+, who lack a 'care network' require specific attention. LASA data shows that 12% of the elderly in Amsterdam do not have any care network, and 9% have only their partner. In addition, the LASA research shows that older people that cognitive dysfunction occur relatively often in both groups, especially the elderly who only have a partner and lack a relationship network with 'care' potential. This means that 21% of the elderly in Amsterdam (= 17,554) has an increased risk that the first signs of dementia will not be noticed in a timely manner. Assuming a prevalence of 6.3% is estimated that in this vulnerable group of elderly, are 1100 clients with dementia. Of course it is not known what percentage of these may already be receiving home care because of some physical condition, or is being cared for in a hospital.

## 5 FAMILY (INFORMAL, UNPAID) CARERS: CARE NEEDS AND OFFERS OF CARE

Given the expected increase in the number of people with dementia in the coming decades and the fact that the care capacity will not grow proportionately, it is increasingly important to ensure effective and efficient services. Especially with the arrival of the WMO act\* the government is returning a portion of the responsibility for care, back to the citizens/people. Care must first be sought in their own circles. Of the healthy citizen, it is expected that he/she participates in the labour force, but simultaneously (more than before) provide care for a sick person in their immediate vicinity. In recent years, therefore more pressure has been applied to carers who combine work and care.

According to figures released by the SCP (2003), two thirds of the carers aged between 18 and 65 years, combine a paid job with providing care. A recent survey of carers of clients with dementia (8), showed that 55% of the carers interviewed provided care daily for a person with dementia and, that 1 in 5 carers of an elderly person with dementia was "seriously burdened". Caring for their loved ones was becoming physically and emotionally difficult, in part, due to the strong sense of "standing alone" in providing the care. One of the effects of 'double aging' (couples) is that in future more care provided by carers well into old age will be required. Older carers will therefore run greater risks of becoming overburdened. It is known that carers have more physical and mental health problems than the general population. (9,10,11) A recent literature review explored the problems and needs of carers.(11) The needs were translated into 14 areas of the aforementioned (Table 2) National Dementia Program.

Carers reported most needs in the areas below:

- 'standing alone in providing care' (the need for support and respite care)
- 'what's the matter and what can help' (information about the illness and care options)
- 'something doesn't feel quite right'
- 'physical care' (need for flexible, high quality care and instrumental assistance)
- 'frightened, angry and confused' (how to deal with unusual behaviours)
- 'miscommunication with caregivers' (need for good contact/ cooperation with caregivers).

They also had a need to continue their own hobbies and their own social life. The Informal Carers Centre (EIZ), the national centre of expertise in the areas of care, identifies four areas where support for carers is needed, which correspond in part to the above-mentioned.

They are:

- . Information, advice and emotional support about (dealing with) dementia, training in care skills and peer contacts
- . practical help: food and shopping service, household maintenance, and temporary respite from providing care (respite facility)
- . material support, including fiscal and leave of absence, and participation and advocacy, such as via 'Alzheimer Nederland' [the Dutch Alzheimer's Society] and LOT.

Support and guidance for carers may lead to a reduction of career stress and thereby improve care. Interventions for carers will only have effect if there is sufficient professional care for the person with dementia. According to the EIZ, sufficient and especially a multidisciplinary mix of care can delay admission to a nursing home from several months to one year. However, care provision can also speed-up the admission if the caregiver becomes aware that they've reached their limits.

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\* The Social Support Act (WMO) says that everyone should be able to participate in society. This involves for example; the removal of obstacles to daily living in and around the home, help with mobility, access to transport and opportunities to meet people and socialise. The municipality is responsible for this and must provide services and support to those who need them, for example, a wheelchair or help with the household.

It is just as important is to know which type of care people/clients need. We are seeing a trend of 'supply-and-demand-based-care' to 'asked-for-care'. A literature survey has shown that elderly people with dementia are rarely asked themselves, what need they have for care and support.(14) During a recent large-scale field study of 236 people with dementia and 322 carers (from the regions of North Holland and Nijmegen) were asked which care needs they had and whether care was available to meet their needs. Using the Camberwell Assessment of Need for the Elderly (CANE), 24 areas of everyday life were investigated; whether people had care needs, and whether their care needs were provided for by volunteer or professional caregivers.(16) For people with dementia, most of their care needs were in the areas of: preparing food, housekeeping, memory, and for managing their finances. The areas where they felt that the care fell short (although sometimes professional help was used) were: help with memory problems, information about their illness, treatment- and care options, assistance in arranging for companionship and for mental/emotional problems. Carers reported shortages, particularly help to support the memory of their loved one, help for suitable activities and companionship.

An inventory of 'care and well-being' provision, in Amsterdam and Nijmegen, shows that in the areas where care needs or shortages are experienced, supply is available. Interviewees indicated may not use offers of assistance because they are not always aware of the offer, or because they thought it no longer had any purpose for their loved one. Even people with dementia sometimes refuse to use the offer, for example for activities or companionship. Even where professional help was accepted, problems still remained. Reasons for this were: that the care that was not tailored enough to individual needs, the amount of care was insufficient and that the regulation of care was often difficult because of the bureaucracy and paperwork. It is therefore recommended- that the information about the care and support services is improved, to simplify access to offers of care, to offer care in a more flexible way and for it to be more in tune with the wishes of people with dementia and their carers.

## 6 SUMMARY

The above information is important for the development of worthwhile dementia care-chain for clients with dementia and their 'care/client system' in Amsterdam. On the basis of demographic data, it was determined that, in Amsterdam, GPs encounter with clients who are developing dementia several times a year. This will need to be taken into account in determining the scale of and size of the regions in which the 'integrated care-chain for dementia' are to be established. Along with the description of the illness process, and the resulting actions that come forth from it, it is essential that clients with dementia and care/client system are closely involved in all decisions about care. This is not only meets the current trend of demand-driven care, but it also shows respect for the autonomy of the person concerned. Also, it appears that care and care needs are not fully connected ('bespoke, customized care ") and that there is already (and certainly in the near future) an increasing proportion of care will be expected of carers. Measures will be needed to achieve a better balance between care and care needs, and in each region there should be sufficient support services and facilities for the carer.

## B. BEST PRACTICE DEMENTIA

### 1 DOCUMENTATION OF THE CARE PATHWAY/PROCESS

The documentation of the care process that is supposed to lead to qualitatively good care, can be separated into several phases, and focused on the activities that are supposed to lead to good delivery of care, from the signalling of a problem through to the evaluation of the procured care. The activities are worked out in terms of the actions of a client (system), and the actions of caregivers. Aside from the documentation of the care process and the actions that follow forth from it, it is of great importance for the maintenance of the quality of life of the client (system), that the caregiver has enough knowledge. That includes:

- knowledge about the progress of the illness and complications
- to be able to work with the diminishing abilities of clients
- to be able to work with the reduced reciprocity in the care process
- to be able to observe and signal, and see the relationship between behaviour problems and the influence of environmental and personal factors
- to acknowledge people as individuals regardless of their diminishing abilities
- to explore meaningful activities with the person
- to support a person by helping to maintain their social support network

The various phases of the care process, collectively, bring the whole chain of activities in focus (care chains), which are represented in the care pathways (see diagrams on later pages).

N.B. These care-chains describe the whole process, from the first signals through to intramural care. This includes not only permanent residence in a nursing home, but also temporary admission to a general hospital, mental health care facility, or a residential and nursing home setting.

In this account, we have tried to bring the whole chain of care for a client with dementia in focus, including the role of the Dementia Care Coordinator (DCM) for clients who are temporarily admitted to mental health care, hospitals, or in day care or 'meeting centres'. (Tools are provided in later appendices.) ['Meeting centres' are specialist centres. For a description see Dries et al (2006), The Meeting Centres Support Programme model for persons with dementia and their carers: aims, methods and research. In: Vol 4, Care-giving in Dementia. BML Miesen and GMM Jones (Eds). Routledge, London. Pp315-340. ]

The following phases can be distinguished:

- signaling of the problems
- diagnostics
- setting up the care plan
- executing the care plan
- evaluating and adjusting the care plan

In sections 1.1 to 1.5, the care process will be described from the view of the person/client with dementia who is still living independently at home. In section 2 the situation of a person who is no longer able to live independently is described.

#### 1.1 SIGNALLING THE PROBLEM

The early signalling of memory problems or behaviour change is of great importance. Early recognition makes timely intervention possible. This is a great importance for the maintenance of the quality of life of the client

(system). The actions which follow from this:

- Client/family carer note forgetfulness or changed behaviour and seek information about this problem (for example, with the Alzheimer's Society). Eventually the self-test 'Recognize Dementia in Time' (RDIT) will be administered (see Appendices). This requires that each district makes available information which is easily accessible
- The client/carer seeks contact with caregivers: directly with the GP, the community nurse or a member of Home Care (Personal Care assistant), those who help with care for other reasons, the community contact centre, the Alzheimer Society Branch, Alzheimer Café or Elderly Advisor
- The caregiver names the problem of the client and administers the UFAR Index and the IQCODE-N to objectify the forgetfulness and distinguish between early dementia and normal forgetfulness. This assumes that caregivers must be educated to recognize signals that point in the direction of dementia, and must be able to administer and interpret the UFAR Index and the IQCODE-N.
- If the caregiver is not the person's GP, then they provide suggestions about various possibilities for tackling this problem, and advise the client (system) to take up contact with the GP, or contact the GP themselves, preferable with the agreement of the client (system).
- The caregiver, also the GP, report the client to the CARP centre to prevent that the client experiencing forgetfulness will be lost from sight, and only come into the care system during a crisis situation (beware of care avoiders and clients who deny or trivialize their problems). A community registry point will need to be established (see later).

There are diverse approach routes to starting to receive the necessary care and support. Most clients will presumably come via the GP, but the remainder will have, in each town, or other geographical area, an independent so called 'Care and Society' Information-Booth where questions and answers about well being can be given. Important functions for the booth are 1) giving information about available services, with or without particular need and 2) assistance with administration and questions. The particular information available at the information-booth will vary depending on the location.

In the early stage of dementia, the emphasis on 'well being' is of importance, including the social contacts and use of free time of the client and carer. As the illness process continues, there comes a turning point whereby professional help will be jointly needed. That turning point will vary by individual and should, by preference, be determined by the Dementia Care DCM [a case manager].

## 1.2 DIAGNOSTICS

- The GP does the illness diagnostics and also makes use of the NHG (standard version) supported by the Old + MMSE, or the TRIADE. Also, the GP determines whether a person's physical condition or afflictions are of influence on the clinical picture and eliminates possible new illness. The GP is primarily the designated expert to perform the basic diagnostics of dementia. It is expected of him/her to have a proactive stance with respect to dementia. Where they are lacking experience and where the 'care diagnostics' are complicated, the GP can decide to ask an employed, extramural geriatrician (or old age psychiatrist) to consult (more details follow). With such a consultation, a direct request and agreement about what will and will not be of essential importance in terms of the management role that the GP has (17).
- A dementia care programme is the whole made up of specified, integrated activities and arrangements, directed toward offering specified services or making proposals to achieve particular effects for the benefit of a specified group of people who have similar difficulties or care needs. A dementia care programme contributes to the working/objective of a care-chain. Cooperation between the various care sectors is one of the starting points.]

Clear referral criteria (**Table 6**) are necessary because investigating the type of dementia a person has, is a

condition of providing accountable/ responsible care. The guidelines, following hereafter can be maintained, when the primary diagnostics have been completed.

TABLE 6 GUIDELINE REFERENCE CRITERIA FOR

**THE DIFFERENTIAL DIAGNOSTICS OF DEMENTING ILLNESSES (18)**

	Alzheimer’s Disease	Other dementia or unclear
Little or no co-morbidity	<p>A. There is evidence of a ‘possible diagnosis’ of Alzheimer’s disease. Client is <i>younger</i> than 70. The client is only be referred to the multi-disciplinary (neurology) memory clinic for detailed diagnostics and cholinesterase inhibitors [or other anti-dementia drugs]. The GP and dementia care coordinator maintain the management.</p> <p>B. There is a likelihood of a ‘possible diagnosis’ of Alzheimer’s disease, no evidence of co-morbidity. Client is <i>over</i> 70. The GP and dementia care coordinator maintain the management. The GP can also decide to consult with a working geriatrician or old age psychiatrist – naturally with agreement from the client (system). Eventual referral to a multi-disciplinary memory clinic for anti-dementia drugs (e.g. cholinesterase inhibitors).</p>	<p>A. Client is <i>younger</i> than 70. Client is referred to the multi-disciplinary (neurology) memory clinic for diagnostics, eventual treatment and additional assistance.</p> <p>B. Client is <i>over</i> 70 but without complex difficulties. Client is sent to the multi-disciplinary memory clinic for diagnostic assessment only. The GP and dementia care coordinator maintain the management of the client and can, after diagnostic findings refer the client to a working extramural geriatrician</p>
Much co-morbidity	<p>A: Client is younger than 70 and there is a likelihood/evidence of much co-morbidity. Referral to a multi-disciplinary memory clinic is indicated when physical conditions appear to have an influence on the clinical presentation.</p> <p>B: Client is older than 70 and there is a likelihood/evidence of much co-morbidity. Referral to a multi-disciplinary Memory clinic, (clinical geriatric day-clinic), is indicated. After the diagnostic work-up, the GP can utilize the geriatrician for additional assistance.</p>	<p>A: The client is <i>younger</i> than 70 and there is likelihood/evidence of much co-morbidity. Referral to a multidisciplinary memory clinic is indicated. After the diagnostic workup, GP can decide to utilize an extramural working geriatrician</p> <p>B: Client is <i>older</i> than 70 and there is likelihood/evidence of much co-morbidity. Referral to a multi-disciplinary (day-clinic) – clinical geriatrics is indicated. After the diagnostic work-up the GP can utilize a working extramural geriatrician.</p>
<p>If there are psychiatric conditions/difficulties or serious behaviour problems in the foreground, then the GP can decide, only for additional diagnostics relating to dementia and decisions/ treatment of the psychiatric problems, to refer to the Old Age mental health services.</p>		

TABLE 6 GUIDELINE REFERENCE CRITERIA FOR

**THE DIFFERENTIAL DIAGNOSTICS OF DEMENTING ILLNESSES (18)**

	Alzheimer’s Disease	Other dementia or unclear
If there is a likelihood/evidence of complex care problems, the GP can in all cases decide (aside from the illness diagnostics done at the multi-disciplinary memory clinic) utilize a working extramural geriatrician. Agreement about tasks and responsibilities with the GP must then be made.		

