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# GUIDING THROUGH THE DAWN

EFFECT OF VISUAL STIMULI AND AIDS ON EARLY ONSET YOUNG DEMENTIA PATIENTS

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## Abstract

Memory is referring to the concept of "remembering" in which several parts of the brain cooperate to complete the process of retrieving information that was "stored" earlier. Disorders such as dementia negatively affect storing and remembering information. On estimate 260,000 people in the Netherlands (Factsheet dementia algemeen, 2015) suffer from dementia. 12,000 people of this group are referred to as "early onset" dementia patients (Factsheet dementia algemeen, 2015). This type of dementia is diagnosed before the age 65 [See Appendix 1]. Dementia causes changes in a person's behavior and personality, as well as in verbal communication, i.e. speech and other forms of language usage. The main indicators of (beginning) dementia in the younger patients are usually not related to storing and retrieval of information, but involve other cognitive and behavioral disorders.

Visual representations, such as pictures, play a role in transferring and perceiving information. Also, some training tools are available which can help dementia patients in dealing with their daily lives. By making use of visual representations and training tools, existing paradigms such as Reality Orientation Therapy and Assistive Technology devices can enable the patients to maintain independence and to engage in social participation and activities (Cohene et al, 2005). However, where most studies focus on elderly dementia this study aims to understand the functional disabilities of young onset dementia patients and to give a theoretical answer and practical solution (e.g. a tool) based on User Centered Design Method. The central question of this study will therefore be: How do young onset dementia patients, who have functional but no physical limitations, respond to visual stimuli as a tool to enhance memory and thereby fulfill the daily activities?

Observation and expert interviews at the day care (Dock van Delft) allowed the researcher to understand the characteristics of dementia patients. Results derived from questionnaires given to the patients and their partners, allowed more detailed

understanding of the patient's needs. Also, it helped to create an archetype of a user or a characterization of a particular type for use (referred to as a "persona") and a prototype version for testing and designing the final design (referred to as a "paper-prototype"; see chapter 4.3 for more explanation).

The outcome resulted in a tool which had the form of a daily calendar. The calendar contained visual and analogue representations of daily activities and events, and was tested over a period of one week.

In the theoretical framework below I address the User Centered Design Method to define characteristics of the patients and form an understanding of the needs to create a supporting tool together with the participants. In addition, Talking Mats, which explains daily social interactions between the patients and their relatives based on using icons, is used as a framework for this study. For implementing the tool, this study relies on technologies such as Rosetta, which provides the patients with reminders using visual resources, and Assistive technology and Reality Orientation Therapy which assists and supports patients to improve their sense of control and self-esteem.

The interviews resulted in minor differences between how participants behave at home and at the day care. Young dementia patients have a tendency to disclaim dementia, where elderly patients seem to accept their disorder and they acknowledge this as an aging disease. Finally, patients indicate their preference for an analogue tool in the form of a visual daily calendar, rather than digital equipment.

A further finding includes that use of images helps to transfer a message, but it doesn't ensure that the patients store or memorize new information and can fulfill daily life tasks independently. Also, patients did respond to visual stimuli, and understood the message of the singular black-and-white, static illustrations, but they were unable to understand written, dynamic, digital text or figures and information of more than one icon integrated in the used calendar.

## 1 INTRODUCTION

A picture says more than a thousand words, is an old saying. In science, visual stimuli such as icons and images in static and dynamic forms have a significant impact on receiving, responding, memorizing and acting of information (G. Schlotterer et al, 1984). A visual medium such as a pictogram provides information enabling the reader to understand

the meaning of a message in a non-verbal way. Mental processing is accountable for receiving, comprehending, storing, retrieving and using information. Some disorders such as Dementia negatively affect this process of storing, processing, and retrieving information. (C.Ko and A. Ally 2011)

Dementia is regarded as a disorder that occurs in elderly people. In The Netherlands an estimated 260,000 people suffer from some form of dementia. Among this numbers there is a small group, approximately 12,000 (5% of the total) who suffer from young onset dementia. This is the target group of patients in this study. Young onset dementia is defined as dementia that affects people under age of 65.

Research in the field of dementia shows that patients prefer to remain in their own home environment as long as possible (Yuginovich et al, 2012). In this regard, the methods and technologies that support patients in remaining independent in their own homes are known as Assistive Technologies (AT).

Assistive Technologies provide patients with the ability to remain home longer. These technologies allow an individual to perform tasks they would otherwise be unable to do. In addition to easing the living situation these devices provide a safe environment (Soar et al, 2007). Assistive technologies refer to devices available for patients with mostly physical- and functional limitations and disabilities. The purpose of assistive devices is to enable patients to maintain their independence and engage them in social participation and activity. Known examples of assistive Technologies are home automation (called assistive domotics ) for elderly and disable people, memory aids, prostheses, walking aids etc.

The symptoms of young onset dementia are different from those found in the elderly people who suffer from dementia. One of the important features of dementia in elderly people is the memory disturbance in the short memory system, not allowing them to store new information. Younger patients mostly suffer from other symptoms. The first symptoms are usually not related to storing information, but involve other cognitive and

behavioral disorders (such as compulsive behavior, paranoia, increased irritability and restlessness). These behavioral disorders are often not associated with dementia, but rather with psychological stress that causes problems in family and work related situations, which in the end causes mental deterioration. Dementia at a young age has a major impact, since most of the patients still work or have partners and (young) children, generally no physical limitations and they also fulfill other roles in society. Due to their functional disability patients lose their job, damage social connections, and eventually become less able to perform the most simple independent tasks such as taking a shower, changing their clothes, etc.

Most existing Assistive Technologies are tested in a lab environment and with elderly dementia patients, who have not only memory loss, but also physical limitations and chronic disabilities, for example walking impairments, diminished sight, hearing and sometimes little or no participation in social activities and interaction.

This study attempts to understand the functional disabilities of younger dementia patients and to give a theoretical account and practical solution (a tool) developed using the User Centered Design Method. This is a framework aimed at understanding the needs and limitations of the intended users by letting them participate in the design process. Using this framework, this study addresses the following core question: How do young onset dementia patients (younger than 65), who have functional but no physical limitations, respond to visual stimuli as a tool to enhance memory and fulfill the daily activities?

The participants in this study were mostly unable to read or write. Therefore, visual stimulation is central in this study, rather than written text. Finally, while other studies are mostly tested in a lab environment, testing the tool took place at patient's home, which is a familiar environment without much distraction to full-fill the tasks.

Dementia at a young age has impact on the whole family. Research into the experiences of children and spouses of Alzheimer patients

showed that they were considerably affected by the disease process. (Zarit e.a., 1985).

Studies show that patients prefer to remain at home with their family as long as possible and to perform daily life activities independently as long as possible (Yuginovich et al, 2012).

This research is a qualitative study consisting of five components. Chapter 2 is dedicated to understanding the background of dementia and Alzheimer disease. Hereby we focus on symptoms and constraints which are related to Alzheimer's disease. The background research is done on two forms of Alzheimer, namely Dementia and Front Temporal Dementia (FTD). This study focuses on patients who are diagnosed before age 65, known as Young Onset Dementia (YOD). The participants in this study were three male patients diagnosed with YOD. Two patients were diagnosed with FTD and the other one with Alzheimer. Symptoms related to FTD are: struggle with decision-making, organising and planning. Patients suffering from FTD see no connection between cause and effect, they have also difficulties with planning, organizing and judging. Due to this most patients tend to neglect personal hygiene. In contrast Alzheimer patients frequently forget names of places, people appointments and events.

In chapter 3 we focus on related work regarding tools, relevant methods, and projects concerning Alzheimer patients. Chapter 4 of the study is dedicated to observations at the day care (Dock van Delft) in city of Delft. This was important for collecting information and getting acquainted with the participants. Secondly, it was useful to determine whether the participants have physical limitations, which could affect the result then performing the final prototype tasks at home. Intense observation at the day care, for a period of two months spread over three days a week allowed the researcher to observe the participants' behaviour and to find out whether they acted differently at the day care and home. Observing the behaviour of the patients and interviews with the experts of the day care, was needed to collect information and allow the researcher to collect significant information about the needs and behaviour of the patients. The observation

showed that some patients acted slightly differently when they are at the day care. For example, activities at the day care are carried out by professionals and the patients are guided to perform tasks in a period of time, while at home the caregivers face other problems with patients, for example getting dressed, planning and performing tasks often requires more time. Noticeable in this observation was the behaviour of patients. While at the day care they are noisy and less obedient and sometimes showing impulsive behaviour by giving comments about someone's appearance. At home they seem to be more quiet.

The second part of the research reported in Chapter 4 involves interviews with patients and their partners, where the needs of participants (thus also the partners) were identified. The interviews took place at participants' residences, since the participants prefer to be interviewed in a safe and recognizable environment. The partners were also asked to join the interview, since some participants tend not to acknowledge the dementia or they cannot remember some events and activities while performing daily life activities. The outcome of the interviews led to the creation of three 'personas' that describe various scenarios of patients and also one partner.

Based on the interview results and personas a prototype in form of an analogue daily calendar was designed and tested over a period of one week. Chapter 5 describes the outcome, prototype design and finally testing and evaluating the design. The calendar background contained visual elements such as seasons in Dutch landscapes. This was to remind them of the season and for partners to start a dialogue with the patients. To keep the participants in a familiar and secure environment, the testing took place at their home. For the prototype both patients and their partners were responsible for the use of images and to fill in the daily tasks for a period of time of one week. The icons used for the calendar focuses on the morning tasks, for example, brushing teeth, shaving, taking a shower etc. The main focus of this part of the study is to find out to what extent visual stimuli can support with these daily tasks. The participants were asked if they

recognize the meaning of the images and find them understandable, disturbing, eye-catching or clear. The participants were asked to fulfill their daily tasks independently and individually.