\*=Richtlijn Diagnostiek by Dementie in Middeen

- In discussion with the GP, together with the client (system) and the [possibly] involved home-care or personal care workers, - a dementia care coordinator (DCM) is appointed - who will support the GP. The DCM, together with the client/ carer, is responsible for setting up, and controlling the delivery of the care plan. The DCM is the point of contact; keeping an eye on, accompanying the client and carer, offering guidance, advocating, and coordinating, and managing the organization of home care, personal care, nursing, domiciliary care, and initiating ‘well being activities’, through the entire illness process. This vision requires that the DCM needs to be appointed in an early stage of the illness process. The DCM should be someone of at least a professional health care background (post secondary professional qualification/ c=HBO-V niveau), for example a nurse with expertise in dementia or a practice-specialist or nurse-specialist (see detailed job description in a following section).
- The DCM does the ‘care diagnostics’ by compiling an inventory of care needs by asking about the aspects of functioning shown in the ‘care diagnostics’, **Table 7**. Potentially, the CANE Tool (Camberwell Assessment of Need for the Elderly) can also be used.
- After the care diagnostics process, **the client (system)** knows what is happening, is adequately informed about dementia and potential changes in functioning, knows what the psychosocial consequences and care-requests/care-needs are, and knows what they can expect for any necessary aspect of care and support

TABLE 7 **CARE DIAGNOSTICS** (19, 20, 21,22)

<p>Decisions about the limitations caused by, and management of the consequences of dementia</p> <p>Is there evidence of co-morbidity?</p> <ul style="list-style-type: none"> <li>• Make an inventory of medication use. Who oversees it? Is it taken safely and as intended?</li> <li>• Are there sensory limitations (eg vision, hearing, touch)?</li> <li>• Is there movement difficulty or restriction? Any tendency to having falls?</li> <li>•</li> </ul>
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TABLE 7 CARE DIAGNOSTICS (19, 20, 21,22)

Are there functional consequences?

- Determine (I)ADL functioning using the IDDD, a tool developed specifically for clients with dementia
- Is there need for help with maintaining the household?
- Is there a need for personal care?
- Assess nutrition and hydration and the use of any substances (eg alcohol)
- Do any adaptations need to be made to the living environment?

Are there psycho-social consequences?

(Check how the person with dementia and their carer, other family and friends cope with the consequences of dementia: for example, what does having this illness do to their self-image, their emotional and social functioning?)

For the client:

- Assess the extent of the person's illness-awareness and illness-insight
- Determine how the person with dementia is reacting to the consequences of their dementia (if needed use Cornell Scale for Depression)
- Assess whether there are any behaviour difficulties (triggers, frequency, severity, and links to other variables such as time of day) and find out whether they are explainable by cognitive limitations (for example reduced language ability and illness-insight), medical problems, unusual happenings, medication, alcohol, interaction with the social environment (if in doubt about depression, administer the Cornell Scale)
- Assess personal safety, risk behaviour, and any neglect
- Assess the person's day-structure and activities
- Assess the need for (more) social contacts
- Is the client(system) able to take responsibility for finances or does a legal representative need to be appointed
- Are there any other types of assistance required (such as transportation, recreation, support, etc.)
- Does the client require additional information about his/her health situation, treatment and support interventions?

For the carer and support network:

- Assess how the carer responds to the consequences of (any of) the behaviour changes in the person with dementia
  - Assess the social network of the carer and existing help and support
  - Assess the subjective burdens and strengths of the carer with the help of the DEBIC [EDIZ]
  - Check for the presence of risk factors for excessive burden on the carer (physical complaints, mental complaints, their care-strategy (confrontations or assistive-caring), little knowledge/understanding of symptoms, little social support, a poor quality relationship with the person with dementia)
- Does the carer require additional information about the health of the person with dementia, and support and treatment options?

### 1.3 WRITING THE CARE PLAN

- The client/carer indicates what he/she sees as the goal of care, and what he/she wants to achieve. Formulating care goals is done together with the DCM. (Possibly, as a guide, the fourteen problem areas listed in Table 1 from the LDP can be used.)
- Depending on the problem/need areas (as determined by the above inventory of care needs and those in Table 1), a care plan is developed by the DCM in conjunction with the client/carer. It is subsequently agreed with the directly responsible GP
- The care plan lists the interventions intended to improve, stabilize, support, or conform to any earlier written goals of the care plan, the client and carer.



- The care plan specifies both the type of help which is desired and which is imperative. Normally, it will largely be about which care and professionals are required.

N.B. At this time there is a great change underway in the conceptualization of and organizational principles in nursing care needs and residential care needs. The entire care sector will shortly be changing over to 'norms and trial framework' for responsible care, wherein the quality of live of the client is determinate, and attention will be given the following domains: Domain A - physical health; Domain B - living and life environment; Domain C – social skills; Domain D – mental well being. (23,24) Since this 'domain concept' has not yet fully crystallized, the PASPC [in Dutch - SAMPC] method is being maintained (Table 8).

TABLE 8 CARE PLANNING WITH PASPC [SAMPC] MODEL

Aspect of care	Action plan	<u>Delivery of agreements:</u>
<b>attention and action points</b>		
<b>(P)hysical/bodily</b>		
Medical history: <ul style="list-style-type: none"> <li>. Existing complaints</li> <li>. Medication</li> <li>. Doctors appointments/ investigations</li> <li>. GP contact</li> </ul>	Treatments with medication/s: <ul style="list-style-type: none"> <li>. anti-dementia drugs</li> <li>. neuroleptics</li> <li>. antidepressives</li> </ul> Depending on the diagnostics, put observations points in the care plan  Compliance, safety and supervision with taking medications is essential	Coördination and observation by the DCM  Coordination and information and of agreed actions by the DCM
Appointments with various health care professionals /therapists/caregivers (e.g. occupational therapy, physiotherapy, speech and language therapy, rehabilitation)		Supervision and support after the treatments by a appropriate caregiver e.g. for taking medications
<b>(A)ctivites of daily living</b>		
<ul style="list-style-type: none"> <li>. physical care</li> <li>. eating/drinking</li> <li>. mobility</li> <li>. sleep</li> </ul>	In case of deficits mobilize Home Care to provide: <ul style="list-style-type: none"> <li>. help via domiciliary care in combination with guidance for managing housework</li> <li>. personal carer</li> <li>. support for maintenance of daily routine (via planned visits)</li> <li>. planning for assistive devices in the home</li> </ul>	DCM monitors any changes in care needs
<b>(S)ocial functioning</b>		

TABLE 8 CARE PLANNING WITH PASPC [SAMPC] MODEL

Aspect of care	Action plan	<u>Delivery of agreements:</u>
<b>attention and action points</b>		
. social situation . accomodation . work/day routine . transport . groceries . household maintenance . administration	. Organizing the day structure / use of time in conjunction with Home Care workers and Well-being assistant,  . Transport, administrative support . Recreational support	Well-being assistant, in conjunction with the DCM to monitor safety in the home environment
<b>Carer</b>		
Burden experienced by the Carer. make an inventory of objective and subjective, strengths and demands upon the carer	guidance/ support the client (system)  e.g. family gatherings, attend Alzheimer Café,  <i>Meeting Centre activities, carer support meetings, discussion groups, respite care</i>	<i>DCM organizes and monitors</i>
<b>(P)ychological/mental functioning</b>		
. cognition . emotion . behaviour	. Meeting centre . Alzheimer Café . Organize Day Care . Psychological education	<i>DCM signalling of any changes to the 'central registry point [cent melding]</i> <i>DCM organized any possible (temporary) admissions to care settings.</i>
<b>(C)ommunication/perception</b>		
Deficits eg language, speech, hearing, reading, writing	<i>Dependent on the diagnosis set up care plan goals</i>	depending on the diagnosis set up care plan

The DCM makes the required arrangements with the most suitable professionals and service providers. Throughout care provision, the DCM monitors the process, how it is being received, and its suitability given the needs.

- . Possible financial implications of the care plan, and the required actions are discussed with the person/**client** (system)
- . Person/**client** (system) agrees with the care plan and its delivery

#### 1.4 DELIVERY OF THE CARE PLAN

- The DCM organizes and coordinates the use of the required caregivers/professionals in agreement with the care plan action points
- The DCM has a central management function role and coordinates the multi-disciplinary care plan

and sees to it that it is appropriately delivered

- The required caregivers/professionals comply with the agreements in the care plan and report progress to the DCM
- If the care plan activities stagnate, the DCM seeks a solution
- The professionals and caregivers involved report, in writing, about the agreed arrangements in the care plan, and at least half-yearly the progress of the planned care activities directly to the DCM. (Depending on the stability of the problem, and eventually, this will be done electronically in a client dossier)
- The DCM reports their findings in the client dossier. (This requires that an electronic client dossier be developed, which all the professionals and caregivers involved in providing care have access to, and can report their notes)
- The DCM prepares a summary of the progress of the multi-disciplinary activities agreed, and evaluates the care plan

### 1.5 EVALUATION AND ALTERATIONS OF THE CARE PLAN

- The care plan, independent of the agreed arrangements in it, is reviewed half yearly by the DCM, GP and client (system). Points for discussion are whether the care offered is meeting the needs even though there may still be problems, and if there are any changes in the (health) circumstances of the client or client (system), which means that the care input is not meeting the goals
- The DCM evaluates the effects of care offered in relation to the goal/s and the effect of the care given to the functioning of the client (system). Of importance is that the quality of care offered is of an appropriate level. (This means that there must be an investment in the education, advice and consultation given to professionals and volunteers. This can be done individually or in groups in the form of education and clinical lessons. The social-psychiatric nurse specialist and old age psychiatrist from the Mental Health Division have obvious expertise because of their knowledge with regards to behaviour difficulties) With regard to the evaluation of the care input, all aspects of care (see details hereafter) must be reviewed. As well, subjective quality indicators must be used (a 'client satisfaction' scale). Evaluation takes place at least half-yearly, more frequently if needed, depending on the situation. Evaluation is done on a multi-disciplinary basis.
- The DCM determines whether the care provided is appropriate to the stage of dementia, and assesses client satisfaction. If there are relevant changes in the health circumstances of the client or carer, the previous steps in the care plan are repeated.
- If there is a complex care situation and/or additional diagnostics are required, then the GP and/or the DCM consult the 'expert team'. If the situation requires only supplementary diagnostics then the GP can also recommend secondary care (Residential care, nursing home care). (*This assumes that, at district level, an expert team must be available*)

## 2 THE CARE PROCESS WITH THE LOSS OF INDEPENDENCE

In many circumstances there comes a time in the illness process when independent living is not longer possible. The transition to a permanent living environment other than one's trusted home, is both the client and carer one of the most radical happenings. It is of great importance that this transition occur smoothly, through, in the previous stage, to make as much use of the care possibilities outside of the home environment: Meeting Centres, Alzheimer Cafes, Elderly Societies, day care, day treatment, temporary admission to a specialist respite care setting, weekend care, night care, vacation admissions to respite care, admission for medication control/adjustment, and 'acclimatization visits and days'. Utilizing such options for quickly intervening and managing threatening care problem-situations (crisis situation), can encourage carers to continue caring at home, longer. That also holds true for temporary admissions which currently, because of waiting lists, are difficult to effect. It is the task of the DCM to manage the transition to the new care/living environment, to make it as good as possible. He/she must be aware of specific waiting lists in the Residential

Home and Nursing Homes in the area, and can also ask the advice of the 'Expert Team' (see details).

Nursing home care is an integral package of care and an intervention which can happen within and without the walls of the nursing home, – in different living circumstances can be offered, whereby the choice of the living situation is determined by personal choice, the limitations of functioning and specific consequences of an illness. The possibly variations include:

- Complete nursing home care at home, although not in combination with the structured day activities / day care (with treatment)
- Living in a care centre/ residential home/ in an independent apartment within a clustered living complex, although not in combination with the structured day activities / day care/ day care with treatment, or exclusive adjunct treatment by a geriatrician
- Living on a 'additional care unit' in a care centre, although not in combination with the structured day activities / day care/ day care with treatment, including adjunct treatment by an [on-site] geriatrician
- Living in a stand-alone complex for small-scale living, clustered living groups
- Living in a small-scale setting in a living-service neighbourhood, where managed functions are reasonably close at hand
- Living in a small scale setting (living group) within a nursing home
- Living in a traditional nursing home

### 3 'BEST PRACTICE DEMENTIA CARE'

If responsible dementia care is to be guaranteed according to 'best practice', than all the parties in the chain-linked care model need to underwrite it and make agreements about working together. Furthermore, the following conditions need to be met (the numbering of the items has a special significance): the availability of readily accessible information about forgetfulness and dementia for the client and carer (eg via folders, CARP centre, Alzheimer Cafés, internet, library, etc.)

- . caregivers have been educated to recognize the signals which can point in the direction of dementia, and know how to make use of standard procedures
- . the application of a standard procedure for the (illness) diagnostics of dementia by GPs with experience in this area, or through extramural geriatricians
- . the availability of and application of referral criteria for the nosological diagnostics to be able to distinguish between different types of dementia
- . the presence of a centrally located CARP centre, where all clients with forgetfulness are registered, and from where, possibly also DCMs will be assigned, or from where it will be arranged 'who will function as a DCM'
- . the assignment of a DCM (who has at least HBO-V qualifications),
- . already in a very early stage of the illness process the presence of a care plan that is based on the care needs of the person/client and care/system
- . the regular provision of information, advice and consultancy to professionals and volunteers to ensure the quality of the care
- . the availability of an Expert-team (at district level) that can be consulted by the DCM and GP
- . the regular evaluation of the quality of care being delivered using objective and subjective (person/client-oriented) quality control indicators
- . the development and procurement of a transmural electronic client dossier

The essence of a 'best practice' model is that :

- . all signals about forgetfulness will be registered, whereby early diagnostics are possible
- . a close working relationship between the GP, DCM, and CARP centre exists so that continuity of care and support is guaranteed from the earliest stage of the illness, also if the client refuses diagnostics
- . there is adequate mobile expertise available also to treat complex problems (Expert-team), and
- (d) through regular (ongoing) education the quality of care will be maintained.

The role of and the cooperation between the primary care and DCM in dementia are central in this model. Of essential importance, is that (paid) caregivers recognize the first signals of dementia and are able to administer the IQ-Code or UFAR Index. Anticipating can prevent crisis situations, but early signalling can also lead to peace of mind. To prevent that a client with suspected dementia 'disappears from sight' if he/she refuses

contact with the GP (for illness diagnostics), there is the possibility that, in discussion with the GP, a DCM is assigned, at least to make an inventory of the care needs and potentially to put care into place. At the same time, the assignment of a DCM offers the possibility to build up a trusting relationship and to motivate the person/client for later assessment.

In addition to the central role of the GP and DCM, the Expert Team has a pivotal function in maintenance of the contact with the CARP centre, in supporting the GP and DCM and if a case concerns complex care – and/or illness diagnostics, in advising with regard to the management at the six-monthly evaluation of the care plan. In the following paragraphs the role and function of the DCM, the CARP centre, and the Expert Team are described in further detail.

## 4 DEMENTIA CASE MANAGER (DCM)

### COMPETENCY PROFILE

It is expected of the DCM that he/she is in possession of the following competencies (25):

#### KNOWLEDGE

- . The DCM has a post-secondary professional qualification [Dutch HBO-level education]. A background in nursing is preferable but also other backgrounds are possible (eg social worker, social-psychiatry nurse[SPV], a relief-doctor for GP practices)
- . The DCM has knowledge about physical and psychological afflictions that arise in older people
- . The DCM has specific knowledge about dementia the functional and psycho-social consequences (eg behaviour difficulties, problems that carers face)
- . The DCM has knowledge about social events and programmes in the region where he/she is working
- . The DCM has knowledge about relevant legislation, and legal guidelines pertaining to care for people with dementia

#### EXPERIENCE

The DCM has professional experience with clients with dementia.