## **2.0 BACKGROUND ON DEMENTIA**

Dementia is often characterized as a disease of old age. However, there is also a significant group of people between 30 and 65 years old suffering from dementia. In the literature on this subject this group is referred to as Young Onset Dementia (YOD) (Dulanji K Kuruppu, 2013). This study concentrates on Young onset dementia patients who suffer from two different forms of dementia, namely Front Temporal Dementia (§2.1) and Alzheimer (§2.3).

### **2.1: FRONT TEMPORAL DEMENTIA**

About 10-20 percent of people who suffer from young onset dementia between the age of 40 and 60 years suffer from Front Temporal Dementia (FTD). This form of dementia particularly affects the frontal and temporal lobes of the brain, whereby brain cells die over time and changes will occur in the connections of brain cell pathways. Eventually over time, the brain tissue of the frontal and temporal lobes will shrink. This damage causes changes in person's behaviour and personality, as well as in verbal communication, speech and language. FTD more commonly occurs in young onset dementia patients (B. Enguland et al ,1994).

### **2.2 THE SYMPTOMS OF FRONT TEMPORALDEMENTIA**

The patients struggle with decision making, organising and planning. Patients suffering from FTD see no connection between cause and effect, they have also difficulties with planning, organizing and judging. In this regards, the most common issues are changes in personality and behaviour of the patients. For example, some patients lose the ability to take initiative and become lifeless, they don't care about personal hygiene or they respond indifferent to emotional events.

Characteristics of FTD are that patients show impulsive behaviour, and they lose inhibitions

in words and deeds. In social community, the patients often tend to behave in an inappropriate way and make improper comments about someone's physical appearances. The patients also show repetitive behaviour causing them reiterating words or phrases and compulsive or ritualised behaviour hoarding and obsession with tracking the time (S.M. Rosso et al, 2001).

### **2.3: ALZHEIMER**

The most common form of dementia is Alzheimer. Estimated 54 percent (140,000 people) of patients with dementia suffer from Alzheimer (Dementie op jonge leeftijd, 2012). This form of dementia is caused by a physical illness of the brain. The development of the plaques and tangles in the brain lead to death of brain cells during the course of the disease. Alzheimer patients also have a shortage of some important chemicals (acetylcholine) for the transmission of messages within the brain. Alzheimer is a progressive process that will increase in its impact over the course of time. As the disease progresses the patients need more support and help in their daily activities. (J. Peeters et al, 2012) Repetitive questioning as one of the main behavioural symptoms of dementia will result in suffering, increasing of care costs, and huge loss in the quality of life for the patients and their families.

Alzheimer can be distinguished in two categories, early- and late stage. Early stage Alzheimer occurs in people between age of 30-60 years and late stage Alzheimer is after 65 years old. Ninety percent of patients suffer from late stage and ten percent of patients suffer from early form of Alzheimer's disease, which is the category of young onset dementia.

### **2.4 THE SYMPTOMS OF ALZHEIMER**

Patients diagnosed with Alzheimer, frequently forget names of places, people, appointments and events. Over time, the patient suffers from orientation disorders, long-term memory impairments and loss of the ability to understand the track of time. (Clare and Woods, 2003)

In a further stage of the disease the patient becomes confused, causing loss of confidence and a feeling of uncertainty. Due to this the

patients become more withdrawn, or they experience mood swings, feel angry, aggressive and frustrated or sad. In many cases patients face difficulty in performing everyday activities and tasks (Sanford I. Finkel et al, 1997).

## 2.5 YOUNG ONSET DEMENTIA

The cognitive and behavioural disorder of young onset dementia is different from that of the elderly patients who suffer from dementia. One of the important symptoms of dementia in elderly people is disturbance of the short memory system and not being able to store new information. However, the main indicators of dementia found in the younger patients are usually not related to storing information, but involve other cognitive and behavioural disorders, such as compulsive behaviour, paranoia, increased irritability and restlessness (H. Fadil et al, 2009).

These behavioural disorders are often not associated with dementia, but rather with psychological stress that causes problems in family and work related situations, which at the end causes mental deterioration. Dementia at a young age has a major impact, since most of the patients still work or have partners and children, generally no physical limitations and they also fulfil other roles in society. Due to this disability patients lose their social activities and their jobs. Moreover, they lose the ability to perform most simple independent daily activities such as showering, going to the bathroom and changing their clothes.

## 3.0 RELATED WORK

To understand the relevant methods, tools and frameworks, works related to this study will be discussed in this paragraph.

Based on the implementation in this study the structure of the chapter is arranged as follow. In §3.1 User-Centered Design method, which describes the theoretical approach used to understand the characteristics and the needs of the user will be discussed. The next paragraph, §3.2 Talking Mats explains a social enterprise for people with communication problems. The framework used in Talking Mats enables social

interactions between the patients and their relatives.

§3.3 Assistive Technology which describes a number of tools will be discussed that are used to support elderly (dementia) people in their daily life activities. Rosetta, discussed in 3.4, is a technology that provides the patients with reminders using visual resources. Paragraph §3.5 discusses Reality Orientation Therapy, an orientation-treatment that improves the patient's sense of control and self-esteem. And finally, in §3.6 the so-called LightAble is discussed.

### 3.1 USER-CENTERED DESIGN METHOD

The aim of the study is to create a solution that suits the participant's needs by involving the user in the design process. In order to achieve this goal a User Centered Design Method (UCDM) was applied.

With UCDM the designer uses elements such as limitations, requisites and needs of the end-user in order to invent a user-friendly product. In this study UCDM consists of these four steps: Analysing, Designing, Evaluation and finally Implementation. In each step verification is required with the previous step of the process.

In the field of young onset dementia there are just a few studies that discuss performing everyday activities, tasks and needs. In these studies, most of the findings are about digital tools and solutions such as ROSETTA-project, tracking devices (e.g. I. Karkowski, 2012), and social robotics for elderly people who suffer from dementia, such as the robot seal Paro (K. Wada et al, 2004). The results of the interviews with patients show the need of a customized analogue solution and not the already existing digital tools. (S. Hwang et al, 2015).

The term of User-Centered Design originated from Donald Norman during his research at University of California San Diego (YCS) in the 1980s. In his Poet ('The Psychology Of Everyday Things'; Norman, 1988) he describes the user needs and interests and focuses on usability of the design. (Abras et al, 2004)

In this study we focus on elements of the method, such as creating personas and co-creation. Important roles of UCD within this study are, Visualization of the final tool, participation of all participants during the design of the tool, and finally usability testing.

In his book, Donald Norman states: 'Simplify the structure of tasks to avoid overload of information'. According to his findings an average healthy user is able to remember five things at the time (Norman, 1988, p.189-201) In creation of the design for this study it was taken into account that patients who participate lost ability to memorize and also were not able to remember events as a average healthy user. This is an interesting point in order to make a comparison between healthy users vs. dementia patients.

### **Relevance of UCD for this Study**

As mentioned in the Introduction the young onset dementia patients have other needs than elderly people who suffer from this disorder. Besides age, another important difference between these groups is the social activities and family situation. Most young onset dementia patients are still physically and socially very active. They have less physical limitations. They live at home and their partners, who mostly have to work, cannot take care of the patients all day. In some cases the patients have also children who still live at home. Therefore, this study focuses not only on participants but also on their partners, given that the partners take care of the patient themselves in combination with often full-time jobs. (C. Schölzel-Dorenbos et al, Denkbeeld, 1994)

Finally, the patients hope to remain independent and active as long as possible. Hence, the tool envisaged here is deliberately based on the needs of both user and partner, to support their needs in every day task activities. (See Interview results in Appendix 3)

### **3.2 TALKING MATS**

Talking mats developed by Scottish University of Stirling is a tool for people with dementia or other cognitive and communication disabilities.

The tool uses simple (black and white) icons divided into three compartments: Positive, Negative and No-idea (Figure 1). A recognizable icon represents each compartment: one with a smiling-facial expression, one with a glum-facial expression and one with a neutral facial expression.

Single cards with recognizable icons indicate topics, emotions and activities. The participant can classify their daily activities based on personal needs. Together with the caregiver the daily task can be divided and organized. Additionally, the patient can rank the activity based on three facial emotional expressions.

The purpose of talking mats is to involve people with dementia and their careers in decision-making. It also allows the patients to clarify their thoughts, and to express them to their family carers, and reach a decision in discussions.

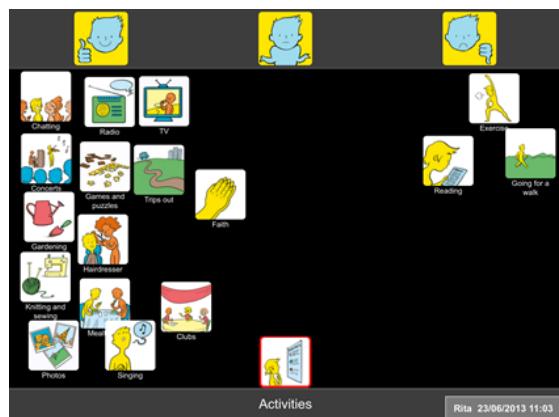


Figure 1: EXAMPLE OF TALKINGMATS

### **3.3 ASSISTIVE TECHNOLOGY**

One of the primary features of dementia is forgetfulness. Assistive technology is a term of products used to support the Dementia patient in their daily life activities. This technology provides solutions to give the patients an easier and safer living environment. Assistive technology can be categorized in different products or activities. The most common are Memory-aids, Telecommunication-care, Safer-walking and Daily-activities. For this research that aims to understand how a tool can help in better memorizing and fulfilling the daily activities, the relevant products based on Assistive Technology are memory aids

(Bewernitz, M.W., et al., 2009) & (T. Yuginovich et al, 2012)

Products based on Assistive Technology are relevant to this research since they support memory aids in daily life activities. Memory aids, such as clocks, calendars, locator devices and medication aids are meant as a reminder for various activities.

### 3.4 ROSETTA PROJECT

ROSETTA is a unique home automation device, combined from several assistive technology products, such as memory aids, contact list, tracking devices that function as a reminder tool. ROSETTA provides support in the different stages of dementia and focuses on visual resources such as pictograms, an analogue-clock and pictures of family-members to recognize close relatives easier and (Figure 2). Furthermore, ROSETTA is a lifestyle monitoring system for patients who live independently and allows the caregivers and possible family carer to track the patient through a computer monitor in their daily life pattern. When notable exception in daily life pattern occurs the system will report this, and alarm the caregivers. Assistive technology decreases workload required from caregiver and allows older adults to increase independence.



Figure 2: Screenshot of a reminder on touch-screen (ROSETTA project).

### 3.5 REALITY ORIENTATION THERAPY

This study will use Reality Orientation Therapy (ROT) ideas, and a translation into patient “real” world instead of abstract exercises. The relevance of this method to this research is the similarity of the techniques (such as visual stimuli) in ROT and the constraints of this research. Reality Orientation Therapy (ROT) was developed in the 1950’s and is the most known cognitive stimulation technique for

patients with Alzheimer (Zanetti et al, 1995). It is a technique that uses targeted and continuous stimulation such as pictures, lamps and signs in order to help the patient to reorient towards the environment. As a result, this seems to improve the patient’s sense of control and self-esteem. (D.Gagnon 1996). There are two forms of ROTs that require a different approach: there is a Formal- and Informal ROT. The Informal ROT approach involves a reorganization of the object in a room or environment. Here lies the focus on aids like calendars, (digitals) board, and clocks featuring various signs, for example saying ‘bathroom’, ‘bedroom’, etc. The use of these aids will cause direct stimulation, which allows the patient to recall information such as day, month year and activities planned for that day.

### 3.6 LIGHTABLE

In partnership with Philips lightning and psychology students from VU Amsterdam, Loek Canton designed an light table called LightAble.

LightAble is an interactive light table for elderly dementia patients. The table enables stimulation of social activities of dement elderly by using dynamic bright light and interactive objects. Canton observed and interviewed participants and caregivers to understand the effect of lighting and interaction. This resulted in that the use of lighting improves the overall state of mind. It also allows the user to become socially more active and communicative.

*Light intensity:*

LightAble consists of dynamic daylight simulation, using intensity and color temperatures. Intensity and color change throughout the day, according to a scheme (see time table of intensity below):

Table 1: Scheme of dynamic daylight simulation .

07.30 PM–09.00 AM	Increasing colours temperatures
09.00 AM–01:00 PM	High colour temperature, high intensity.
01:00 PM – 02:00 PM	Low colour temperature, low intensity.
02:00 PM – 05:00 PM	High colour temperature, high intensity.

### *Metaphor:*

Moreover, the table allows the users to interact with each other by using objects. One metaphor used for interaction is called: Mother and Child (see figure 4). The participants use the larger objects 'mother' by putting it in the middle of the table, when the small objects 'children' surround the mother, the table responds by adjusting the light and light intensity. When a Child object is removed from the table the color of the table changes. Thus the user learns that they have to interact with objects in order to collect all the objects around the mother object. This metaphor refers to the care of children. The aim of this metaphor is to create interaction and to arouse emotion and sense of bonding between elderly dementia patients. (L. Canton, 2012)



Figure 3: The light changes in intensity and color.



Figure 4: Lighting table objects. The blue object represents the mother. Smaller object with red eyes represent the children.

## 4.0 METHOD

This study is a qualitative research composed of three components: (1) observation inquiry

including expert-interviews, (2) questionnaires with the patients and their partners and (3) personas and paper-prototype testing. In order to find a solution together with the patient the User Centered Design Method is applied.

### 4.1 OBSERVATION AND EXPERT INTERVIEWS

The first component of this study consist of an observation inquiry at day care (Dock van Delft) and is dedicated to studying patients' behaviour in detail. An important reason to do this was to understand similarities and differences between elderly and young dementia patients. Another important aspect of spending time at the day care was bonding with the patients before the interviews and gathering information about different forms of dementia and consequences in patients' lives, and to determine whether the participants show different behaviour at home compared to at the day care. Also, physical limitations were observed, such as difficulty in walking and performing tasks, which could affect the result when performing the final prototype testing at home.

Interviews with the experts at the day care, allowed the researcher to understand the needs and differences between taking care of elderly and young dementia patients. See box 1 for experiences during the observations and box 2 for a summary of results of interviews with the experts. **Box 1: Spending time at the day care.**

#### *What caught my attention during the observation*

The rooms for elderly patients were decorated with objects and art craft from the 50s and 60s. Elderly Alzheimer patients tended to remember those artifacts better than technologies from the past 20 years. The elderly dementia patients remembered much about the past. They often went back to their childhood in conversations and became like young children. For example they saw a caregiver as their mother or aunt.

The room for young onset dementia patients had a varying interior. Patients were allowed to bring a collection of items which is related to their hobby or the job that they used to perform. During my observation period a patient brought items that were related to his previous job as a computer engineer. I noticed that the alteration in the room allowed patients to communicate and to ask questions about each other's previous jobs and activities. I noticed also that Young onset dementia patients lost memory parts of the past, for example their childhood. One of the patients in this study was no longer able to remember his life before age of 30.

#### *Repeating sentences*

One of the patients saw a sailing boat crossing over and she kept repeating one sentence (did you see the boat sailing over there?) Although the boat was not visible anymore, she kept telling others about the boat she saw. Remarkably, other patients agreed that they saw the boat to and kept repeating the same.

To avoid and restrict confusion, everything needs to be set and arranged beforehand. For example, when using public transport, the bus needs to be on time, otherwise the patient gets confused and distracted and therefore no longer able to finish the journey by himself.

Another point that caught my attention was the level of education among the patients. Patients who participate in this study are highly educated (master degree) males. One of the patients has two master degrees from Technical university of Delft. He said: as a physics student I was among the top in my class . He was also involved in the design and introduction of speed camera in the Netherlands. It was sad to see that someone with such ability , expertise and knowledge was losing his memory due to Alzheimer.

#### **Box 2: Interview with the experts at the day care.**

##### *Interview at day care*

According to caregivers it is easier to work with elderly dementia patients. When elderly patients are asked to perform a task they immediately participate, while young patients are stubborn and have to be asked multiple times before they participate in a game or in performing a task. Elderly patients are also more polite to other patients and the caregivers. They treat each other with more respect. Young onset dementia patients often give inappropriate remarks about a person's appearance. They tend to not acknowledge the disease when they are together at the daycare, and are more often rude to each other compared to elderly patients.

## **4.2 QUESTIONNAIRES WITH PARTICIPANTS**

The second component of the research is the interviews with the participants. The interviews took place at a participant's residence, since the participants preferred to be interviewed in a safe and recognizable environment.

The participant's partners were asked to join the interview, since they are responsible for classification of and decisions on daily life activities. Another reason for participation of partners was to validate the facts and events. Some participants tend not to acknowledge their dementia disorder and were unable to remember events and activities. (see box 3 for observations during the interview).

#### **Box 3: Interview with the participants.**

Asking patients whether they were aware of dementia was hard, since beforehand I had no idea about how the patients would respond to this questions. But it resulted in that patients suffering from dementia are aware that they have Alzheimer's disease, but forget the symptoms constantly and thus become depressed every time that they have an awareness moment. One of the patients told that he is mentally more exposed and thus more vulnerable in comparison with physical illnesses. When asked whether the patients have difficulty to perform daily life tasks they answered as follows: We have no difficulty in carrying out the tasks, we face problems in order of the tasks. For example, once when I am distracted by the doorbell I cannot perform a task again. This causes having difficulty in linking processes such as cause and effect. Due to error in the brain system, patients are more often exposed to dangerous situations. At a certain stage of the disease most patients lose the ability to distinguish differences between hot and cold, rain or sunny weather, and also ability to face emotional feelings.

## **4.3 User interface**

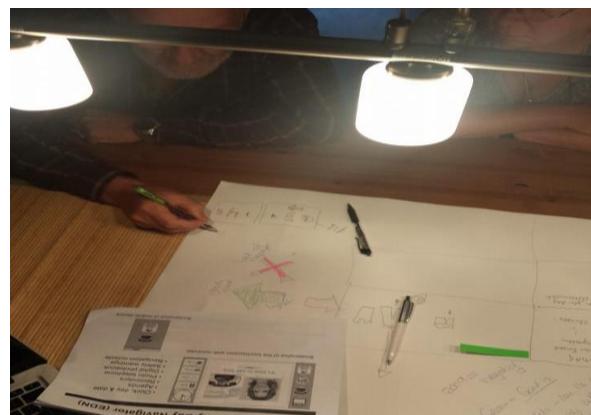
### **4.3.1 Personas**

In the UCDM, Personas are fictional characters created for different types of users. Personas are useful to describe, compare and represent different user types in how they interact with a product.

### **4.3.2 Paper prototype**

A prototype is a first model of a product, which can easily be adjusted and tested with the user, to measure different ways of usage. A prototype allows the user to determine the classification of a product by its needs and interaction.

Figure 5: Participant working on the paper prototype.



## **4.4 STUDY POPULATION**

The study population consist of three male patients. Two patients are diagnosed with Front temporal Dementia and one with Alzheimer disease. The patients diagnosed with FTD are 68 year old, diagnosed at the age of 64, and a 60 year old , diagnosed at the age of 54. The patient with Alzheimer is a 72 year old diagnosed at the age of 65.

Some participants tend not to acknowledge dementia or they cannot remember some events and activities while performing daily life activities , therefore two experts from the day care and three partners are interviewed to gather more information and to learn more about characteristics of dementia patients and their behaviour at the day care and home.

## 4.5 PROCEDURE / VALIDATION

The interviews with the participants are based on different categories such as personal questions, daily life activities, understanding, recognizing icons and support tool.