#### COMMUNICATION

- . The DCM is able to maintain good communication with the client, carers, other staff assisting in care and agencies
- . The DCM is able to build an effective trusting relationship with the client and carer
- . The DCM is able to provide a basic form of psychological education to the client and caregiver

#### Collaborative work

- . The DCM is able to effectively work with all professionals in the 'care-chain'
- . The DCM is able to work in a team context

#### Professional actions

- . The DCM is client-focused and needs led
- . The DCM has sufficient analytical abilities
- . The DCM is pro-actively minded to help prevent problems
- . The DCM is able to work independently and take decisions independently
- . The DCM has the ability to coordinate, monitor and evaluate the care allocated to the client and if necessary to make adjustments to it

#### TASK DESCRIPTION

- . Home visits to person/patient(system) also when there is not yet a diagnosis in place
- . 'Intake [into the care-chain] discussion' with the client (system), setting up care and plan to provide care
- . Provides information and advice to the client and client (system) about the consequences of dementia and possibilities for care and assistance
- . The DCM is the point of contact for the client (system) and, together with the client/carer, is responsible

- for carrying out of the care and assistance plan
- . The DCM keeps an overview of, guides, the client and carer, advises, advocates and mediates for, and coordinates, has the management of organizing home care services, nursing, domiciliary assistance, and the putting in place of services and well-being activities during the illness process
- . Maintains contacts with co-workers and others in order to optimize client care
- . Maintains contacts with clients, carers and family. Executes the necessary 'system interventions' to get those involved working along 'the same line'.
- . Maintains contacts with caregivers and other institutions/organizations such as GPs, hospitals, home care organizations, co-workers in Mental Health services, day care and 'Meeting centres'
- . Organizes 'Care Plan Review Meetings [MDO's] at least six-monthly for each client
- . Keeps the client reports and client dossier up to date
- . Evaluates the effect of the care input
- . Determines whether the care input is suitable to the stage of dementia, and the needs of the person with dementia and the client system, and judges client satisfaction. If there are relevant changes in the health circumstances, repeat one of the previous steps in the chain of care.
- . Carries out crisis intervention. Seeks solutions with the client (system) during 'threatened' emergencies
- . Is the contact point clients/ GPs/ organizations in a defined area/district/region
- . Signals gaps in the care in a region and reports this to management
- . Contributes to the development of the case management

#### ROLE OF THE DCM DURING TEMPORARY ADMISSION

Good communication is necessary during temporary admissions to a hospital, mental health setting, temporary residential home, nursing home and day care (in short: for all 'times of care transference'). Insufficient communication about care, the functioning and behaviour problems of people with dementia can lead to a complicated course of stay during the admission, delay in discharge, unnecessary functional deterioration of the client and insufficient (agreed) care after discharge.

To prevent this, at the time of admission, it is expected that the DCM that he/she will, as soon as possible make contact with the Transfer Nurse of the institution where the client is. Herewith, the following information should be provided:

- . Name and telephone number of the DCM (to be noted in the nursing documentation/notes)
- . Role of the DCM in the home situation of the client
- . The care being offered for admission and the 'bottlenecks' involved
- . Level of functioning prior to admission (also before and during illness episode)
- . Behaviour problems prior to admission (also before and during illness episode)
- . The DCM requests the Transfer Nurse to let him/her know in good time about the date of discharge in regard to recommencing with care after the period of intake. This will be documented in the nursing charts/documentation.

#### 5 FUNCTION OF THE 'CARP CENTRE' AND THE EXPERT TEAM

**The function of the CARP centre is** the central registration point for all reported signals about people with forgetfulness and dementia in the community [district/region]. Also clients and those that support them can ask questions at this location, eg to prevent crisis situations arising. The coordinator of the CARP centre refers the client to a suitable DCM and informs the GP who this is. The DCM maintains close contact with the CARP centre. A CARP centre can be coupled to a community health-related information-booth, a care facility or a GP practice. The care-territory of a CARP centre is dependent on multiple factors, such as the number of clients with dementia who are living in their own homes in a region, the existing services which thus could be expanded, a collective of GPs who want to function as a CARP centre.

It is of importance that the CARP centre is a 'low-threshold' service, where knowledge about dementia is available, and where CARP staff also know which social activities are available for people with dementia in the community. (It doesn't have to be a 'physical' place.) This place in the community has contact with GPs and

the DCM. The CARP centre can also make use of the Expert Team. The CARP is independent and can maintain contacts with all 'care and well being services' and 'service providers'.

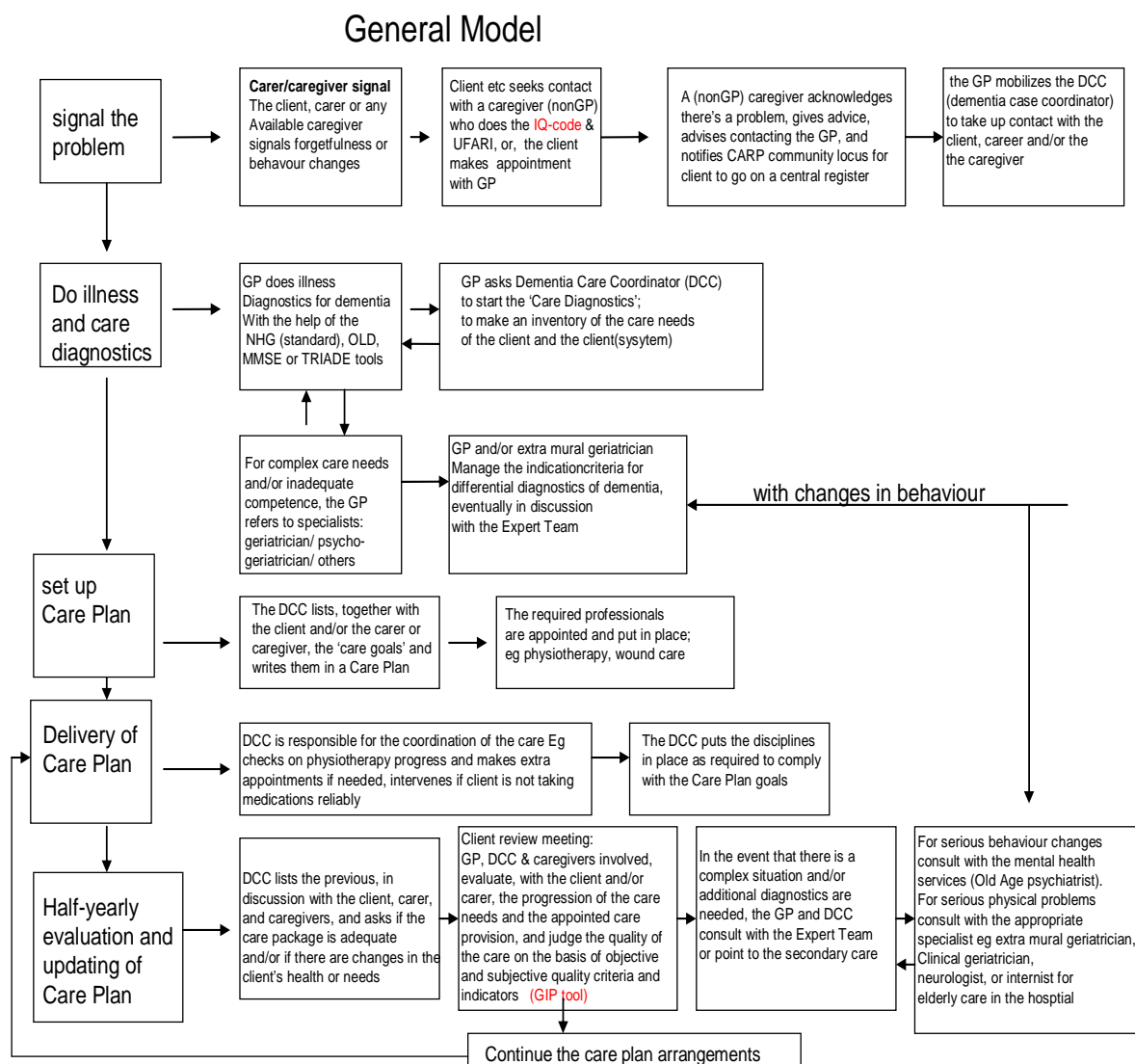
**The Expert team comprises of**, among others, the DCM, a working extramural geriatrician, the local government 'Elderly Care and well-being Advisor/official' [ouderenadviseur (welzijn)] and a 'social-psychiatry nurse' [SPV]. The Expert Team is closely linked with (in every instance the DCM) and the CARP centre. The role of the Expert Team is to support the GP when complex and crisis situations arise and require treatment or intervention. The coordinator of the CARP centre is simultaneously the case coordinator of the Expert Team. The members of the Expert Team report cases which they wish to discuss to the coordinator of the CARP centre. At the request of the GP the Expert Team in this instance, the working extramural geriatrician, can temporarily take over the responsibility of the care. An important task of the DCM – who is closely linked to the CARP-, is to start action when forgetfulness and early dementia are signalled.

# C FLOW DIAGRAMS

## 1 FLOW DIAGRAMS FOR DEMENTIA CHAIN-CARE

The flow diagrams provided in this section give schematic information about the care process. The first flow diagram below (Figure 3), provides the model of the care process. In the following three flow diagrams (Figures 4-6), the progression of the care process is shown using various illness histories (cases).

**FIGURE 3 MODEL OF THE GENERAL CARE PROCESS**

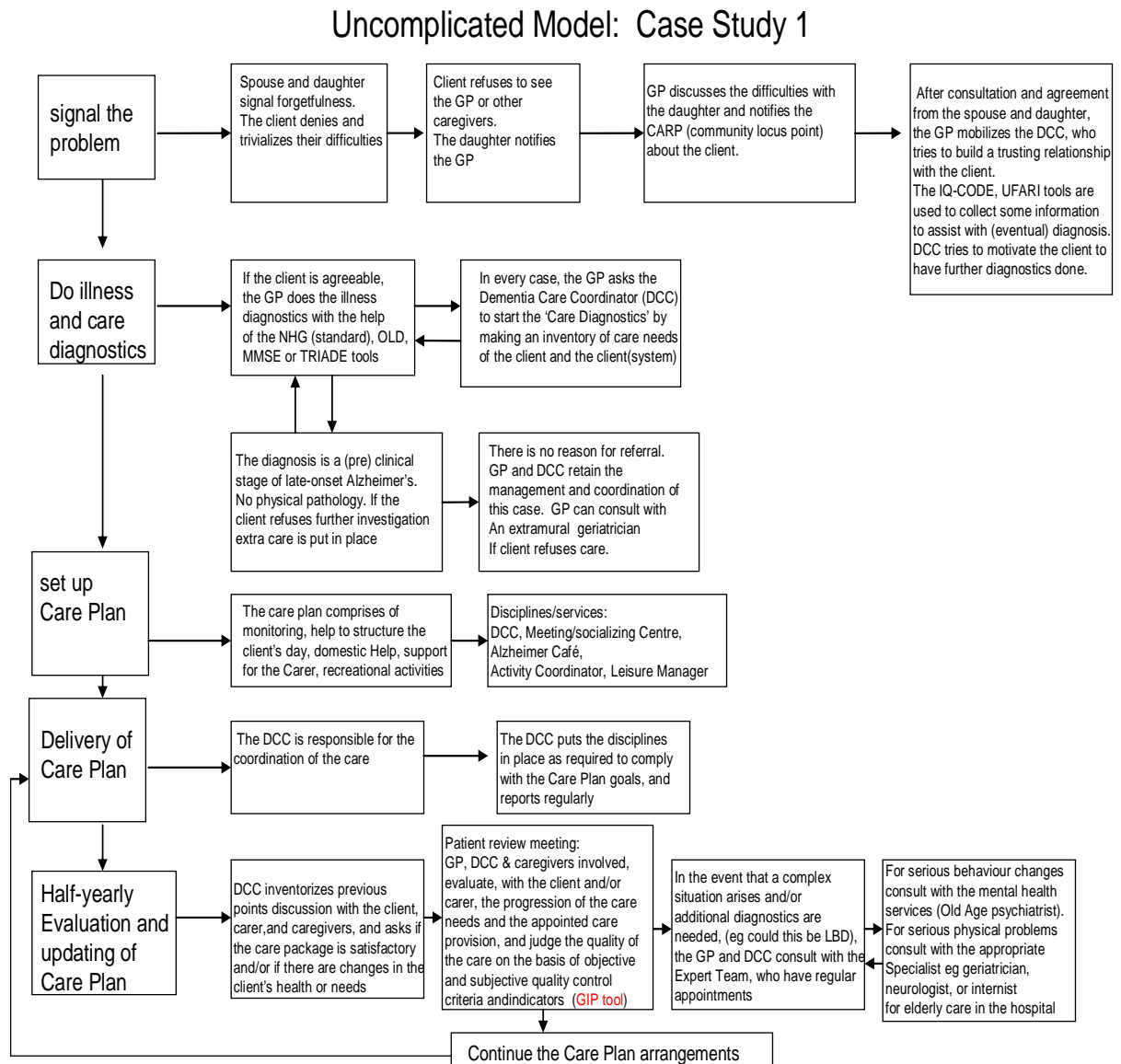




CASE 1

A 78 year old gentleman, married, is gradually becoming forgetful. His physical health is good. Since his partner has severe rheumatoid arthritis, the household work rests mainly with him. The last while he has forgotten groceries or buys the same things twice, and burns the dinner. His wife confronts with his worsening memory and advises him to visit the GP. He does not want to and becomes irritated- he thinks things are still fine. Even more so, he feels responsible for her care. His daughter has also noticed that her Dad is becoming more forgetful, and informs the GP (See Figure 4, Case 1).