To keep the participants in a familiar and secure environment, the interviews and testing the prototype took place at a participant's residence. The interview with the participants and their partners consisted of four parts: The first part focuses on participant's personal issues. Second part of the interview focuses on participation of partners and their needs. The partners were asked to participate and to answer questions that the patient was unable to answer. Third part of the interview focuses on starting the early day activities and finally the fourth part focuses on creating a tool that suits the participant's needs. To understand the need of the participants and to identify what the needs are, the questions are divided among different categories named in Table 2.

**Table 2: Question categories**

<i>Patients</i>	The questions with the participants were categorized in three categories: 1: personal questions such as age, when diagnosed with dementia, type of dementia, use of medication. 2: Home situation: special changes in the home environment, memory support and guidance in and around the house etc. 3: support and supervision: obstacles for patients relating to supervision, advising about how to deal with different situations.
<i>Partners</i>	The questions with the partners dealt with different categories, namely: effect on their personal life, and how the partners deal with the situation. Also major changes in life and forms of therapy and support, which have been consulted.
<i>Starting day</i>	Together with the partners the participants were asked to answer questions about: e.g how they start the day. Help while getting dressed and questions about how the wardrobe is sorted.
<i>Support tool</i>	This part of the interview focuses on designing a suitable tool to support the participants in their daily life activities. Questions related to support tool were: describe the ideal tool, requirements for the tool, understanding the icons. (See Appendix 3 for full interview questions)

## 4.6 ETHICAL CONSIDERATIONS

The study components were discussed and approved by participants, their partners and the staff of the day care institute. Prior to the interviews an agreement was settled not to use any pictures and names of the participants in this research, due to privacy reasons. Furthermore, the participants were allowed to stop their contribution to the study at any time.

## 5.0 RESULTS

Analysis of the observations and results can be separated into five components, based on the steps given in the UCDM. These are as follows: analysing the needs of the participants and *studying* users' needs (§5.1); defining the interaction based on co-creation (§5.2); designing the paper prototype based on personas (§5.3); testing the paper prototype (§5.4) and finally evaluating the prototype (§5.5).

### 5.1 ANALYSING THE OBSERVATIONS, INTERVIEWS AND QUESTIONNAIRES

In order to comprehend the patients' needs, as well as the obstacles they meet in their daily lives, the experts at the day care (DOCK van delft) were interviewed. From the interviews it became clear that there are differences between how the patients behave at home and at the day care. The social- and psychical behaviour between elderly and young dementia patients differs as well.

Observation at the day care shows that Young onset dementia patients have tendency to disclaim dementia when they are among other patients at the day care, where elderly patients accept their disorder and acknowledge this as a part of aging process.

According to interview with the experts at the day care, elderly patients tend to hold to their childhood memories and sometime act like a child. While interview with patients and their partners shows that some Young Onset Dementia patients lose parts of their childhood. One of the patients was not able to remember his life before the age of 30. Young onset dementia (male) patients tend to say whatever comes to their mind and sometimes create an insulting environment to one another. That

environment often leads to discomfort of caregivers, while elderly patients are more polite and speak with more respect towards each other.

Additionally, observation and interview shows that both elderly and young onset dementia patients, often repeat an event and sentence. In contrast to elderly patients, young onset dementia patients copy each other behaviour or sentence. During this study this was not identified in Alzheimer's patients.

Observation at the day care allowed the researcher to observe the patients' behaviour and physical limitations. In addition, it allowed for bonding with them to some degree, and created an atmosphere in which it felt right to ask their permission for participation in the study. Furthermore, the observation allowed for deepening the understanding of the differences between elderly and young onset dementia patients. (see box 4 for a description of observed behavioural disorders).

#### **Box 4: Behavioural disorders .**

Patients diagnosed with Front Temporal Dementia (FTD) have problems with short memory storage. Therefore, they lose track of the steps in a sequence when performing a task. One consequence can be that don't see the difference between dirty and clean anymore: they don't remember what they have just cleaned and what not. This affects their personal hygiene. Due to Dementia, all kinds of co-morbidity arises: behavioral changes and mental disorders such as compulsive behaviour, paranoia, increased irritability and restlessness. These in itself again cause confusion and depression. When the patients are tired, the symptoms of dementia are the worse. Taking a rest and sleep helps them to feel better. Therefore it is important to take a nap at the daycare.

Observation at the day care shows that elderly patients have physical problems and cannot participate in most activities. Young onset dementia patients didn't show physical problems, however some patients were tired after practicing an activity.

#### **Patients sensitivity to visual-information**

The three patients who participated in this study are high-educated males, who were

diagnosed with dementia before the age of 65. Before diagnosis, they were in a healthy condition, and physically and socially active. Due to age of patients the doctors didn't associate symptoms directly to dementia, but more with depression and burn out. The patients are still physically and socially active and they like to perform task themselves and remain independent as long as possible.

Interview analysis show that all three participants have difficulty in understanding a narrative (audio or movie). The Patients are also not able to read or write. Except for one patient who has Alzheimer's disease and still able to read a digital clock on his television screen.

According to patients and their partners a list of visual elements such as picture would help to memorize and perform activities. For example type of signage in and around the house. Therefore it was decided to use visual information in the design tool.

The results from the questionnaires with both patients and their partners can be summarized as follows:

The visual-information (images and/or icons) must be simple (black-and-white, without text) to reduce distraction, be recognizable, and associable to daily life activities. To avoid distraction and irrelevant information, the context of visuals must be clear: for example, no audio, dynamic images and written text.

The patients indicated that they have no need for digital equipment, but rather prefer a clear analogue calendar, to plan daily activities. The reason that participants prefer analogue method is because they usually forget the purpose of digital objects. According to the patients an analogue calendar is more visible and useful.

The 72 year old patient diagnosed with Alzheimer is still able to read a digital clock (only at his television screen). During the interview he said that he is able to read small sentences and write some words, for example his name and numerical digits. He was also able

to read text on a card that read 'Happy Birthday' provided with a picture of a cake.

Two other patients both diagnosed with FTD were unable to read and write. They had difficulty to read digital clocks and only preferred analogue clocks.

Finally, all participants confirmed that they didn't need audio stimulation and aids at this stage of dementia. According to interview with partners audible information might work if the patients were recently diagnosed or if they were in early stage of dementia, at this stage audible information would only cause confusion. All participants were able to listen to music that they already knew. They enjoyed the melody more than understanding the lyrics.

## 5.2 DEFINING THE INTERACTION

Based on results from the questionnaire, three personas were created: two of patients and one of a patient's partner. The aim of the first personas is to understand the patient's needs, daily activities and potential benefits. The second persona is created to identify the partner's needs, and benefits in use of the daily calendar (See appendix 3)

### Personas

A description the patient's persona can be given as follows:

*Stefan is a 72-year male, diagnosed with Alzheimer before age 65. Stefan is aware of his disorder, and sometime this causes frustration and depression. To avoid depression he enjoys visiting his grandson, listening to (70's) music, and doing yoga. Twice a week he visits his neighbour for coffee. He only memorizes this event by using a cooking alarm, which is set by his partner before she leaves the house. Stefan gets distracted if the alarm doesn't work or when he is performing other tasks. Among the participants Stefan is the only participant who is capable to read a digital clock, but only on his television screen. He likes to watch the 8 pm news, but he doesn't memorize the news. He is not able to read anymore, but he can write words and short sentences.*

*Hank is a 67- year male, which is no longer able to memorize dates, weeks, months and*

*seasons. By using pictures and icons, Hanks partner assigns him task around the house. Hank is easily distracted; therefore he is no longer able to follow storylines in movies, news, radio and conversations.*

*Recently, Hank has lost his ability to understand some of the icons' use. He knows the meaning of, for example, an icon of a phone, but he doesn't understand the task conveyed within the icon's message.*

*Rina is a 65 years old female, who still enjoys working as a part time secretary. Since her partner has been diagnosed with dementia, she takes care of him. In the mornings she must get up early to make everything ready for herself and her partner, which she experiences as a time consuming process. She worries about her partner and tries to make use of tools as much as possible, so that her partner can independently perform his daily tasks. She is most benefited by a visual tool that reminds her partner of the date, month and seasons, but also contains images or icons to represent daily activities and tasks. She misses the conversations with her husband and hopes that the tool also contains visuals that allow her and her partner to start a dialogue.*

### Similarities between personas

The similarities among the three participants are that they are still socially and physically active.

Interview with the partners shows that partners are responsible for patient's agenda, daily planning, putting their clothes ready and sometimes in carrying out the order of the tasks.

The participants indicated that they easily get distracted; therefore they can only focus on one task at the time. Audio and video messages will cause confusion, since the participants are not able to understand or to follow the narrative.

There is an overall need to become more independent and engage more in conversations, especially with their partners.

### *Differences between personas*

In contrast to Hank, Stefan is able to read a digital clock from his television screen and write sentences. Rina is the caregiver, in her life she misses the conversations, interacting and communication with her partner.

### *Digital versus analogue*

As mentioned earlier the patients have difficulties in understanding the message conveyed in digital media. Due to dementia, the patients do receive messages, but are often unable to store and understand the meaning of it.

### *Framework paper prototype*

The framework used for the design of a prototype tool is derived from the study with Talking Mats. Differences are the colored icons used to define the tasks, and the choice not to use text:

During interview both patients and partners indicated preferring black and white pictures in order to avoid confusion and distraction. The 68 year old patient with FTD mentioned that he gets distracted by bright colors. He said: since I cannot read text I prefer simple images without color.

However, In the study with Talking Mats, they used colour images with text. All icons used for this study are already used in other studies with dementia patients.(werkenmetvisualisaties.be)

### **5.3 DESIGNING THE PAPER PROTOTYPE**

Based on interview results, an analogue daily calendar was designed, which was divided in hours and photos related to seasons (figure 5). The reason for using background images of different seasons emerged from the interviews. The participants and their partners preferred images as a reminder for seasons. To avoid distraction, the partners indicated to use faded images on the background, and black and white characters. The partners also hoped to start a dialogue with their partners while asking them about the images, and whether they understand the meaning behind the image.

Figure 6: example of a page from the calendar



In order to accommodate the needs of the participants a prototype was created for final testing. The prototype consists of a daily calendar divided into hours, and the use of various images, which represented daily tasks.

Figure 7: example of icons used in the study



The icons used for this study are simple and recognizable for all participants. The decision to use these icons has emerged from the study Talking Mats combined with the present interview results. The participants in this study gave preference to black and white icons that are easy to recognize. The images used in Talking Mats contain text, but patients in this study were unable to read or write the text in the images, therefore this was not included in icons used here.

### *Design of the Calendar according to the UCDM*

The calendar is created based on the results from the interview (*Studying users*), creating personas (*designing a solution*) and co-creation with the participants (*creating prototype*) in order to design a suitable tool and finally testing the prototype (*evaluating prototype*). During the Co-creation the participants were asked to create an ideal tool. The literature, interviews and personas resulted in use of analog materials, therefore materials such as papers (A2), colored signs, sticker icons and markers were used to design the tool.

### *The background image*

The background of the calendar is designed based on needs of the partners.

Interview with partners resulted in having the need to start a dialogue with their dement partner, since they often have no topic to start a conversation. Another important point was the understanding of seasons and timetables. According to the partners a dialogue about a simple image, allows them to understand whether the partner is has a mentally sharp moment and still recognize things.

The images at the background of the daily calendar represent seasons and Dutch landscapes, which the patients sees and potentially recognizes every day. The colored image on the background draws attention to itself from a distance.

#### *The foreground icons*

The foreground of the calendar focuses on requirements and needs of the patients. An important factor is whether the patients understanding the icons and exercise activities as shown on the icon.

This study focuses on understanding visual elements in order to perform daily life activities. The use of black and white icons originated from the literature and previous studies with Alzheimer patients and people with Autism. (e.g. Talking mats uses similar icons in color and containing text). The study (J. Murphy, et al, 2007) shows that Alzheimer's patients understand simple images rather than photos of people or objects.

The patients who participated in this study had difficulty recognizing a picture that changed context. For example: image of a white toothbrush, while the patient has a red one. Or the size and color of the bus that might change causes much confusion.

#### **5.4 TESTING THE PAPER PROTOTYPE**

A identical weekly calendar was given to all patients, together with sticker sheets with black and white icons that represented daily life activities. Beforehand it was mentioned that patients were able to stop participation at any time. The patients also received an evaluation form to fill in during the testing. The partners were asked to observe the patients during the use of the calendar and finally to fill in the evaluation list.

For using the prototype patients and their partners were responsible for the use of icons and to fill in the daily tasks for a period of time of one week. The calendar focuses on morning tasks, for example, brushing teeth, shaving, taking a shower etc. This is the most hectic moment of a day: the partners need to get ready to go to work and cannot always explain the order of tasks.

The main focus of this part of the study is to find out to what extent visual stimuli can support these daily tasks. The participants were asked whether they understand the meaning of the icons and find them understandable, disturbing, eye-catching or clear. The participants were asked to fulfil the daily tasks independently and individually.

The 68 year old patient with FTD was not able to see the link between the images and his daily activities. He became confused and therefore stopped using the calendar after three days, however he mentioned that he knew what the message on the images contained, but he forgot the purpose of the message in combination with the calendar. For example, this patient saw the icon of the sun, but for him it was difficult to understand whether it represent daytime or sunny weather. Though he uses the bus every day, he was unable to understand that bus icon was representing the public transportation. However he did mentioned, using picture of the bus that he takes every, day might have work better.

The 60 year old patient, diagnosed with FDT , also got distracted by the calendar after two days. he was not able to understand the meaning of the icons and images. This patient had difficulty in understanding the meaning of an icon that represented a family, he said that he prefers a picture of his own family rather than a icon.

The patient, 72 year old, diagnosed with Alzheimer was the only person in this study who was able to read a digital clock and still able to read and write short sentences. He was the only participant who finished all the days of the calendar.

Result from the evaluation form show, The singular icons were recognizable and easy to understand for all patients. But usage of one or more images integrated on the calendar was causing confusion. In all cases the patient did walk to the calendar, but as soon as they were back on the sofa they forgot the calendar.

According to two participants and their partners the use of a calendar on long term might cause a positive impact and enhance the benefits, but since they have difficulty to store information on their long and short memory they forget about the calendar. Partners indicated that use of this calendar would be more useful if the patients used the calendar from the early stage of the disorder.

Filling in the daily tasks through icons on the calendar, allowed the patients and partners to plan a day and to start a dialogue

## 5.5 EVALUATION

The paper prototype was evaluated on different components: usefulness, usability, and user experiences. Questions related to background and to the icons representing daily activities. Background image (table 3)

**Table 3: understanding the background images of the calendar**

Do you find the images	Disturbing	Recognizable	Clear
Participant 1	No, not really	Yes, it means Autumn	Yes, clear enough
Participant 2	No.	Not all Images	Not all images
Participant 3	No.	Autumn and Holland	Yes

Icons representing daily activities (table 4)

**Table 4: understanding icons representing daily activities**

Do you find the images	Clear	Recognizable	Comprehensible
Participant 1	Yes, Clear	Yes most are, but I don't get all	Yes

		meanings	
Participant 2	Yes	Yes	Yes
Participant 3	Yes, some are. Except: Bus and family.	Yes	Yes

## Most used icons

The most used icons are associated with morning rituals. One participant was able to read digital clock on his television, but digital times taken out of the context on the calendar were a problem for him as well. Therefore, eventually all participants ended up using the analogue clock icon to assign hours to the tasks.

## 6.0 DISCUSSION AND CONCLUSION

The theoretical study done for this thesis shows that research on Assistive Technology has focused on elderly (65-plus) dementia patients, but not on younger patients. The current study focused on young-onset dementia patients and, contrary to the lab-developed tools used in almost all the other studies so far, it introduces a tool in the form of daily calendar designed in interaction with patients.

During interview the patients gave their preference for black and white images rather than colored icons. However, the results from testing an evaluation show that this is not beneficial, in contrast it causes confusion because the environment exists of colored objects.

The patients understood the meaning of the images and experienced them to be clear. The singular icons were recognizable and easy to understand for all patients. But usage of one or more images integrated on the calendar was causing confusion. Digital tools can prevent distraction by isolation and presenting singular icons. However, interview results revealed preferences for an analogue tool, the testing

result show that is complicated to implement singular icons on a paper calendar.

The prospect of partners as caregivers: by using the calendar the partners hoped that the partner would become more independent in fulfilling the daily tasks, so that they would be less occupied preparing, repeating and explaining the events. The partners also hoped for more communication and conversation topics through the images on the calendar.

In this study, at the stages of the disease the patients were in, use of calendar had not the desired effect. According to the partners the calendar might have had effect if it had been used from the moment that the patients were diagnosed with dementia. A possible explanation for this would be that in early stages of dementia, use of images and icons is useful since patients are still in a stage where they can store information to some extent.

Not all the images and icons were recognizable for the patients. Some icons were been used, since the patient misunderstood or did not understand the message contained in the icon.

They had difficulty to store and memorize new information, which possibly caused the lack of taking action in line with the message of the visual stimuli. Thus we can conclude that the use of images helps to transfer a message, but it doesn't ensure that the patients can fulfill daily life task independently.

The number of participants is not sufficient to draw a conclusion whether this applies to patients with dementia more generally. All three participants were male and diagnosed before the age of 65, so we also cannot conclude whether this applies to both sexes at same age and same stage of dementia.

## 7.0 FUTURE WORK

This study focused only on image information transfer and not on audio stimuli, or a combination of visual and audio stimuli. Interview results show that patients who participated in this study cannot follow a narrative. However, they represent a small group of Young onset Dementia patients. Further studies in combination with a larger group of patients in different stage of disease

might give an answer on, whether use of audio tools in combination of visual images helps to guide the patients in their daily life activities.

The research gives insight into which are the most used icons and which the less or not used icons. Some icons have not been used at all, since the patient misunderstood the message contained in the icon.

Suggestion for further studies: Make use of recognizable images, for example pictures of the family and friends. Use photographs of public transport that the patients use on daily base, instead of icons.

In this study we only focus on male participants, for future work, it is clearly recommend to involve female participants and assess similarities or differences between two genders.

Finally, the numbers of participants in this study consisted of three diagnosed with Alzheimer and Front Temporal Dementia (DTP) patients. For future work, it is recommend to study more numbers of patients and make a distinction in different types of dementia.



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## Appendix 1: what is dementia and statistics of patients in the Netherlands.



Factsheet | datum: 03-02-2015 | www.alzheimer-nederland.nl

### Wat is dementie?

- Dementie\* is een ziektebeeld waarbij de geestelijke vermogen ernstig zijn afgenoem. Als gevolg hiervan kan iemand dagelijkse handelingen, die voorheen moeiteloos werden gedaan, minder goed of niet meer uitvoeren. Het gaat dan om handelingen als zich aankleden, het bereiden van voedsel, correcte inname van medicatie, of het betalen van rekeningen.
- De meeste voorkomende vorm van dementie is de ziekte van Alzheimer (70%), gevolgd door vasculaire dementie (16%).
- Mensen met dementie leven gemiddeld 8 jaar met de ziekte. Gedurende het ziekteproces neemt zowel het aantal als de ernst van de klachten toe. Er is geen genezing mogelijk voor dementie. Uiteindelijk overlijdt een patiënt aan de gevolgen van dementie. Dementie is na kanker en hart- en vaatziekten de meest voorkomende doodsoorzaak in Nederland.

### Hoeveel mensen lijden aan dementie?

- In Nederland hebben ruim 260.000 mensen dementie.
  - Hiervan zijn er 12.000 jonger dan 65 jaar.
  - Hiervan wonen er ruim 70.000 in verpleeg- of verzorgingshuizen.
  - Hiervan hebben er 100.000 nog geen diagnose.
- Iedere uur krijgen vier mensen in Nederland dementie. Erkenning duurt echter lang. Gemiddeld duurt het 14 maanden voordat de diagnose wordt gesteld. Bij jonge mensen duurt dit gemiddeld meer dan vier jaar.
- Het aantal mensen met dementie zal als gevolg van de vergrijzing in de toekomst explosief stijgen naar meer dan een half miljoen in 2040. In 2055 bereikt het aantal mensen met dementie een piek van ruim 690.000.