Figure 4 Flow diagram for case study



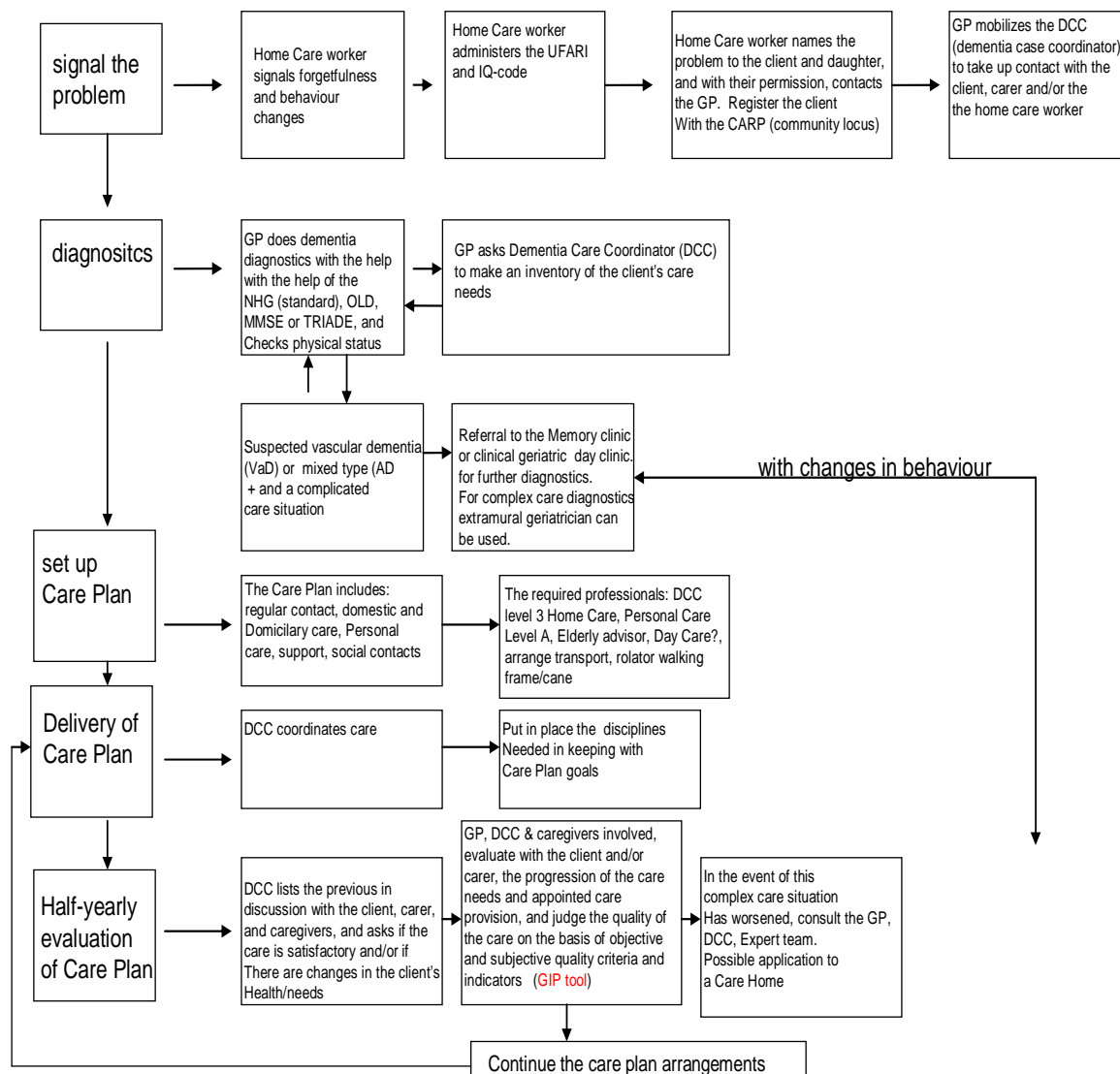
CASE 2

For several years a Personal Care worker from Home Care services has been helping a 79 year old lady, Mrs. Halsteren, who lives alone. She is an insulin-dependent (late-life onset) diabetic, has an 'open leg ulcer', chronic rheumatism and Chronic Aspecific Respiratory Disease [CARA]. With the help of a walking stick she can

still move around the house. She needs help to wash but can get to the toilet independently. Her daughter does groceries for her three times a week. The caregiver has noticed that the last while Mrs. Halsteren is slowing down, forgetting appointments and that she is sometimes mixed up about what day of the week it is (See Figure 5, Case 2).

FIGURE 5 FLOW DIAGRAM FOR CASE STUDY 2

### Complicated Model: Physical comorbidity, Case study 2

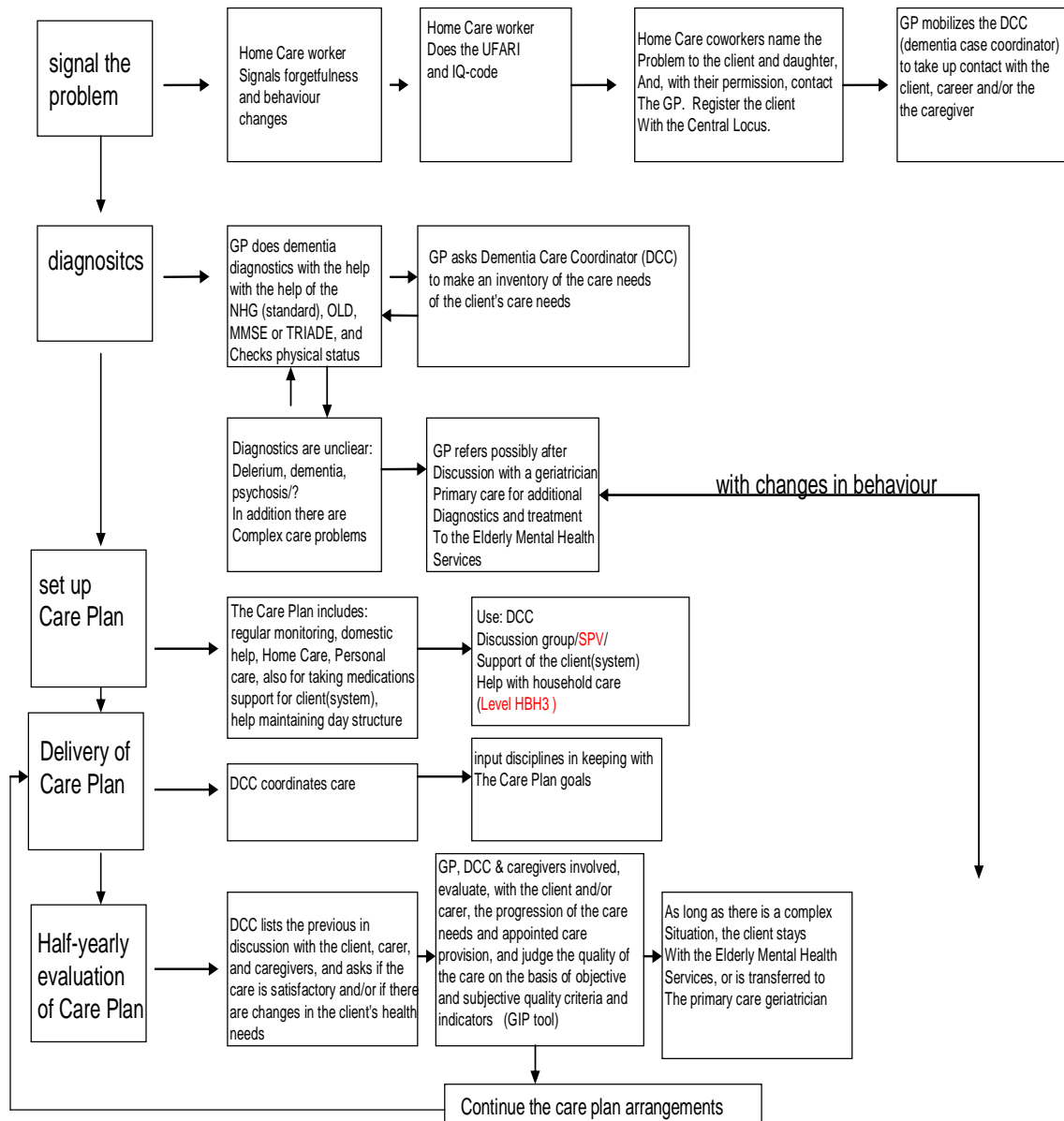


### Case 3

A 70 year old gentleman, who lives with his spouse, has already been known to be in an early stage of Alzheimer's (MMSE 19) for two years. His is in good physical health. His whole life he has worked in construction as a carpenter. His has two children, and his son, who is a public notary lives only a few kilometers away from them. His spouse has some difficulty managing the household on account of her chronic rheumatism. She gets help domiciliary help twice weekly from Home Care. The past months he is becoming increasingly suspicious, and sometimes says he sees people sitting in the living room, and especially in the evenings is not always able to recognize his wife and home. At these times he wants to leave and becomes agitated if his wife tries to stop him (See Figure 6, Case 3).

FIGURE6 FLOW DIAGRAM FOR CASE STUDY 3

### Complicated Model: Psychiatric comorbidity, Case study 3



## D IMPLEMENTATION

### 1 IMPLEMENTATION

In this section, the whole course of implementation will not be described - only single aspects which are of importance, in the judgment of the 'StIDA Initiative work-group', in regard to the implementation of the dementia care-chain.

#### QUALITY INDICATORS

In order to deliver qualitatively good chains of care, it is important to have information about the quality of aspects of the care delivered. This quality must be measurable and ideally comparable to a norm, so that departure from the norm is able to be steered back in aid of the quality of the chain-of-care.

A 'quality indicator' is a measurable aspect of the care which that can give an indication about the quality of the care (Colsen & Casparie, 1995). Three types of indicators are often distinguished between:

- . **Process indicators:** these give an indication about the course of processes within an organization or between organizations in the chain-of-care
- . **Structure indicators:** these give an indication about the organizational terms and conditions within which the organization or a chain-of-care can deliver care
- . **Outcome indicators:** these give an indication about the outcome of the care

A quality indicator is always defined in relation to the quality goals which are set. The definition for good quality for dementia chain-care is: a care arrangement that is goal-oriented effective, safe, is given in a patient focused way and is adjusted to the need of people with dementia with respect for their autonomy. The care arrangement is delivered through institutions and organizations which have a clear task- and have distinguished between responsibility on the grounds of well-being, care and living, and guarantee continuity of care.

In order to realize these goals a number of aspects of best practice dementia chain-care were defined, which can serve as departure point for the description of quality indicators. In Table 9) these quality indicators are reproduced as well the measurements and suggested norms for them.

TABLE 9 QUALITY INDICATORS AND THEIR MEASUREMENT			
Process indicators			
Goal	Indicator	Measurement	Norm
GPs must apply/use a standard procedure for the (illness) (ziekte) diagnostics of dementia (possible explanation: NHG, OLD, MMSE, TRIADE)	GPs utilize a standard procedure for (illness) diagnostics for dementia	DCM (dementia casemanager) checks to see if the GP has used the standard procedure	95%
Referral criteria are used for nosological diagnostics	Applies/uses referral criteria for nosological diagnostics	The DCM or multi-disciplinary memory clinic staff are asked whether referral criteria have been well applied	95%
Presence of a CARP centre where all clients with forgetfulness are registered and from which the DCMs are directed	Registration of clients at the CARP centre  Appointment of the DCM for the registered people/ <b>clients</b>	For all organizations in the care-chain, check whether the client is registered with the CARP  At the CARP, check if all people/ <b>clients</b> have been assigned a DCM	95%
Provide regular information, advice and consultation to professionals and volunteers	Regular information, advice and consultation is given to professionals en volunteers	There is a plan present for additional education	100%
Having use of transmuraal electronic client dossier (ECD)	All relevant data is recorded in an ECD, such as diagnostic information, client needs, caregivers involved (including DCM), care plans	Random sample from the ECD to check if relevant information is present	95%
All people with dementia have a care plan that is adjusted to their needs and evaluated half-yearly	Presence of care plans adjusted to needs and the evaluation of care plans	Check if all registered clients with the CARP centre have a care plan that is based on client needs  How often are the 'half-yearly' evaluations taking place?	Care plan 100%  Evaluation 80%
There will be clear agreements made with all relevant professionals/ organization involved in the dementia chain-care about a task/ terms of reference, - and the division of responsibilities – in regard to well-being, care and living, and about the guarantee of continuity of care	establishing agreements about the task, terms of reference, - and the division of responsibilities and guarantee of continuity of care	Keep track of agreements made (weekly?)	90%

<b>Structure indicators</b>			
<b>Goal</b>	<b>Indicator</b>	<b>Measurement</b>	<b>Norm</b>
Can readily find information about forgetfulness and dementia for the client and carer	Availability of clear information	At the CARP/ GP take an inventory (random sample) how clients and caregivers accessed information.  Was the information easy to find?  Was the information comprehensible/ understandable?	80% must find the information readily and find it comprehensible
(Non-GP) caregivers must be trained in the timely recognition of dementia	(eg) Home Care workers must be trained in the timely recognition of dementia	How many Home Care workers have received a dementia education course?	80%
In a very early stage of the illness process appoint a DCM (with at least post-secondary professional qualifications)	The speed of appointing a DCM	How quickly is the GP involved via another caregiver  How quickly post-diagnosis made by the GP is a DCM appointed  What is the severity of the dementia at the time the DCM is appointed	Within 1 month  Seriousness of the dementia: mild dementia (MMSE 20-24)
The availability of an Expert Team (at area/regional level) that can be consulted by a GP or DCM	The presence of an Expert Team (at area/regional level) that can be consulted by a GP or DCM	In how many areas/regions are there Expert Team? How often do they give consultations?	95%
<b>Outcome indicators</b>			
<b>Goal</b>	<b>Indicator</b>	<b>Measurement</b>	<b>Norm</b>
People with dementia and carers are satisfied about the care arrangements	Satisfied people with dementia and carers	Ask the person with dementia or carer about the items on the Satisfaction list	90%
Reviewers are satisfied about the care-chain	Satisfied referees	Satisfaction question list / interviews with professionals in the field	90%
The chain-care is evaluated and if necessary adapted	There should be an annual report about the activities provided by the chain-care (appointments, activities, number of people and materials, client satisfaction)	Annual report	100%

## **2 ACTION POINTS FOR IMPLEMENTATION**

How does chain-care for dementia need to be organized at a area/district/regional level?

Hereafter follow the most important ground rules (26):

- . Determine the catchment area for which chain-care is being established
- . Sit around the table with all relevant professionals, municipal representatives, and all other stakeholders who have a role in the care-chains at area/regional level. A large care institution in the region could take the initiative in this.
- . Form a project group and name a project leader who is responsible for the chain-care-process and ensure that they received the funding required [NB A project leader can lead project groups in other areas/regions].
- . Let everyone gathered, indicate where the bottlenecks in the chain are. Use the notes of Chain-care Amsterdam [Ketenzorg Dementie Amsterdam].
- . Ask the 'Dutch Alzheimer's Society' [Alzheimer Nederland] to inventorize, using the LDP (National dementia Programme) model, the questions/needs of clients in the area/region, and to recommend ideas for improvement targets. Formulate improvement targets and make concrete agreements how, by whom and when the improvements will be realized.
- . Determine the number of clients expected annually, based on local demographic information
- . Determine where the CARP will be located, what its function is and who will assume the responsibility for it
- . Operationalize the goals of the care-chain (what do you want to accomplish exactly?) before establishing quality indicators. Choose indicators that, by preference are easy to measure and to continue to measure; minimally once a year.
- . Make clear and transparent, contractually agreed, agreements with the 'chain-partners' about the participation in the chain, the task distribution and financing
- . Evaluate annually the agreements made between the chain-partners'

## **3 WORKLOAD OF THE DCM (DEMENTIA CARE MANAGER)**

The use of a DCM is given in net and gross hours. For calculating the number of DCMs the gross number of hours is the basis (both direct and indirect care). Below (Table 10) the number of net and gross hours per module per year are given. The net hours are fact-to-face contact; the indirect care (coordination, meetings, etc.) together with the net hours, forms the gross time investment (see later notes for more details).

TABLE 10 NET/GROSS HOURS OF DCM 'REVIEW INPUT' PER CLIENT

<b>Start up period</b>			
The start of such care will take great time (27,28)			
	<b>Net</b>	<b>Gross</b>	
<b>Intake</b>	<b>3</b>	<b>6</b>	
<b>First 3 months 4 hours per month</b>	12	<b>24</b>	
Remainder of year 1 hour per 3 months	3	6	
<b>Total hours in first year</b>	18	36	
<b>Monitoring/ guidance in complex situations.</b>			
De CBO guidelines assume 1 full-time DCM [case manager] for 50 people/clients. This averages 30 hours of care from the DCM per client per year, where of 50% are face-to-face contact and 50% are indirect contact.			
	<b>Net</b>	<b>Gross</b>	
<b>One full time DCM for 50 clients</b>	<b>15</b>	<b>30</b>	
	that means 1.25 hours per month net		
<b>Monitoring/ guidance in uncomplicated situations.</b>			
The hours in this module are based upon guidelines from the Lesa,(29) de NHG standard (30) and the experiences of the pilot LDP in Zuidoost en Diemen.			
	<b>Net</b>	<b>Gross</b>	<b>per year</b>
1 x per 3 months	1	2	4/8
<b>Crisis guidance under the following criteria.</b>			
<ul style="list-style-type: none"> <li>. Loss of the primary carer</li> <li>. delerium</li> <li>. sudden serious behaviour change (i.e. aggression, unrest, wandering, increasing disorientation and fear)</li> </ul>			
	<b>Net</b>	<b>Gross</b>	<b>per 6 week</b>
Per day 30 min. contact = per week 3.5hours	3.5	7	21/42

<sup>a</sup>Improvement projects as per the LDP (national Dementia programme). Amsterdam Area Zuidoost/Diemen. 30 januari 2007. The time registration of case-management in de period of Mar. 2007 up to and including Oct. 2007.