\* Bekijk voor meer informatie de factsheet 'Wat is dementie'

## Appendix 2: Interview results Day care Experts

### Observatie:

Tijdens de observatie viel het op dat de jong demente patiënten geen lichamelijk beperkingen hebben. Ze nemen actief deel aan meeste activiteiten bij Dock van Delft. Patiënten hebben vaak de neiging om zinnen, woorden en gebeurtenissen te herhalen. In de kamer waar de patiënten zitten hangt een grote klok en daar kunnen de patiënten de tijd van af lezen. Dit ging bij de meeste patiënten erg gemakkelijk, maar sommige hebben geen benul wat tijd inhoud. Tijdens sommige activiteiten zoals raad het woord, doen meeste deelnemers actief mee en als ze hints krijgen hebben ze weinig moeite om het woord te raden.

Om 10:00 uur wordt iedereen verwacht bij Dock van Delft. De patiënten nemen allemaal eerst plaats aan een tafel, waar ze koffie of thee drinken, ze nemen de dag door met de begeleiders en vertellen bijzondere verhalen. Tussen de middag gaat iedereen samen lunchen, soms zorgen de patiënten voor een maaltijd. (smeren van boterhammen, zakken soep in een pan gieten etc.) dit gebeurt altijd onder toezicht van een begeleider, want alleen koken kunnen ze niet. Daarna wordt de tafel gedekt en na het eten wordt deze weer afgerruimd. Tussen de middag kunnen de patiënten slapen, of iets voor zichzelf doen. (een van de vrouwelijke patiënten kleurt graag kleurplaten voor volwassenen in) dit geeft haar rust. Meeste mannelijke patiënten slapen. Sommige dagen gaan ze met z'n allen wandelen en anders gebeuren de meeste activiteiten binnen het dagverblijf. Rond 15:00 uur worden de patiënten opgehaald. Sommige gaan met speciaal vervoer anderen worden opgehaald door hun partners. Er is een patiënt die graag nog de bus neemt, deze patiënt wil graag zolang het kan onafhankelijk blijven.

### 1: Wat zijn de verschillen tussen ouderen en jong demente patiënten?

#### Gedrag verschillen?

Ouderen patiënten zijn makkelijker in omgang, vaak erg beleefd en spreken elkaar met u aan, terwijl jong demente patiënten soms ongeremd opmerkingen maken over iemands uiterlijk. Daarin verschillen zij veel van elkaar. Wij merken ook dat jonge patiënten neiging hebben om dingen vaker te herhalen. De jonge patiënten hebben soms een haantjes gedrag naar elkaar toe, ze proberen grappig over te komen en daarbij maken ze vaak ongepaste opmerkingen. Ouderen gaan veel meer met respect met elkaar om.

#### Sociale verschillen?

Daarin schelen zij niet veel van elkaar, behalve in eerder genoemde.

#### Beperkingen?

Ouderen weten vaak, veel over vroeger. Dingen die wij niet eens meer kennen. Ze gaan vaak terug naar hun jeugd, terwijl jong demente patiënten, vaak grote delen uit het verleden vergeten zijn. Zo is er een patiënt die niets meer voor zijn 30ste herinnert.

## Fysieke verschillen?

De ouderen zijn beperkter in uitoefenen van activiteiten, omdat ze last hebben van hun spieren. Maar yoga en lichte sport oefeningen doen ze soms met ondersteuning nog wel.

## 2: Houden jullie rekening met plannen van activiteiten?

Meeste activiteiten voor beide groepen zijn gelijk, behalve als het fysiek veel last bezorgd. Dan doen we dit niet met ouderen. Wij hebben hier 2 x per week Yoga lessen, en soms koken wij lichte maaltijden met de groepen, wat ze zelf voor lunch kunnen opeten. Ook vragen wij mee te helpen in dekken en afruimen. Daarin blijven zij actief en is een hulpje voor thuis. Kunnen ze thuis ook doen.

## 3: Met welk groep is het makkelijker om mee werken ?

Dat is elke keer anders, sommige werken makkelijker met elkaar als anderen. Ouderen die luisteren wel in een keer, terwijl we bij jonge patiënten vaak moeten herhalen en of vragen voordat er iets gebeurt.

## 4: Hoe vaak hebben jullie contact met de partners van de patiënten?

Als wij iets merken laten we dit gelijk aan de partner weten, indien van toepassing is dat zee en partner hebben. Sommige patiënten worden met de bus opgehaald en anderen worden gebracht door hun partners of kinderen. Op zulke momenten hebben wij vaker contact met elkaar.

## 5: Zijn de ruimtes voor beiden groepen anders ingedeeld?

Ja, bij ouderen hebben wij veel voorwerpen van vroeger staan, in ruimtes voor onze jonge patiënten hebben wij een kast waar we elke keer iets nieuws voor gebruiken. Bijvoorbeeld patiënten kunnen iets meenemen wat met zijn/haar baan ( voordat hij/zij ziek werd uitoefende) of hobby te maken heeft en daar kunnen ze samen over praten.

## 6: Wat zijn dagelijkse activiteiten bij Dock van Delft?

Koken, zingen, koffie/thee drinken. Elke vrijdag doen we aan een borrel. Als de patiënten mogen drinken, krijgen ze 1 glas wijn van ons.

## 7: Zijn de patiënten bewust van hun ziekte?

Ja de meeste zijn er wel bewust van. In een groep hebben wij een jong patiënt die aan MS lijdt en geleidelijk ook dement wordt.

## 8: Welke groep heeft het meeste zorg nodig?

In sommige gevallen de ouderen.

## 9: Waar moet een onderzoeker rekening mee houden tijdens het onderzoek?

Zorg dat je altijd de patiënten als gelijke behandeld. Spreek ze aan en ga een dialoog aan. Het is erg belangrijk om een band op te bouwen voordat je aan je onderzoek begint. Vraag zowel de patiënt als partner om toestemming voor deelname aan het onderzoek. Vooraf alles doornemen en als de patiënten mogen ten alle tijden deelname aan het onderzoek stoppen.

## Appendix 3: Interview results with patients

### Persoonlijke vragen

Wat is uw leeftijd?

68 jaar oud, de ziekte en de diagnose is vastgesteld voor zijn 65<sup>ste</sup> dus deze participant valt onder jong dementerend.

Wanneer is de diagnose bij u vastgesteld?

Ongeveer 3 jaar geleden.

Hoe bent u erachter komen dat u aan Dementie lijdt?

Het begon allemaal met gehoorproblemen die voornamelijk door de partner werden opgemerkt. Dingen drongen niet echt door, mensen werden niet herkend die al jaren bevriend waren met de participant.

Welke vorm van dementie heeft u?

Front Temporale Dementie.

In welke stadium van de ziekte bevindt uw zich?

Nog in het begin, maar is als nog moeilijk te zeggen, omdat we niet weten wanneer het allemaal begonnen is.

Gebruikt u medicijnen om de aandoening te vertragen?

Nee

Bent u bewust van uw ziekte?

Ja, erg bewust, maar kan er niets aan doen dat ik steeds dingen vergeet.

Hoe fysiek actief bent u? Bijv. sport u nog?

Ik ben fysiek erg actief, doe 2 keer per week aan sport, boven hebben we een loopbank etc. staan, daar maakt ik soms gebruik van. Ik merk steeds dat ik erg moe wordt, dus tussen de middag of wanneer ik thuis ben moet ik min 1 uur slapen!

Hoe zelfstandig bent u in het uitvoeren van alledaagse dingen? Bijv. douchen, aankleden, koken en eten?

Ik kan niet meer koken maar de rest doe ik allemaal nog wel zelf, kan wel koffie zetten en een magnetron maaltijd warm maken. Wel moet mijn partner mijn kleding klaar leggen, want ik weet gewoon niet welke kleding ik aan moet. Daar ben ik niet van bewust. Ik kan ook niet een onderscheid maken tussen wat ik heb aangehad en wat vuile was is en wat niet.

Heeft u nog hobby's?

Ik doe aan beeldhouwen op de verzorging huis Dock van Delft\* DVD is een verzorgingstehuis , thuis speel ik vaak Sudoku. Werk soms ook met computers. Ik was vroeger een echte computer nerd, vooral aan software kant.

Wat vinden de patiënten nog interessant om doen?

Op vakantie gaan, Sudoku en beeldhouwen.

Thuis situatie:

Zijn er activiteiten die u voorheen deed en nu niet meer kan uitoefenen?

Ik kan niet meer koken, kleding uitkiezen, de was doen, lezen, ik kan bijvoorbeeld geen boeken of hele zinnen meer lezen en/ of schrijven. Ook is het moeilijk om de klok nog te lezen. Met analoog heb ik geen moeite, maar digitaal gaat niet meer. En alleen reizen of ergens naartoe gaan is niet meer mogelijk. Ik kan bijvoorbeeld van huis naar Dock van Delft met het OV, maar er moet echt niets tussen komen. Als de bustijden veranderen kan ik niet meer met de bus en zelfstandig daar naar toe. Buiten dit allemaal probeer ik wel veel zelf te doen, maar er moet echt niets tussen komen. Bijvoorbeeld als in de ochtend moet aankleden en de deurbel gaat of de kat loopt even naar binnen krijg ik een black-out en weet gewoon niet wat ik aan het doen was. Er komt ook niet in me op wat ik aan het doen was en waarmee ik verder moet gaan.

Zijn er bepaalde aanpassingen thuis? BIJV gebruik van stickers etc op de deuren.