<sup>b</sup>Final reporting of 'case-management dementia' from Leiden and district - 2 May 2006

<sup>c</sup>Improvement project as per the LDP. Amsterdam Area Zuidoost/Diemen. 30 Jan. 2007. The time registration of case-management in the period of Mar. 2007 up to and including Oct. 2007.

<sup>d</sup>Final reporting of 'case-management dementia' from Leiden and district, 2 May,2006

<sup>e</sup>Lesadementie

<sup>f</sup>NHG Standaard dementia

#### 4 ELEMENTS OF THE DEMENTIA CARE-CHAIN WHICH EXISTING FINANCES DO NOT COVER

The dementia care-chains are based on best practice in all aspects of offering care. The 'renewed' element is especially that there will be cooperation in the delivery of care offered. This model [the existing offer] relies on



financing which provides sufficient possibilities to deliver best practice. The additional financing is necessary where cooperation should be forthcoming in the existing offer [of care]. The elements which underpin this cooperation in effect, in the Amsterdam dementia care-chain, are:

#### THE DEMENTIA CASE MANAGER (DCM)

The DCM is the role which provides the continuity factor in the care offered to the client; the linked gear between the client and various care-providers and the gear between these care-providers themselves. The DCM is a new function which cannot be financed from existing financial provisions.

#### THE EXPERT TEAM

The Expert Team supports the DCM and comprises of all existing professionals who which to provide such support as an extra task. For this extra task, no extra coverage has been found in existing financial provisions.

#### THE CARP CENTRE (COMMUNITY AREA REGISTRATION POINT CENTRE

The CARP centre is the central registration point in the region where the client with dementia is recorded. For all service participants and users, it is the central point where the care-chain is set in motion. The CARP centre can be 'located' at an existing organization but extra funding will be needed to facilitate the CARP centre and the CARP centre functionary.

#### TRANSMURAL ELECTRONIC CLIENT DOSSIER (ECD)

A transmural electronic client dossier is an important support for a care-chain and one of the quality criteria. For adequate and meaningful interventions for the client and carer it is essential that the [various] caregivers can quickly and purposefully view and exchange information.

Also the carer(s) need to be able to access the dossier, the parts that are of importance to them.

The CARP centre and ECD can generate the required information for research and benchmarking. Financing is also required for the development of a transmural ECD.

#### THE PROJECT LEADER

To implement the 'Amsterdam dementia care-chain model' in various regions support is crucial. One of the care-providers could be the leader. All parties must invest in this development, but for a certain time one project leader will be needed to really give the implementation of this model a chance.

#### A WEBSITE

A website is a good intermediary for all parties participating in the care-chain. This is so for the implementation phase as well as for existing care-chain. The website will cover the region and can be a forum for discussion, questions, and a resource for information. It offers the possibility for all participants to link together with their care provision. Financing will also be required to develop and maintain the website.

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## APPENDIX OF TOOLS

### Translated tools:

- UFAR Index – ‘Uncomfortable feeling about a resident’ Index  
[original title: Niet Pluis Index]
- IDDD - Interview for Deterioration in Daily living tasks in Dementia  
[original title: Interview voor deterioratie in dagelijkse levensverrichtingen bij dementia]
- RDIT - Are you forgetful? - Recognize dementia in time questionnaire  
[original title: Erken dementia nu]
- OLD (Observation list for early signs and symptoms of dementia  
[Original title: Observatielijst voor vroege symptomen van dementia]
- DEBUC - Duress Experienced by unpaid [family] Carers) questionnaire  
[original title: EDIZ – Ervaren druk door informele zorg]
- TRIADE -Triage in Dementia, [still being researched], from the Academisch Medisch Centrum, Univ. of Amsterdam, Dept. of Neurology [original title: same]
- GIP 28 tool (The GIP-28 abbreviated version of the 82-item Behaviour Rating Scale for Psychogeriatric and dementia Inpatient settings)  
[original title: Gedrachtsobservatieschaal voor de intramurale psychogeriatric]

### Tools not translated - because the original versions are in English:

- MMSE
- CANE (Camberwell Assessment of Needs in the Elderly)
- Geriatric Depression Scale (30 item questionnaire)
- IQCODE (N) [A. F. Jorm and P. A. Jacomb, 1989]
- Cornell scale for depression in dementia (CSDD)

## **UNCOMFORTABLE FEELING ABOUT A RESIDENT INDEX (UFAR INDEX)**

Original Dutch “Niet Pluis Index” (Version for Care Homes)

© GGz Groningen, Centrum preventieve ggz [Centre for preventative mental health]

[Translated for CARPE DEM illustration, by GMM Jones and WJ van der Eerden, with permission]

### **WHAT IS THE ‘UFAR INDEX’?**

The UFAR Index is a simple tool to help you recognize behaviour changes in a resident. We developed the NPI to assist you to signal (better or earlier), any emotional/mental difficulties that residents may be experiencing. The aspects of a resident’s behaviour that you need to be aware of are described very practically, so that in principle, everyone can use this tool. The ‘overall behaviour’ of a resident will be cut up into separate pieces, as it were.

The UFAR Index is a simple list of various topics which are worded in practical terms. The UFAR Index certainly doesn’t give a total picture. It is for getting more insight into what is happening at present. Scoring is only done with ‘ticks’, so there are no complicated ‘numerical sums’ to work out. The intention is, that with the help of the NPI score, discussion is stimulated between colleagues, to try to find out what is going on with a resident.

### **WHEN CAN YOU USE THE UFAR INDEX?**

You can use the UFAR Index whenever you get an ‘uncomfortable feeling about a resident’. For example if, a lady was always active but recently she is not doing anything. You ask yourself if anything is going on, if some ‘isn’t quite right’. You ask yourself if anything is the matter, if something doesn’t seem quite right about a resident. That’s what we call an ‘uncomfortable feeling about a resident’.

You fill in the list of questions, and ask a colleague to do the same. It works best if you do it separately from each other, and later on, compare the scores that you have given the ‘current situation of the resident’. You can also discuss the scores with your duty/managers or raise your concerns at a work meeting.

### **SCORING**

If there are two or more ticks per section, it is wise to discuss the resident at a work meeting. Namely, if there are changes in a resident that you are concerned about, we recommend that they are discussed at a work meeting. More ticks may be added then.

### **PERMISSION**

It is customary to ask the resident’s permission if you are observing their behaviour using the UFAR Index. You may also choose to discuss the scoring with the resident. Generally, it is a good idea to inform the resident’s family or other loved ones, that you are using this tool, at least if the resident’s relationship with them is a good one. It is also a good idea to tell other caregivers who are involved with the resident.

### **CRISIS TIMES**

Times of crisis for a resident might involve the loss of a partner or a close family member. Or, for example, they may occur during the summertime, when residents are vulnerable if fewer activities take place in the Care Home and their children are away on vacation. Other people may develop difficulties during the wintertime. Therefore it is important always to be alert. A resident can feel low or depressed and develop physical symptoms, which can be accompanied by fear, disorientation and/or loneliness.

This tool is intended not only to signal emotional/mental difficulties, but to do something with such indications. Discuss the difficulties that you are noticing with others. This is also important if you are working in isolation of other colleagues. It is also important to discuss this with the resident, and eventually the resident’s family. Everyone has a particular responsibility in this. The criteria for taking action, is usually that you are concerned about a resident.

## UNCOMFORTABLE FEELING ABOUT A RESIDENT INDEX (UFAR INDEX) – (VERSION, 2004)

A tool for signalling emotional or mental distress of a resident in a care home [translated by GMM Jones and WJ van der Eerden, with permission]

Resident name/ID number \_\_\_\_\_

Form filled in by \_\_\_\_\_

Date \_\_\_\_\_

The UFAR Index is a tool to help identify behaviour changes in a resident. It is important to recognize behaviour changes, and to respond to them helpfully.

If two or more items are identified in any given section, it is advisable to discuss the resident at a work meeting. Also this is advised, if there are any changes in the circumstances of the resident,

Times of crisis for a resident might involve the loss of a partner or a close family member. Or, for example, they may occur during the summertime, when residents are vulnerable if fewer activities take place in the Care Home and their children are away on vacation. Other people may develop difficulties during the winter time. Therefore it is important always to be alert. A resident can feel low or depressed and develop physical symptoms, which can be accompanied by fear, disorientation and/or loneliness.

UFAR INDEX	Tick if applicable
<p>1. General</p> <ul style="list-style-type: none"> <li>• The resident recently lost a partner or family member</li> <li>• Complains about sleep (too much, too little, or poorly)</li> <li>• Has vague physical complaints</li> <li>• Cries a lot, or regularly</li> </ul>	
<p>2. Observations</p> <ul style="list-style-type: none"> <li>• The resident does not manage 'self-care' well, or soils themselves</li> <li>• Has no appetite</li> <li>• Speaks little, or, too much</li> <li>• Has poor or no concentration ability</li> </ul>	
<p>3. Mood</p> <ul style="list-style-type: none"> <li>• Resident is very tired or apathetic, doesn't feel like doing anything</li> <li>• Complains more than other residents</li> <li>• Has lost hope, and is losing perspective</li> <li>• Is reactive or gets angry easily</li> <li>• Makes all sorts of accusations, or is rebellious</li> </ul>	
<p>4. Social contacts</p> <ul style="list-style-type: none"> <li>• Has few or no social contacts</li> <li>• Feels alone and lonely</li> <li>• The resident withdraws (within and outside of the Care Home)</li> <li>• Is not (physically) able to attempt, or to undertake activities</li> <li>• Doesn't want to have or make contact with neighbours or others</li> </ul>	



## **IDDD - INTERVIEW FOR DETERIORATION IN DAILY LIVING TASKS IN DEMENTIA**

Developed by: S. Teunisse en M.M.A. Derix (1991),  
[translated for CARPE DEM illustration by GMM Jones & WJ van der Eerden]

### VERBAL INSTRUCTIONS:

In this list of questions, you will be asked about changes in the daily functioning of your Partner/father/mother. You are being asked to give a judgment because you know them best. For each question, it is the behaviour that has occurred in the past month that is being asked about. We'd like you to compare the behaviour of the past month with previously, a year ago. Using these questions we'd like to determine how dependent your Partner/father/mother has become because of their illness. We'll ask, for example:

Do you have to say to him/her that they need to wash themselves?

Follow-up questions:

For an unknown answer, ask: Has there been no change in this compared to before?

For a positive answer, ask : Is your help really necessary? What happens without your help?  
Do you need to assist more often than before?

### SCORING

- 1 = (almost) never needs help / no change compared with before
- 2 = sometimes needs help / more often than before
- 3 = almost always needs help/ needs help much more often than before
- 8 = not possible to judge
- 9 = not applicable

1 Do you have to tell him/her to wash themselves? (take the initiative to remind them to wash themselves, for small and larger cleanings?)

1                      2                      3                      8                      9

2 Do you have to help him/her to get washed (get the facecloth, soap, lathering and rinsing their body?)

1                      2                      3                      8                      9

3 Do you have to tell him/her to dry themselves (take the initiative to start drying, for example getting or giving them the towel?)

1                      2                      3                      8                      9

4 Do you need to help him/her dry themselves (dry the wet parts of their body?)

1                      2                      3                      8                      9

5 Do you need to tell him/her to dress themselves (take the initiative to help them to dress, for example, by going to the wardrobe?)

1                      2                      3                      8                      9

6 Do you have to help him/her to put on their clothing (the order of the clothes and individual items?)

1                      2                      3                      8                      9

7 Do you need to help them close zippers, buttons, and laces?

1                      2                      3                      8                      9

8 Do you need to tell him/her that they need to brush their teeth and comb their hair?

1 2 3 8 9

9 Do you need to help them brush their teeth?

1 2 3 8 9

10 Do you need to help them to get their hair parting or hair style right?

1 2 3 8 9

11 Do you need to tell him/her that they need to eat (take the initiative to start eating; if meals are served or brought in, ask if the person would eat spontaneously?)

1 2 3 8 9

12 Do you need to help him/her to prepare a sandwich?

1 2 3 8 9

13 Do you need to help him/her cut or mash food?

1 2 3 8 9

14 Do you help him/her to eat or drink (the various actions?)

1 2 3 8 9

15 Do you need to tell him/her to go to the toilet (take the initiative to go to the toilet when needed?)

1 2 3 8 9

16 Do you need to help him/her with various actions to go to the toilet? (undressing, use of toilet paper?)

1 2 3 8 9

17 Do you need to help him/her to find their way around the house? (can they locate the various room?)

1 2 3 8 9

18 Do you need to help him/her to find their way outside the house (to find their way in familiar places?)

1 2 3 8 9

19 Does he/she do the groceries as often as before (get them ready to go shopping, or ask about what is needed)?

1 2 3 8 9

20 Does he/she need help with personal shopping (to find what they need in the store, or the right quantity?)

1 2 3 8 9

21 When he/she has to pay, do they need to be reminded to do so?

1 2 3 8 9

22 Does he/she need help to pay (to know how much money to give and what change to expect?)

1 2 3 8 9

- 23 Does he/she read a newspaper, the post, or a book as often as before?
- 1                      2                      3                      8                      9
- 24 Do you need to help him/her to read (to understand the meaning of a message?)
- 1                      2                      3                      8                      9
- 25 Do you need to help him/her to write a card or fill in a form (for writing more than one sentence?)
- 1                      2                      3                      8                      9
- 26 Does he/she start a conversation with others, of their own initiative as often as before?
- 1                      2                      3                      8                      9
- 27 Is he/she able to express what they mean, or do you need to help them with that?
- 1                      2                      3                      8                      9
- 28 Does he/she listen as often as before to what others are saying?
- 1                      2                      3                      8                      9
- 29 Does he/she understand what others are saying to them, or do you need to help them understand?
- 1                      2                      3                      8                      9
- 30 Do they use the telephone as often as before (take the initiative to pick up the phone or phone someone?)
- 1                      2                      3                      8                      9
- 31 Do you need to help him/her to use the phone (to pick it up and dial the number?)
- 1                      2                      3                      8                      9
- 32 Is he/she able to find the things in the house that they need, or do they need your help for that?
- 1                      2                      3                      8                      9
- 33 Do you need to tell him/her that they have left the gas on, or remind them to turn off an appliance?
- 1                      2                      3                      8                      9

## OLD (OBSERVATION LIST FOR EARLY SIGNS AND SYMPTOMS OF DEMENTIA)

[translated for CARPE DEM illustration, by GMM Jones and WJ van der Eerden, with permission]

The named signs and symptoms on this observation list will be scored as follows:

A = yes;

B = hesitant;

C = no;

D = was not asked about

Key aspect	Signs and symptoms	Observation	Hints
Forgetfulness	Keeps forgetting what day of the week it is	A B C D	When were you last here?
	Routinely forgets events that happened recently	A B C D	
Repetition	Cannot repeat recently heard information	A B C D	Why did you come here for on the last visit? Key question: How is it going with you (partner, children and so forth)
	Repeats him/herself often without realizing it	A B C D	
	Regularly repeats the same story during a conversation	A B C D	
Language	Routinely, has difficulty finding particular words	A B C D	Observe during conversation
	Quickly loses the thread of a conversation	A B C D	
Comprehension	From the answer you can tell that the question was not understood	A B C D	Observe during conversation
ADL	Has difficulties to understand the question	A B C D	
Orientation			
Façade			
Dependence	Mixes up the time/s	A B C D	Think about person looking sideways (head turning syndrome)
	Makes up excuses and cover-ups	A B C D	
	Increase in dependent behaviour compared with before	A B C D	

## RDIT (ARE YOU FORGETFUL? RECOGNIZE DEMENTIA IN TIME)

[original title: ISD - Is er sprakke van dementie?] [source: <http://www.herkendementie.nu/>]

[translated for CARPE DEM illustration, by GMM Jones and WJ van der Eerden, with permission]

This list will give you an impression about your forgetfulness. With each question, mark whatever is applicable.