Nee, nog niet. Ik merk dat ik niet meer weet waar de borden en kopjes liggen, dat was tot voor kort niet zo. Partner geeft aan wel voorgesteld te hebben om stickers te plakken op de kasten, maar de participant weet dat niet meer. Verder een grote kalender waar de afspraken op vermeld staan.

Heeft u een dagboek of houdt u of uw partner een agenda bij?

De partner houdt de agenda bij, en moet steeds blijven herinneren aan de afspraken. Ze verteld: veel plannen heeft nooit zin, hij weet gewoon niet wat er al besproken is.

Zijn er geheugensteunen in en om het huis?

Behalve de kalender nog niets, maar de partner overweegt om dat wel anders te doen.

Begeleiding

Hoe vaak is er begeleiding per week/ dag?

Er is geen begeleiding, behalve verzorgsters van Dock van Delft, ik bezoek de ontmoetingscentrum 4 keer per week, voorheen zat ik maar thuis en daardoor werd ik depressief.

Wat krijgen de partners als advies?

Niet vanuit de zorg of huisarts, wel vanuit de Alzheimer café, waar ze veel steun uit kunnen halen m.b.t. hoe ze met een partner met Alzheimer om moeten gaan en gesprekken met lotgenoten. Je gaat je steeds meer aanpassen

Zijn er knelpunten voor de patiënten ( evt. met betrekking tot begeleiding)?

Een knelpunt is meer dat ik niet meer in staat ben om te schrijven. Niet m.b.t. begeleiding.

Zijn er knelpunten voor de partners ( evt. met betrekking tot begeleiding)?

Wij moeten het zelf doen en steeds meer aanpassen. Ik vond het jammer dat we niet werden begrepen door de huisarts en daardoor veel later achter kwamen dat mijn partner ziek is.

## Partner

Wat waren de grote veranderingen in uw leven?

Plannen dat we samen voor de toekomst hadden gemaakt, om bijvoorbeeld na ons pension op reis zouden gaan. Verder is het dat je je dierbare steeds van je vervreemd. Zij herkennen jou niet en andersom. Ik mis ons leuke gesprekken en contact samen. Je past je rol als partner aan.

Wat voor effect of impact had de ziekte op kinderen?

Ik heb zelf een dochter uit mijn vorig huwelijk, samen hebben we geen kind. Ik heb veel steun aan me dochter, want haar schoonmoeder lijdt ook aan dementie.

Hoe zijn jullie daarmee omgegaan?

Ik heb veel gelezen over de ziekte de symptomen en waar ik evt. Rekening mee moest houden.

Hoe zijn de klachten begonnen? Waar heeft u dat aan gemerkt?

Met gehoor problemen. Vergeetachtigheid, niet herkennen van kennissen, dingen door de war halen.

Wat waren de grootste veranderingen in jullie gezamenlijke leven?

Het verlies van je partner, terwijl hij nog leeft.

Welke vormen van therapie of ondersteuning heeft u geraadpleegd?

Geen vormen van therapie, want het heeft weinig zin. Wel deelgenomen aan dagbehandelingen bij Dock van Delft. Daar doen ze aan denk spelletjes en activiteiten etc.

Van welk van eerder genoemde heeft u het meeste steun gehad? Aan begeleiding van Dock van Delft hebben we meeste steun gehad.

## Klachten

Welke momenten van de dag verergeren de klachten?

Wanneer ik erg moe ben en dat is meestal rond 16:30 en 17:00, soms ook wel in de ochtenden, want ik slaap heel slecht. Ik lig vaak wakker maar weet niet wat de oorzaak of waarom ik niet kan slapen.

Welke momenten van de dag bent u wel erg scherp en merkt u weinig van uw ziekte?

Dat is meestal na mijn middag dutje of vroeg in de morgen na dat ik Koffie heb gedronken

Waar zou u als partner meeste ondersteuning in kunnen gebruiken?

In planning en regelen van dingen. Het is vermoeiend om alles te moeten herhalen. Soms komt hij naar de kalender toe gelopen om iets te lezen, tegen de tijd dat hij terug loopt, is hij alweer vergeten waarom hij ergens naar toe loopt. En dit herhaalt zich meerdere keren per dag.

Wie helpt uw partner met het aankleden?

Dat doet hij nog wel zelf, maar ik moet alles voor hem klaar leggen, wassen en strijken. Vroeger deed hij dit allemaal zelf. Wij hebben ook een beperkte aantal kleding, het is anders te veel keus.

Hoe begint de dag voor jullie?

Meestal staat de participant op om brood te maken, alles moet in de koelkast op hetzelfde plek staan, anders weet hij niet waarom hij de koelkast open deed. Hij zet ook koffie klaar, daarna ontbijt hij en

vervolgens gaat hij naar boven. In tussentijd legt zijn partner zijn kleding klaar op het bed. Hij gaat douchen en tandenpoetsen daarna omkleden om naar de bus te lopen richting Dock van delft.

Wat zijn de knelpunten waar uw tegenaan loopt?

Dat ik niet weet waarom ik iets doe, als de kat binnen loopt dat weet ik niet meer wat ik moet doen. Ook niet als de kleding al klaar liggen, mijn vrouw moet dan vertellen dat ik me moet aankleden. Daarna kan ik weer zelfstandig aankleden.

Hoe zou u dat anders willen hebben, of hoe zou u dat willen oplossen?

Geen antwoord.

Aankleden

Omschrijf uw ochtenden.

Heeft u een vaste ochtend routine? (Bijv gaat u eerst koffie drinken dan omkleden?) Reeds beschreven bij vraag 31 en 32

Hoe lang doet u er over om u te kleden?

Met douchen en aankleden 20 a 25 minuten.

Is dat anders als voor de diagnose?

Ja toen deed ik dat in 10 a 15 minuten

Hoe is uw kledingkast gesorteerd?

Wij hebben een gezamenlijke kledingkast. Beetje en puinhoop!

Is dat speciaal gedaan?

Niet relevant

Houd u rekening met het weer?

Ik weet meestal dat ik een jas moet aan trekken, maar de rest van me kleding weet ik niet. Ik weet wel dat ik een broek aan moet trekken en een trui aan moet doen, maar ik kan zelf uit de kast geen kleding sorteren.

Heeft u moeite met de volgorde van aankleden? Nee niet echt, partner beaamt dit.

Applicatie

Voor welke activiteit zou u het gebruik van een tool als een ondersteuning zien?

Planning en agenda, misschien ook wel in datum en dagen in de week. Ik vergeet meestal welke dag het is.

Aan weke eisen moet het voldoen?

Het moet in ieder geval analoog zijn, iets met korte zinnen, een evt. foto's. Audio zou ook kunnen werken, maar ik ben bang dat ik snel afgeleid raakt. Het moet feedback kunnen geven. Of dat ik evt. een kruis kan zetten op de dagen die voorbij zijn.

Wat vindt u van visuele begeleiding ? Bijvoorbeeld Pictogrammen?

Ik snap beperkt aantal plaatsje, wel kan ik zien wat het betekend, maar niet wat de doel van zo een plaatje is. Bijvoorbeeld weet dat een plaatje telefoon betekend, maar soms weet ik niet wat ik ermee moet.

Wat vindt u van korte informatieve filmpjes in het algemeen?

Werkt niet bij mij, ik raak het meestal kwijt.

Denkt u daar baat bij te hebben?

Nee, niet echt

Wat vindt u van geheugen steuntjes in slaapkamer?

Hangt ervan af wat voor een. Ik weet niet of ik snap waarvoor ze bedoeld zijn.

Bent in bezit van een Smartphone?

Nee. Ik kan ook niet meer mee I-pad werken.

Bent u handig in het gebruiken van uw Smartphone?

N.V.T

Waar mag een tool volgens u in verwerkt worden?

Van mij mag het in een kalender vorm, zo lang het niet te digitaal en moeilijk is.

Zou u een ideale tool kunnen tekenen of beschrijven?

Het moet simpel zijn, geen kleur of teksten hebben want lezen gaat niet. Leuk om plaatjes van seizoen te gebruiken want dan kunnen we samen over praten.

Het moet groot en zichtbaar.

Denkt u dat gebruik van info graphics nuttig is als geheugen steun?

Ja, wij denken van wel.

Herkent u de volgende iconen? Ja.



Persoonlijke vragen

Wat is uw leeftijd?

72 jaar oud.

Wanneer is de diagnose bij u vastgesteld?

4 december 2009. 2008 al bezig begon op zijn 65ste

Hoe bent u erachter komen dat u aan Dementie lijdt?

Kon niet veel onthouden, onzeker, gingen aantal keer naar de huisarts en die geloofde hun niet en dacht dat zij de boel in de maling namen. Niet serieus genomen en de arts schrok van de uitslag.

Welke vorm van dementie heeft u?

Alzheimer.

In welke stadium van de ziekte bevindt uw zich?

Weten we niet, omdat wij niet meer bij een neuroloog komen. En die onderzoeken in Amsterdam geloven wij niet. We willen het liever niet weten.

Gebruikt u medicijnen om de aandoening te vertragen?

Eentje wel, om hem wat rustiger te krijgen.

Bent u bewust van uw ziekte?

Ja. Best wel

Hoe actief bent u? Bijv. sport u nog?

Vroeger wel, jeu de boules. Yoga bij Dock van Delft en lichaams beweging.

Hoe zelfstandig bent u in het uitvoeren van alledaagse dingen? Bijv. douchen, aankleden, koken en eten?

Douchen, gaat wel, koken niet. Aankleden gaat alleen als alles klaar ligt.

Heeft u nog hobby's?

Muziek luisteren. zingen

Wat vindt u nog interessant en leuk om doen? (Bijv. dagjes uit, vakantie etc.)

Dagjes uit, naar de kleinkind, uit eten gaan, koffie drinken.

Thuis situatie:

Zijn er activiteiten die u voorheen deed en nu niet meer kunt uitoefenen thuis?