- 1) Reading something and just afterwards not remembering what you read, so that you have to read it again  
Never 0 0 0 0 0 very often
- 2) Forgetting why you walked to a certain part of your home  
Never 0 0 0 0 0 very often
- 3) Not noticing signposting  
Never 0 0 0 0 0 very often
- 4) Mixing up left and right for written directions  
Never 0 0 0 0 0 very often
- 5) Bumping into people by accident  
Never 0 0 0 0 0 very often
- 6) Not remembering if you turned off the light or gas, or locked the door  
Never 0 0 0 0 0 very often
- 7) Not listening to the name of a person at the time the person introduces themselves  
Never 0 0 0 0 0 very often
- 8) To let something 'flop out' in conversation and later realize it may have been hurtful  
Never 0 0 0 0 0 very often
- 9) Not noticing that someone that someone is speaking to you when you are busy with something else  
Never 0 0 0 0 0 very often
- 10) Becoming angry and later regretting it  
Never 0 0 0 0 0 very often
- 11) Letting important letters sit for days unanswered  
Never 0 0 0 0 0 very often
- 12) Forgetting which street you turn on when you are following a route you know well, but don't often use  
Never 0 0 0 0 0 very often

	Never	0	0	0	0	0	very often
13)	Not being able to find what you are looking for in a super market although it is there						
	Never	0	0	0	0	0	very often
14)	Asking yourself suddenly if you are using a word in the correct way						
	Never	0	0	0	0	0	very often
15)	Having difficulty with making decisions						
	Never	0	0	0	0	0	very often
16)	Forgetting appointments						
	Never	0	0	0	0	0	very often
17)	Forgetting where you put something down, like a book or the newspaper						
	Never	0	0	0	0	0	very often
18)	Accidentally throwing away something that you needed - saving something you wanted to throw away						
	Never	0	0	0	0	0	very often
19)	Day dreaming while you actually should be listening to someone or something						
	Never	0	0	0	0	0	very often
20)	Forgetting people's names						
	Never	0	0	0	0	0	very often
21)	Beginning something but not completing it, because without noticing you started doing something else						
	Never	0	0	0	0	0	very often
22)	Not being able to find a word although it's on the 'tip of your tongue'						
	Never	0	0	0	0	0	very often
23)	Forgetting what you came to buy whilst in a shop						
	Never	0	0	0	0	0	very often
24)	Letting things drop from your hands						
	Never	0	0	0	0	0	very often
25)	Not knowing what else to talk about during a conversation						

Never    0        0        0        0        0        very often

[RDIT Scoring: the items ticked as 'never' are not scored. One, two, three and four points, respectively, are assigned to incremental circles ticked.]

The questions:

Your score in the ISD was \_\_\_\_X (out of 100).

Below you will see average scores of the population. Hence, you can see how your own forgetfulness compares.

-----

#### SCORE 0-9

You score below to the 2 or 3 per cent of people who pretty much do not have any difficulties with forgetfulness. An exceptional memory thus.

#### SCORE 10-20

About 15 of people achieve this score. You forget less than the average. A good memory.

#### SCORE 21-43

Over 65 per cent of all people achieve this score. It is an average score that indicates that your memory in general works well.

#### SCORE 44-54

About 15 % of people achieve this score. You forget more than average, but you are not amongst the most forgetful. Everyday memory is fragile, hence you make regular errors and mistakes.

#### SCORE 55 AND HIGHER

You are noticeably forgetful. Barely 2 to 3 percent achieve this particular score. Everyday memory is not working so well. This is a good reason to check on why this could be so.

A score of 44 or more does not at all have to mean the start of dementia. There can be other explanations for forgetfulness, such as a low mood, lack of confidence in yourself or other ails or afflictions.

Dementia is more than forgetfulness. Watch out for other signals of dementia.

## DEBUC (DURESS EXPERIENCED BY UNPAID CARERS [FAMILY]) QUESTIONNAIRE

EDIZ tool -Ervaren Druk door informele Zorg, by AMPot (subjective, self-perceived pressure experienced by family/carers)

[Translated for CARPE DEM illustration, by GMM Jones and WJ van der Eerden from the original]

### VERBAL INSTRUCTIONS TO BE GIVEN TO THE CARER

. Hereafter, are some statements. The intention is that you indicate how relevant each one is for you. You have the following options for replying. (Hand the answer sheet, to the carer, on which is printed the following.)

**No!**      **No**      **More or less**      **Yes**      **Yes!**

. If a statement describes your situation or thoughts, circle 'Yes!' (Point to this.) If it does not, circle 'No!' (Point to this), or else circle one of the other answers (Point to these.)

. Do you understand how this is meant to work? Use statement 1 as an example.

Let the Carer fill in the remainder of the questionnaire independently.

### STATEMENTS

1 As a result of the situation my [?] [your relationship to the person you are caring for] is in, I don't have enough time for my own life

*No!*    *No*    *More or less*    *Yes*    *Yes!*

2 The combination of responsibilities for my [?] and for my work and/or family isn't easy

*No!*    *No*    *More or less*    *Yes*    *Yes!*

3 Because of my involvement with my [?], I deprive others

*No!*    *No*    *More or less*    *Yes*    *Yes!*

4 I always have to be available for my [?]

*No!*    *No*    *More or less*    *Yes*    *Yes!*

5 My independence is suffering

*No!*    *No*    *More or less*    *Yes*    *Yes!*

6 The situation involving my [?] requires my constant attention

*No!*    *No*    *More or less*    *Yes*    *Yes!*

7 My involvement with my [?] brings me into conflict at home and/or at work

*No!*    *No*    *More or less*    *Yes*    *Yes!*

8 I'm never free of this situation which involves my [?]

*No!*    *No*    *More or less*    *Yes*    *Yes!*

9 In general, I feel very pressured because of the situation with my [?]

*No!*    *No*    *More or less*    *Yes*    *Yes!*



## TRIADE (TRIAGE IN DEMENTIA)

AMC, Univ. of Amsterdam, Neurology, [still being researched]

[Translated for CARPE DEM illustration, by GMM Jones and WJ van der Eerden from the original]

The Triade can be used with patients aged 65 and older, in whom the GP is concerned about the possibility of dementia.

Item		Yes	No	
<b>A</b>	1	Cognitive/mental deterioration is interfering with personal activities of daily living		
	2	The deterioration has been occurring for at least 6 months		
	3	First symptom: memory disturbance		
	4	Course: almost imperceptible begin, slow and continuous progression		
	5	The patient stands upright, walks and moves normally		
	6	MMSE (see explanation)*		
	a	Was this the 'best' possible presentation of the patient		
	b	score 'less than' 24		
	c	the score cannot be explained completely by a newly acquired cerebral disturbance		
	d	normal speed of thinking and reacting		
<b>B</b>	7	Headache/s or a focal insult as a new symptom		
	8	The cognitive/mental deterioration can be explained (in part) by:		
	a	a cerebrovascular event*		
	b	another neurological or internal affliction that is often associated with cognitive disturbance/event		
	9	The cognitive/mental deterioration can be explained (in part) by:		
	a	depression*		
	b	other psychiatric condition/s / event		
	10	The cognitive/mental deterioration can be explained (in part) by:		
	a	chronic, excessive alcohol consumption		
	b	medication*		
	c	findings of blood tests*		

\* for explanation see the next page

TRIADE scoring - If 'A' is repeatedly answered with "yes", and 'B' with "no", the clinical diagnosis is: 'probable Alzheimer's disease'.

	Findings	Yes	No
	"probable Alzheimer's disease"		

#### ADDITIONAL NOTES OF EXPLANATION FOR THE TRIADE TOOL

Item	Note
6	MMSE requirements: a watch, pen and paper
a	'Best' possible presentation: Reasons for a person presenting below their 'normal/actual level' could be: . less-than optimal circumstance for assessment, in regard to the condition of the patient (eg sleepiness, poor vision, poor hearing) . less than optimal motivation, or (psychiatrically) disturbed (eg unwillingness, depression)
b	Scoring
b	Question 1 In reply to 'What season is it?', some flexibility is acceptable if it is near to time season change <ul style="list-style-type: none"> <li>• March = winter/spring</li> <li>• June = spring/summer</li> <li>• September = summer/autumn</li> <li>• December = autumn/winter</li> </ul>
b	Question 3 Give 1 point for each good answer given at the first attempt. If, a mistake is made on the first attempt, or words are forgotten, repeat all the words until the patient has learnt them all (up to a maximum of 5 repetitions)
b	Question 4 Note the answer. Award 1 point for each time that the 'difference' is 7, even if the previous answer was wrong. If the patient forgets the task instructions, then do not give them help but score it wrong. The maximum score is 5. If one or more errors are made during calculating, then as: Would you please spell the word 'WORLD' backwards. Note the answer. Give one point for each letter in the correct order. (D) (L) (R) (O) (W) = 5 points From these two tasks (calculating and spelling), use the highest score for deriving the Total test score
c	The score can <b>be totally</b> explained by a newly acquired cerebral disturbance/ event, means that the score is not determined by: 1. low premorbid level, lack of education or a different cultural background 2. aftermath of an event (eg brain infarct, cerebral contusion)
8	a Cerebrovascular event: brain infarct or brain-bleed in the patient's history
9	a Depression. Possibly use the Geriatric Depression Scale (short version) for this item
10	b Medication. Look critically at all medications used. Suspect especially benzodiazepines and medications with anti-cholinergic effects
c	Standard blood-work: Hg, Ht, MCV, BSE, glucose, TSH and creatinine. Where indicated (with gastro-intestinal comorbidity, alcohol abuse and unusual nutrition patterns) vitamin B1, B6, B12 and Folic Acid

'Probable Alzheimer's Disease'. This clinical diagnosis does not rule out cerebrovascular comorbidity. However, the question about whether with cerebrovascular damage intensive treatment of risk factors can lead to a reduction in the rate of developing dementia, has not yet been answered.'

## GIP 28 Scale by PFJ Verstraten and CWJM Eekelen (Behaviour Observation Scale ~ for Inramural psychogeriatric and dementia inpatient settings)

[GIP 28 - Translated and adapted to illustrate CARPE DEM, by GMM Jones & W van der Eerden, with permission]

Details of the person/patient observed
Name
Date of Birth
Gender
Date admitted
Name of ward/unit/ or care setting

Details of the person making the observations
Name
Role/function
Date
Time/s of day person was observed
Any pertinent circumstances surrounding the time/s of observation

### Instructions

Choose the phrases which most accurately describe the behaviour/s you observed in this person/patient, in the last two weeks.

Answer each phrase by underlining one of the four possible answers.

Choose only one answer per phrase. Even if, for example you are hesitating between 'sometimes' and 'often' – don't underline both but try to choose only one answer.

Do not miss out any phrases. Answer them all.

Sometimes there are phrases that cannot be filled in for people/patients who are totally bed-ridden. On the left side of the page, you'll see the abbreviation '**bedr**'.

Also there are phrases which cannot be answered with regards to people who 'absolutely cannot speak anymore'. In this instance, you will see, on the left side of the page, the abbreviation for '**apha**'. Occasionally you will see '**dayc**' written. This means that this particular phrase is not applicable for people visiting day-care centres.

In these instances, you can skip the phrases, but only if they really are not applicable.

There are markings on the right side of the phrases, which are for eventual scoring: you do not need to fill these in at all. The only thing you have to do is underline the answers to the phrases.

In answering these phrases, it is important that you make only minimal use of other information about the person/patient. If a particular diagnosis of a person/patient is known to you, then perhaps you may be readily inclined to answer a number of phrases similarly. Try to suppress this inclination. You must record what you have seen and experienced yourself with this person/patient, even if it is possibly conflicting with a given diagnosis.

### GIP - Subscale 1

possible exceptions	descriptive phrase	scoring	only
dayc	appears happy with visits from family members never - sometimes - often - always	( )	<
dayc bedr	takes part in group activities outside of the ward/unit never - sometimes - often - always	( )	<
bedr	is prepared to help someone, all the more if asked to never - sometimes - often - always	( )	<
apha	starts conversations with others of their own initiative never - sometimes - often - always	( )	<
	has contact with the caregivers (with or without words) never - sometimes - often - always	( )	<
	appears to listen to what others say never - sometimes - often - always	( )	<
	gets along very well with other people/patients never - sometimes - often - always	( )	<
	shows interest in members of staff never - sometimes - often - always		

Total score  
8  
(for day care 6)  
Scale-score \_\_\_\_\_

#### GIP - Subscale 2

possible exceptions	descriptive phrase	scoring	only
	reacts when he/she is spoken to never - sometimes - often - always	( )	<
	reads a paper and/or magazine never - sometimes - often - always	( )	<

	shows emotions for unusual or touching events never - sometimes - often - always	( )	<
	reacts visibly to music never - sometimes - often - always	( )	<
	looks up if someone enters or if something happens never - sometimes - often - always	( )	<
	listens to the radio and/or watches television never - sometimes - often - always	( )	<

Total score

6

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 3**

possible exceptions	descriptive phrase	scoring	only
	sits dozing never - sometimes - often - always	( )	<
	startles from a sort of dream-state if he/she is spoken to never - sometimes - often - always	( )	<
	gives the impression of being absent minded never - sometimes - often - always	( )	<
	during the day, if awake, is clearly awake never - sometimes - often - always	( )	<
	must be touched/shaken if one wants to reach him/her never - sometimes - often - always	( )	<
	during the day, lives in a dream of trance-like state never - sometimes - often - always	( )	<
	dozes off during conversation or activities never - sometimes - often - always	( )	<

Total score

7

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 4**

possible exceptions	descriptive phrase	scoring	only
bedr	sits with bottom slid forwards without making effort to sit upright never - sometimes - often - always	( )	<

	makes an effort about their outward appearance never - sometimes - often - always	( )	<
	burps or passes wind without embarrassment never - sometimes - often - always	( )	<
	maintains normal manners (greeting, thanking, apologizing) never - sometimes - often - always	( )	<
	lets moisture run out of their nose or mouth (without wiping it off) never - sometimes - often - always	( )	<

Total score

5

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 5**

possible exceptions	descriptive phrase	scoring	only
bedr	tries to escape the care setting, to resist staying here never - sometimes - often - always	( )	<
	mutters protest if something is asked of them never - sometimes - often - always	( )	<
	keeps to the rules and use of the ward/unit never - sometimes - often - always	( )	<
	refuses the help of caregiving staff never - sometimes - often - always	( )	<
	cooperates when it is asked of them never - sometimes - often - always	( )	<

Total score

5

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 6**

possible exceptions	descriptive phrase	scoring	only
bedr	removes own clothing in the wrong place (without sexual intent) never - sometimes - often - always	( )	<
apha	speaks in a confusing manner (e.g. mixed words and sentences through each other, invents new words) never - sometimes - often - always	( )	<

apha	gives answers totally unrelated to what was asked never - sometimes - often - always	( )	<
	can express themselves clearly enough that people understand what was intended never - sometimes - often - always	( )	<
	urinates or defacates in the wrong place never - sometimes - often - always	( )	<

Total score

5

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 7**

possible exceptions	descriptive phrase	scoring	only
apha	knows other residents by name never - sometimes - often - always	( )	<
apha	knows close family members by name never - sometimes - often - always	( )	<
	remembers what was asked or was done never - sometimes - often - always	( )	<
	forgets that he/she has been admitted to care (and isn't, for example, just visiting) never - sometimes - often - always	( )	<
	knows own name never - sometimes - often - always	( )	<
	appears to forget what he/she is doing (e.g. eating, drinking) never - sometimes - often - always	( )	<
	seems to recognize caregiving staff never - sometimes - often - always	( )	<

Total score

7

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 8**

possible exceptions	descriptive phrase	scoring	only
bedr	is watched carefully to prevent their getting lost never - sometimes - often - always	( )	<
	sees residents and staff as being other people never - sometimes - often - always	( )	<

	from their behaviour, it seems that he/she thinks they are in a different place never - sometimes - often - always	( )	<
	seems to understand what time of the day it is never - sometimes - often - always	( )	<
	from their behaviour it is possible to conclude that he/she is mixing up the present with the past never - sometimes - often - always	( )	<

Total score

5

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 9**

possible exceptions	descriptive phrase	scoring	only
bedr	shuffles their feet back and forth never - sometimes - often - always	( )	<
apha	repeats words, sentences or, bits of sentences never - sometimes - often - always	( )	<
apha	speaks or mutters for long periods, to no one in particular never - sometimes - often - always	( )	<
	touches clothing, bedding, tablecloths e.g. plucking at them never - sometimes - often - always	( )	<
	makes meaningless sounds for long periods never - sometimes - often - always	( )	<

Total score

5

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 10**

possible exceptions	descriptive phrase	scoring	only
bedr	walks restlessly through the care setting never - sometimes - often - always	( )	<
apha	speaks a lot and quickly never - sometimes - often - always	( )	<
	can remain sitting or lying still, peacefully never - sometimes - often - always	( )	<



	behaviour appears to be nervous/tense ever - sometimes - often - always	( )	<
	is too restless to be occupied with something for a length of time never - sometimes - often - always	( )	<

Total score

5

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 11**

possible exceptions	descriptive phrase	scoring	only
apha	claims that others are watching them never - sometimes - often - always	( )	<
apha	says others are deliberately offending/injuring them never - sometimes - often - always	( )	<
apha	claims to be abandoned or poorly cared for never - sometimes - often - always	( )	<
apha	says things are being stolen from them never - sometimes - often - always	( )	<
apha	says that others don't like him/her never - sometimes - often - always	( )	<
	behaves in a mistrustful way towards caregiving staff never - sometimes - often - always	( )	<
	behaves in a mistrustful way of other residents never - sometimes - often - always	( )	<

Total score

7

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 12**

possible exceptions	descriptive phrase	scoring	only
apha	says they feel useless never - sometimes - often - always	( )	<
apha	are afraid of things which might happen never - sometimes - often - always	( )	<
apha	says they feel dejected or depressed never - sometimes - often - always	( )	<

	has a sad facial expression never - sometimes - often - always	( )	<
	appear to feel unhappy never - sometimes - often - always	( )	<
	becomes sad quickly if something goes against expectation never - sometimes - often - always	( )	<

Total score

6

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 13**

possible exceptions	descriptive phrase	scoring	only
bedr	behaves in way that is very dependant on caregiving staff never - sometimes - often - always	( )	<
apha	asks to be helped by things that he/she appears to be able to do for themself never - sometimes - often - always	( )	<
apha	asks caregiving staff for counsel or advice never - sometimes - often - always	( )	<
	tries in all possible ways to get attention for themself never - sometimes - often - always	( )	<
	appears hesitant or uncertain in making small decisions never - sometimes - often - always	( )	<

Total score

5

Scale-score: \_\_\_\_\_ -

**GIP - Subscale 14**

possible exceptions	descriptive phrase	scoring	only
bedr	gets into a panic when leaving the ward/unit of care setting never - sometimes - often - always	( )	<
	expresses fear of particular people or things never - sometimes - often - always	( )	<
	is suddenly anxious, without an obvious reason never - sometimes - often - always	( )	<

	is anxious in the presence of particular residents never - sometimes - often - always	( )	<
	expresses anxiety when he/she is being helped by caregivers never - sometimes - often - always	( )	<
	is anxious in the presence of 'unknown others' never - sometimes - often - always	( )	<

Total score

6

Scale-score:

**GIP Scales scores**

Subscale 1 ( )

Subscale 2 ( )

Subscale 3 ( )

Subscale 4 ( )

Subscale 5 ( )

Subscale 6 ( )

Subscale 7 ( )

Subscale 8 ( )

Subscale 9 ( )

Subscale 10 ( )

Subscale 11 ( )

Subscale 12 ( )

Subscale 13 ( )

Subscale 14 ( )

GIP Tool description - What is the GIP tool?

The GIP comprises the following 14 scales:

- 1 non-social behaviour (lack of contact with others, avoidance of contact, self-isolation)
- 2 apathetic behaviour (social withdrawal, lack of interest, indifference other presence)
- 3 disturbances of consciousness (decreased response to environment, narrowed consciousness, consciousness reduction, fluctuations in awareness)
- 4 loss of decorum: (lack of shame, loss of sensitivity in social conversation, inappropriate gestures and sounds)
- 5 incoherent behaviour (apparent confusion, thought disorders)

- 6 memory problems (forgetting names and appointments, not recognizing context or neighbourhood, etc.)
- 7 disoriented behaviour: (disorientation in time, place or person)
- 8 repetitive [seemingly] senseless behaviour (picking at clothing, hand-rubbing, senseless verbal expressions, etc.)
- 9 restless behaviour (anxiety, compulsion to move)
- 10 suspicious behaviour (mistrustful, fear of being 'kept an eye on')
- 11 melancholy / sad behaviour (depression, uselessness, powerlessness, increased sleeping)
- 12 dependent behaviour (inability to help themselves or perform certain activities)
- 13 fearful behaviour (feelings of panic, fear of others, restlessness, concentration problems)
- 14 defiant behaviour: (obstruction of actions, or or other people)

#### Abbreviated version of the GIP (GIP-28)

- . Measure: psychological and psychiatric problems
- . Age Range: elderly
- . Decrease Duration: approximately 5 minutes
- . Applicable in: nursing homes, psychiatric and psychogeriatric
- . Qualification Level: 2 (psychodiagnostic power required)

#### Purpose of test

GIP 28 is an abridged version of the Behaviour Observation Scale for Inpatient psychogeriatrics (GIP) and is designed for the efficient mapping of behavioural problems resulting from mood disorders and cognitive problems in the elderly.

#### Applications

- . Screening: to determine abnormal behaviour, to identify changes in behaviour to assist in decisions about the elderly, and to describe patient populations.
- . Diagnosis: to support clinical diagnosis.
- . Treatment: for evaluating therapies and treatment interventions.
- . Research: to describe patient populations

#### For whom?

The GIP-28 may be conducted by nurses, business leaders, (psychiatric) nurses and psychologists who have achieved the earlier observation.

#### What does the GIP-28 do?

GIP contains some 28 questions from each of the 14 subscales of the BIP. This creates three scales:

- . apathy (lack of attention, awareness reduction, social withdrawal behaviour, insensitivity mental stimuli, decreased initiative, decreased self-care, lack of interest, indifference Attn others)
- . cognition (memory impairment, incoherent behaviour, disoriented behaviour, senseless repetitive behaviour, confusion)
- . affect (sadness, fear, suspicion, dependency, rebellious and restless behaviour)

#### **Abstract (GIP- 28) Behaviour observation tool for use in psychogeriatric settings**

Eisses AMH, Kluiters H (2002) De Gedragsobservatieschaal voor de Intramurale Psychogeriatric (GIP-28) in het verzorgingshuis: een psychometrische evaluatie. [Behaviour observation scale for intramural psychogeriatrics [GIP-28] in residential care homes: a psychometric evaluation]. Tijdschrift voor Gerontologie en Geriatrie 2002;33: 112-118.

The 28-item version of the Behaviour Rating Scale for Psychogeriatric Inpatients (GIP-28) for use with inhabitants of residential homes: a psychometric evaluation. The GIP-28 is the shortened version of the 82-item Behaviour Rating Scale for Psychogeriatric Inpatients. Originally it was meant and psychometrically evaluated for use in psychogeriatric and elderly psychiatric inpatients. We supposed that the GIP-28 might be useful to detect psychosocial and cognitive problems in residents of elderly homes. Therefore it was tested in 15 residential homes (n=949). The instrument consists of three, factor-analytically derived, scales: 'Apathy', 'Cognition', and 'Affect'. These three principal components were also identified in the data of the inhabitants of the residential homes. Internal consistency of the scales, as measured with Cronbach's Alpha is .75,

.67, .80 respectively. Construct validity of the GIP-28 is satisfactory: the correlation between the Affect scale and the GDS was .36 and between the Cognition scale and the MMSE was -.36. The GDS was associated with another observation scale for care needs ( $r=.54$ ). The GIP-28 can be used to detect mental problems in the population of residential homes. However it is neither meant nor suited to replace psychiatric diagnostic procedures.

## APPENDIX - CASE STUDY: MRS BUNDEL

### VARIATIONS ON POSSIBLE OUTCOMES IN THE COMMUNITY

The chain of care, for noticing and helping people 'at risk' in the community, described in this case study will be an adjunct to the Amsterdam dementia care-chain model.

Translation (with permission) by GMM Jones and W van der Eerden, from the original document prepared by the National Programme for Eldercare, [Nationaal Programma Ouderenzorg] Amsterdam, 8 April 2010.

Note: some of the abbreviations in this text refer to additional documents that were not available for translation, e.g. [T1: ISAR] , [T1: CGA & integral careplan]

Below is the case study of Mrs Bundel. We first got to know her as an active participant in our regional 'Elder Network' and would like to tell you about her experiences when she changed from being a 'vital elderly person', to a more 'vulnerable elderly lady'. Following the account of her real experiences, two additional versions of possible 'transition-experiments' and outcomes that could have happened are given. This process did not occur without setbacks. You will be reading the ongoing history of her existence in the fourth and fifth stages of her life.

- . firstly, as it really happened with the offer to join a drug trial
- . secondly, how it could have happened, with the implementation of the 'Transition 1 assistance – Function maintenance in times of transition (FIT)
- . thirdly, how it could have happened, with the implementation of 'Transition 2 assistance - the Transmural Care Bridge

[Some research suggestions have been incorporated throughout. [The authors] would be grateful for additions, comments and recommendations for improvement, to make this case study best fit with practice and everyday life. ]

### CASE STUDY OF MRS. BUNDEL, AGE 78

#### AS IT HAPPENED IN REAL LIFE

It is August 24th, 2009. Mrs Bundel is a 78 year old widow who lives in an apartment that is all on one floor. She lives in Sunninghill. She goes to the shops for her groceries, daily. Recently, she has been trying to avoid travelling longer distances by bus or train. Her 76 year old neighbour lady drives Mrs Bundel to the supermarket once or twice a week and helps her to get the larger and heavier groceries. Mrs Bundel thinks she's reasonably healthy; she has some hypertension and retinopathy. Last week, she fell for the first time. She tripped on a small step outside, and has now decided to take her walking stick with her more often.

She receives help twice-monthly to do heavier household tasks because she has arthritis in both knees. She can do her own self-care, but finds it difficult to take a shower. Since her TIA-like episode last year, she's finding going to the weekly choir practice a real effort, and, she's afraid of falling. In November she sees her GP for a yearly flu-jab; otherwise, she doesn't go to the GP surgery very often. She participates in the target-group panel of the local, university-linked, 'Regional Elderly Advice Committee'. Fortunately, she gets a ride with someone because, even though the meetings are nearby, it's not always easy to get oneself out of the house.

It's November 5th, 2009. Mrs Bundel has slipped on some wet leaves on the pavement by her front door and broken her wrist. She's put her choir practices on hold and Personal Care Assistants are helping her to get showered. She thinks she'll keep this help when her cast comes off. She's getting weekly help with the household chores now. But alas, it's not always the same person, but usually it is. She didn't know how she was going to organize all this, but eventually she got the paperwork filled in with a little bit of help from her neighbour lady. Her neighbour lady will be moving to Sheltered Housing soon, in Bath, to be closer to her daughter. She'll really be missed. The other neighbours work and don't speak to her very often.

Now it's the 12th of January, 2010. Mrs Bundel has fallen in the kitchen; she heard a dry, cracking sound in her left hip. She has a lot of pain in her thigh and cannot stand on her left leg; she doesn't even try. The next day,

domiciliary worker arrives, and has to use the spare key, since Mrs. Bundel didn't answer the door. She finds her lying on the cold kitchen floor, somewhat disoriented. The worker phones for emergency assistance. A GP is on the way. Mrs. Bundel has a possible hip fracture and is being taken to the hospital.

#### MELATONIN VERSUS PLACEBO IN ELDERLY PERSONS TRIAL (MAPLE)

Mrs. Bundel is still in a lot of pain, but has become more oriented after being given medication for pain in the Accident and Emergency department. A doctor, probably a surgeon, explains to her that the X-rays clearly show that her hip is broken and that she will be admitted for emergency surgery to repair it. First though, a cardiologist will come and have a look at her because her blood pressure is very high at the moment and her heartbeat is somewhat irregular.

When the cardiologist arrives, Mrs. Bundel is already on a ward. Alas, she can't eat anything because she could be operated on at any moment. The cardiologist agrees and says that the irregular heartbeats are not serious.

After a nap, Mrs Bundel awakens to find a lady next to her bed. She introduces herself as Jose and explains that she's one of the nurses of the 'elderly medicine ward' and that she'd like to ask some questions. Is that OK? Mrs Bundel says it's fine, and Jose goes to find a chair. She explains that after the hip operation, like the one Mrs. Bundel Katz is having to repair the fracture, older people often experience some disorientation and poor sleep. A research study is underway to try to help prevent this. In this study, people over 65, who have been admitted in an emergency, will be split into two groups. One group will get a fake-pill (placebo) and the other group will get a pill of melatonin, which is often called the 'anti-jetlag pill'.

The research involves looking to see if this pill can prevent the disorientation after the operation. Also, it will look at whether taking this melatonin pill will prevent the need for prescriptions of sedatives or sleeping pills, that elderly people are more sensitive to. Mrs Bundel was a subject for some medical research years ago, and she would like to be of help the medical field, although she hopes she is lucky and gets the real pill. Jose explains to her that she doesn't even know which is which, so that she can't 'spill the beans'. Even the doctor, who will come by later, doesn't know. That is because of the importance of the research and for calculating the results. On account of a full surgery schedule, the operation has been delayed another day, so that Mrs. Bundel will be assured of a well-rested surgeon who can operate well on her tomorrow. Luckily she can eat something and she gets her pill for the study at 9:00pm. The doctor who came by, explained things again, and thereafter, the evening nurses came to introduce themselves.

What a lot of people, and busy-ness; fortunately her thigh and leg do not hurt so much, except when she tries to move. The following morning she is operated on, and, according to the nurse who spoke to her in the recovery room, everything went according to plan. Sometime later she was allowed to return to her ward where she saw Jose, who quickly came to have a look.

In the afternoon, her neighbour lady came for a little chat and brought along a clean night-gown. Luckily she had a key and said she would water the plants. She would also phone to tell the domiciliary worker (who'd had such a shock at finding Mrs. Bundel on the floor), that everything was going well. Later, Jose came to ask some questions. They were a nuisance, but Jose told her she'd done well.

After a few days, Mrs Bundel was allowed to go to an 'Intermediate Care Unit' in a nursing home some distance away. She was very upset that she had to go to a nursing home, and under the covers, while no one was watching, she cried. But that's how it was and you had to get on with it, after all, it was in her best interest.

Alas, after a long period of convalescence in the Intermediate Care Unit, she could not return to her own home. On the 27th of May, Mrs. Bundel arrived in her new room in a Residential Care Home. She misses her old home; she was not able to see it again, except for one afternoon when her niece took her, by wheelchair, in the disabled-taxi to sort through her things to take to her new room. Her niece did her best, but it's still difficult to adjust to the new surroundings. If she had been able to choose.... many things can happen in six months.

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AFTER IMPLEMENTATION OF THE T1 (FIT) ASSISTANCE: FUNCTION MAINTENANCE IN TIMES OF TRANSITION

CASE OF MRS BUNDEL, AGED 78

It is the 24th of August, 2009. Mrs. Bundel is a 78 year old widow who lived in an apartment that is all on one floor, in Sunninghill. She goes to the shops for her groceries, daily. The last while, she has been trying to avoid travelling longer distances by bus or train. Her 76 year old neighbour lady drives Mrs. Bundel to the supermarket once or twice a week and helps her to get the larger and heavier groceries. Mrs. Bundel thinks she's reasonably healthy; she has some hypertension and retinopathy. She can do her own self-care, but finds it difficult to take a shower. Since her TIA last year, she finds going to the weekly choir practice a real effort, and, she's afraid of falling. In November she sees her GP for a yearly flu-jab; otherwise, she doesn't go to the GP surgery very often.

Along with the invitation to have her flu-jab, there was also a short letter from her GP. Would she mind if Frances, the practice nurse came to visit her and have a talk about her health and what she thought about getting older?

[T1 (FIT) Function Maintenance in Times of Transition]

It is the 5th of November, 2009, and **Frances, the practice nurse drops** by with some papers. She explains that that Mrs. Bundel's fall was reported by the (eg domiciliary worker) [PROFIT]. This always happens nowadays when someone has a fall, and such notification automatically prompts a message to be sent to the practice nurse, via the GP's computer. (ICOVE : Improving Care of Vulnerable Elders).

To prevent her falling again, Frances wants to talk to Mrs. Bundel about what she still can do, and what she might eventually be able to do better. First, Frances asks her four questions.

- Does she need help with self-care?
- Can she travel alone?
- Whether she uses an assistive device to help with walking?
- Whether she can do her groceries alone? [T1: ISAR]

Mrs. Bundel answers Frances' questions. Frances says that she'd like to ask her some more questions on account of the answers she's already given. They will take about 30 minutes [T1: CGA & integral careplan] Frances has a lot of questions, but Mrs Bundel actually doesn't mind talking like this for once. She feels fine, but some things are faltering. Her blood pressure is also measured again, both while she is standing and lying down. Also, some tests are done. They involve her getting out of a chair and walking a way as fast as she can, and squeezing a handle. According to Frances, she could still open jam jars easily, however, she could do it far better with her right hand than her left one. Frances also, asks her about her medicines and whether she knows which each one is for.

Frances relates the findings of her questions in order.

- Mrs. Bundel has an increased risk of a further fall
- she has difficulty with her sight
- she cannot walk very far, which means she can't go out as often as she'd like
- she finds it difficult to shower herself

Moreover, the neighbour lady has said that she will be moving to be near her daughter in Bath. That's a pity because she will miss the contact, and it will be a problem to get her groceries. And, truth be told, she hasn't as many people around as before; she sometimes feels a bit useless, and if she looks into her heart, maybe



even lonely. Aside from that, there are all kinds of small problems in the house. The front door has been sticking a while now. The light in the hallway by the kitchen is broken, and she doesn't dare to stand alone on a ladder. [T1: CGA and integral care plan].

Her niece will visit soon, maybe she can ask her. Frances asks Mrs. Bundel what she would like to do, and what she can do; such as, childminding, a reading aloud club, a telephone-circle, a movement course, fall-training...and all manner of other things. Frances also gives advice about how to prevent another fall, and how to make the house safer.

They make an appointment for the neighbourhood representative of the building association to come by in two weeks, to sort out the odd jobs. They also agree that Mrs. Bundel will think about what she'd like to do before meeting with Frances and the Elderly Advisor next week. [T1: Personal Strengths Conference]. Thereafter, the Elderly Advisor will come to speak with Mrs. Bundel again, and together they will make a nice plan.

It is now the 12th of January 2010 and Mrs. Bundel goes with her neighbour lady to the supermarket. Oddly enough, this lady has been living around the corner for a while; she saw her sometimes with her two daughters. The neighbour lady is a single mother and likes it that Mrs. Bundle-Katz keeps a watchful eye out for her children. Her own parents live far away. It is ideal that the practice nurse of the GP's surgery suggested this liaison. Mrs. Bundel is in time for the course 'More Movement for Elders' session, which she attends in a nearby Residential Home. This is comfortable using her new rolator, [wheeled zimmer frame] and is getting outside more often. Sometimes, she has a bite to eat in a restaurant where she has made some new contacts. This week, she's pretty busy; Frances is visiting tomorrow for her 3-monthly visit. Mrs Bundel has a list of questions ready to ask her. Her niece is treating her to a meal out, still owing for her birthday. A lot can happen in half a year.

It is the 5th of March, 2011. Mrs. Bundel still isn't feeling right after a bout of flu. She has no appetite and still has a nasty cough. She's decided to phone the GP and ask him to come by. The same evening the doorbell goes, she comes out of bed and walks to the front door to open it but she's very dizzy. When the GP sees her, he's visibly shocked. He helps her back to bed and checks her lungs. He explains that she has a heavy chest infection and that her blood pressure is too low although her heart-rate is very high; 150 beats per minute. This necessitates hospital treatment. She understands that, although she's not too keen on it; does it make sense to transplant an old tree, even for a few days? But she'd like to get better. Her GP phones the hospital and asks if there is a bed available. The local hospital doesn't have a free bed, but the next hospital he phones does. The ambulance picks her up and brings her to the Accident and Emergency department. There, an intravenous line is put in, they take some blood and she is given antibiotics.

Sigrid, the nurse, brings Mrs. Bundel to the Internal Medicine department, where she is admitted to ward B6. There, she gets another bed and another nurse, who introduces himself as Fritz. Fritz explains that he will be caring for her during the day shift the coming days and that she can ask him anything she likes. During the night Fritz returns, with a colleague. This time he is not nice. He scolds her and takes away her blankets. Terrified, she lays awake all night to see if he is coming back. The next morning someone wakes her up. When she awakens, there are about 8 people in white coats standing around her bed. Luckily, she has her blankets back. A lady introduces herself as Marion (she can't understand her last name very well), and explains that she is the ward doctor. The whole day she broods about why Fritz was so unkind to her. That night, Fritz arrives again- with a recorder, and a colleague who has a trumpet and a guitar. The whole night they make music at her bedside. She can't sleep because of it and doesn't dare to complain. She can't understand it. Why are they pestering her? What has she done wrong? She resolved not to say anything about it. After a few nights like this, luckily, she can return to her own home.

She returns home by taxi and that evening her niece drops by with some groceries. She notices that Mrs. Bundel is shuffling around the house, totally exhausted, and at risk of falling. She resolves to stay and spend the weekend with her aunt until the Personal Care Assistant arrives on Monday morning. She phones her work and says she's ill. Only on Tuesday will there be a meeting to arrange additional services for clients, and only on Thursday will the new worker drop by. The niece phones the GP on Wednesday to say that Mrs. Bundel is back at home and that her medications have been changed. The GP doesn't yet know what has been changed since the report from the hospital hasn't arrived yet, but he'll drop by after the afternoon surgery appointments. The next morning, the niece waits for the Personal Care Assistant, so she can give her a spare key, and then goes to her work. It is Thursday, and after four days of sick-leave she phones her work to say she

is better. That evening, she gets a phone call to relate that her aunt has fallen at home and has probably broken her hip; she has already been taken to the hospital.

After a few days, Mrs. Bundel went to an 'Intermediate Care Unit' in a nursing home some distance away. She was very upset that she had to go to a nursing home, and under the covers, while no one was watching, she cried. But, one had to get on with it; after all, it is in her best interest to do so.

Alas, after a long period of convalescence in the Intermediate Care Unit, she could not return to her own home. On August 27th, 2011, Mrs. Bundel arrived in her new room in a Residential Care home. She misses her old home; she was not able to see it again, except for one afternoon when her niece took her, by wheelchair, in the disabled-taxi to sort through her things to take to her new room. Her niece did her best, but it's still difficult to adjust to the new surroundings. If she had been able to choose... many things can happen in six months.

#### AFTER IMPLEMENTATION OF T2 ASSISTANCE: THE TRANSMURAL CARE BRIDGE

It is March 5th, 2011. Mrs Bundel still isn't feeling right after a bout of flu. She has no appetite and still has a nasty cough. She's decided to phone the GP and ask him to come by. The same evening the doorbell goes, she comes out of bed and walks to the front door to open it but she's very dizzy. When the GP sees her, he's visibly shocked. He helps her back to bed and checks her lungs. He explains that she has a heavy chest infection and that her blood pressure is too low though her heart-rate is very high; 150 beats per minute. This necessitates hospital treatment. She understands that although she's not too keen on it; does it make sense to transplant an old tree, even for a few days? But she'd like to get better. Her GP phones the hospital and asks if there is a bed available. The local hospital doesn't have a free bed, but the next hospital he phones does. The ambulance picks her up and brings her to the Accident and Emergency department. There, an intravenous line is put in, they take some blood, and she is given antibiotics. Sigrid, the nurse, brings Mrs. Bundel to the Internal Medicine department.

She is admitted to ward B6. There, she gets another bed and another nurse, who introduces himself as Fritz. Fritz explains that he will be caring for her during the day shift the coming days and that she can ask him anything she likes. During the night Fritz returns, with a colleague. This time he is not nice. He scolds her and takes away her blankets. Terrified, she lays awake all night to see if he is coming back. The next morning someone wakes her up. When she awakens, there are about 8 people in white coats standing around her bed. Luckily, she has her blankets back.

A lady introduces herself as Marion (she can't understand her last name very well), and explains that she is the ward doctor. In the afternoon, after she has been worrying the whole morning about why Fritz was so unkind to her, a nurse comes to introduce herself as Harriet. [T2: The Transmural Care Bridge] She explains that she is **from the Geriatric team** and that she'd like to speak with Mrs. Bundel about how things were going at home and in hospital. She'd also like to go through a list of questions with her. Mrs. Bundel feels tired, and relates this to Harriet. Harriet doesn't mind and they agree that she will drop by tomorrow morning to see how Mrs. Bundel is feeling. That night, Fritz arrives again - with a recorder, and a colleague who has a trumpet and a guitar. The whole night they make music at her bedside. She can't sleep because of it and doesn't dare to complain. She can't understand it. Why are they pestering her? What has she done wrong?

When Harriet arrives the next morning, Mrs. Bundel's room-mate has just been taken to get an X-ray. Harriet is so friendly, she decides to tell her secretly, about what has been going on the past two nights. To her astonishment, Harriet explains that this has been a sort of nightmare, and that Fritz hasn't been working the night shifts. She calls it a sort of 'delirium', which occurs sometimes when older people become acutely ill. Harriet gives her a pamphlet and asks if it OK if she meets with Marion and the ward doctor. Sometimes it's useful to take some medication for this so that Mrs. Bundle-Katz can sleep better. That night, she gets a sleeping tablet and rests well.

The following morning Fritz is standing by her bed. He winks at her and asks if he left her in peace during the night. Mrs. Bundel is a bit ashamed, and while Fritz is helping her to get dressed, they talk about it. Fritz says that delirium does happen frequently and that she shouldn't be ashamed about it; it happens when people are ill and could happen to anyone. He asks her if his performance had been a good one. He does play guitar, but

not the recorder. She tells him that years ago she played flute, and that the tune 'he had played for her' sounded familiar but she couldn't name it. Luckily, they can laugh about it. Harriet comes by a few times, and also the dietician and physiotherapist appear at her bedside. They organize all sorts of things with her. During the day she can wear her own clothing and walk in the corridor. After four days in the hospital, to her great surprise, **Frances, the practice nurse from her GP surgery comes to visit**. Frances tells Mrs. Bundle-Katz that she is helping with a project that involves helping elderly people to leave the hospital in good condition, and that Harriet had phoned Frances. She asks if things are going better and if she'd like to return home in a few days. Mrs. Bundle-Katz would like nothing better than that, and together they discuss what preparations need to be made. Frances and Harriet prepare a report for the Home Care organization, called a 'care management plan. They also speak with Fritz about a possible discharge date.

On March 13th, 2011, Mrs. Bundel is back at home. Many things have been arranged, extra 'personal care' time for help with washing and taking medications, and also 'Meals on Wheels'. The neighbour lady has filled the fridge for her and put the piles of post into neat bundles. Mrs. Bundel is still very tired and weak, so a commode chair and rolator walking frame have been arranged. Also, she has been given a necklace-alarm and that gives her a safe feeling. Little by little, she's getting her life back 'on the rails', but still, she's back at home.

She has been given physiotherapy and **Frances comes by regularly**. After two months, Frances, the neighbour lady, the Personal Care worker, the physiotherapist and the Elderly Care Advisor have a meeting. Frances had suggested to her to think about, together, what she could still manage do independently versus what she would like to do, and to see if some alternative arrangements could be made to help with those things. It's very tiring but actually a pleasant discussion. Mrs. Bundel explains that she finds it difficult to request and receive help, but that she does appreciate it greatly. It is also discussed that, since it is more difficult for her to get outside, she might want to get out once in a while to meet others and to do something together with them.

Mrs. Bundel confirms this. She isn't lonely (she's not going to admit to this, just like that) but she would enjoy doing some painting or clay sculpting with others. Not just to drink coffee- she can do that at home too. It is agreed that this daytime activity can be put into place; the Home Care organization has an artwork room. Her neighbour lady will bring her there once in a while, and maybe some of the other neighbours would offer to do that too? And if no one can, she could phone for some transport? This is how the afternoon finishes, with even more good ideas agreed. Fine that everyone wants to actively help and think along with her.

For now, this account ends here.

[ This case study is also being used by the work-group considering financial costs associated with 'transition from care' and its consequences for various health and care departments in the Netherlands. ]