Kleine reparaties doen, dat lukt niet meer, vaatwasser uitruimen gaat niet meer. Lezen en schrijven gaat niet, schrijven gaat nog wel. Plaatjes kan hij onderscheiden en vertellen maar blijft nieuw. Analoog gaat bijna niet meer, maar digitaal nog wel.

Zijn er speciale aanpassingen in het huis? (Bijv. gebruik van stickers, beelden op de deuren en kasten)

Op vakantie wel, doen we post-its voor waar de kamers toe behoren. Kook wekker aan zetten, als die afloopt ga ik bij een vriend koffie drinken. Kalender, met de dagen.

Heeft u een dagboek of houdt u of uw partner een agenda bij?

Nee geen dagboek, maar wel een agenda. Dat houdt de partner bij.

Zijn er geheugensteunen in en om het huis?

Tot de hoek van de straat, maar de rest moet ik altijd met iemand erbij, en er wordt vaak gebeld door de partner.

Begeleiding (dit in geval wanneer er buiten de mantelzorg nog externe begeleiding is)

Hoe vaak is er begeleiding per week/ dag? 2 dagen bij Dock van Delft

Krijgen de partners nog speciale adviezen m.b.t. hoe ze met de situatie om moeten gaan?

Ik ben lid van Lotgenoten groep, daar haal ik voldoening uit en adviezen, maar voor de rest niet.

**Zijn er knelpunten voor de patiënten (evt. met betrekking tot begeleiding)?**

Kan kleine dingen niet meer doen, ik heb moeite met fijn motoriek.

**Zijn er knelpunten voor de partners (evt. met betrekking tot begeleiding)?**

Het duurde lang voordat we serieus genomen werden en duurde 1 jaar lang voordat we naar een neuroloog konden.

Partner

Wat waren de grootste veranderingen in uw leven?

Je moet alles van een ander over nemen, bijvoorbeeld overnemen en beslissingen nemen. Je werkt en denkt voor twee. Je bent niet meer gelijkwaardig.

(indien van toepassing) Wat voor effect of impact had de ziekte op kinderen? Kinderen zijn heel erg van geschrokken. Ze woonden niet meer thuis. Wel 1 jaar 1 kind in huis gehad, maar niet op het moment zelf.

Hoe zijn jullie daarmee omgegaan? We hebben met kinderen gesproken, we gaan jaarlijks 1 week weg met de familie. En tijdens de eerste vakantie hebben we veel gesproken.

Hoe zijn de klachten begonnen? Waar heeft u dat aan gemerkt?

Door dat haar partner aangaf dat hij dingen vergat, voornamelijk op het werk. Ik gaf aan dat dit door stress van het werk kwam.

Wat waren de grote veranderingen in jullie gezamenlijke leven?

Geen gesprekken, je heb gesprekken en gespreksonderwerpen waar je samen over wilt hebben, dit kan nu niet.

Welke vormen van therapie of ondersteuning heeft u geraadpleegd?

Wel ondersteuning vanuit Dock van delft.

Van welk van eerder genoemde heeft u het meeste steun gehad?

Laatste want we zouden de case manager van dock van delft altijd benaderen, indien nodig.

## Partners

Welke momenten van de dag verergeren de klachten?

Later op de dag wanneer ik vermoeid ben.

Welke momenten van de dag is de patiënt scherp?

In de ochtenden en soms in de middag na een middag dutje.

Waar zou u als partner meeste ondersteuning in kunnen gebruiken? Moeilijk te beantwoorden. Wij hebben ondersteuning in familie, maar chaotische in zijn denk patroon kunnen we niet weg nemen.

Wie helpt uw partner met het aankleden?

Ik leg alles klaar, en hij trekt alles zelf aan. Ik moet niet twee overhemden hangen.

Hoe begint de dag voor jullie? ( bijv. Moet u kleding klaar leggen voor uw partner?)

Wassen, scheren daarna brood maken. Partner legt alles klaar ook zijn kleding. Als de kookwrekker gaat dan ga ik koffie drinken en twee dagen is de partner thuis.

Wat zijn de knelpunten waar uw tegenaan loopt?

Het moet klaar staan , en als het anders staat dan anders dan raak ik de klus kwijt. Ik heb geen besef van tijd en dag.

Hoe zou u dat anders willen hebben, of hoe zou u dat willen oplossen?

Vraag aan partner. Een dagkalender met foto's. Bijvoorbeeld op de dinsdag een foto van Dock van delft, en op woensdag een foto van Jeus de Beul.

Regelmaat is heel erg bedankt. Ik moet wel aangeven wat ik ga doen maar niet te lang, misschien 1 uur van te voren.

Aankleden ( vragen 2 t/m 9 zijn gericht naar de patiënt, met evt.. aanvulling door de partner.

Kunt u een korte omschrijving geven van hoe u en uw partner de dag beginnen?

Ik sta vrij vroeg op, douchen en dan tandenpoetsen tot die tijd is het rustig , maar daarna komt mijn partner vragen wat hij moet doen. Hij verplaats een hoop bijvoorbeeld riemen en overhemd liggen apart, hij loopt rond met zijn kleding. Daarna ga ik naar me werk. Andere dagen doen we samen activiteiten.

Heeft u en uw partner een vaste ochtend routine? (Bijv. gaat u eerst koffie drinken dan omkleden?)

Eerder genoemd.

Hoe lang doet u er over om u te kleden? 15 minuten tot 20 minuten.

Is dat anders als voor de diagnose? Nee, ik werkte altijd thuis en had minder stress.

Hoe is uw kledingkast gesorteerd? Opgestapeld zomer beneden. Hemden hangen en die zijn gesorteerd op kleur. T-shirts liggen opgestapeld.

Is dat speciaal gedaan?

Het is altijd al zo geweest.

Houd u rekening met het weer?

Partner houd rekening mee wat voor trui etc. Partner kan zelf geen onderscheid maken in tempratuur. En of het regent of niet.

Heeft u moeite met de volgorde van aankleden?

Nee, dat gaat wel. De kleding ligt klaar voor hem en wel op volgorde.

Wie bepaalt wat uw aantrekt?

Mijn partner

### **Applicatie**

In welke activiteit zou u het gebruik van een tool als een ondersteuning zien?

Dat ik weet welke dag het is, mits er vee plaatjes bij zijn. Ik zou het ideaal vinden.

Aan weke eisen moet het voldoen?

Groot, en duidelijk, en veel plaatjes.

Wat vindt u van visuele begeleiding ? Bijvoorbeeld Pictogrammen?

Ja lukt wel. Telefoon aanschaffen met plaatsje i.p.v de huidige digitale telefoon.

Wat vind u van korte informatieve filmpjes in het algemeen? Ik begrijp ze wel.

Denkt u daar baat bij te hebben? Nee, liever een kalender. Filmpje blijft niet hangen. Kalender kan ik nog terug zien.

Wat vindt u van geheugen steuntjes in slaapkamer?

Bent in bezit van een Smartphone, IPad of laptop?

Nee, een makkelijke telefoon.

Bent u handig in het gebruik van de eerder genoemde bij vraag 7?

Waar mag een tool volgens u in verwerkt worden?

Kalender.

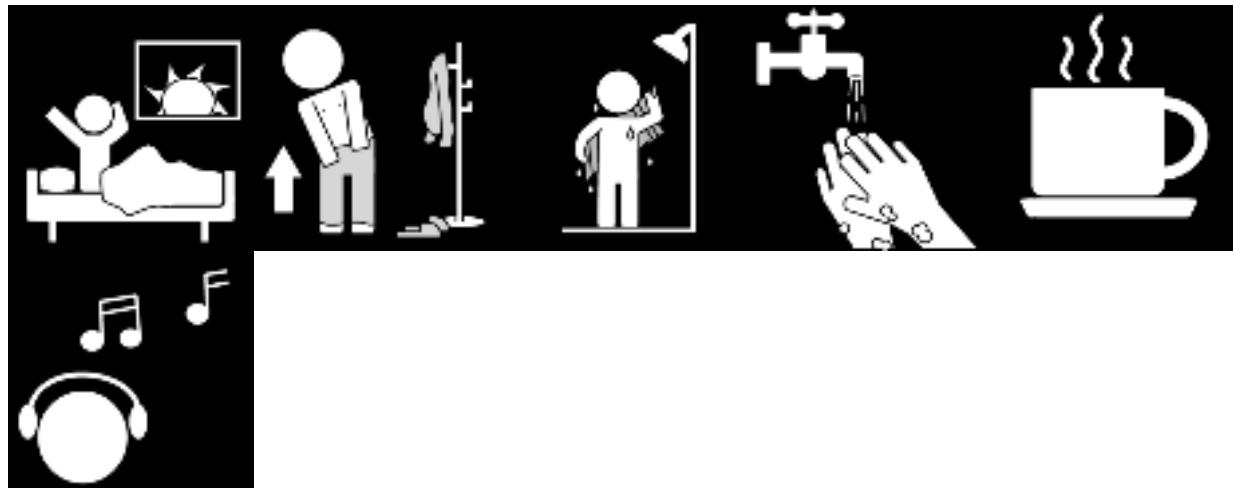
Zou u een ideale tool kunnen tekenen of beschrijven?

Houd het simpel, ik kan niet meer lezen maar wel klok kijken. Herken wel veel plaatjes en foto's, vooral van Nederland.

Denk u dat gebruik van info graphics nuttig is als geheugen steun?

Ja, wij denken van wel.

Herkent u de volgende iconen? Ja.



Persoonlijke vragen

Wat is uw leeftijd?

60

Wanneer is de diagnose bij u vastgesteld? 2009

Hoe bent u erachter komen dat u aan Dementie lijdt?

Via de huisarts, mijn vrouw werkt als huisarts assistent, zij herkende de symptomen.

Welke vorm van dementie heeft u?

Front temporale dementie

In welke stadium van de ziekte bevindt uw zich?

Wil ik niet weten, maar heb het al 6 jaar

Gebruikt u medicijnen om de aandoening te vertragen?

Geen antwoord

Bent u bewust van uw ziekte?

Ja, soms wel.

Hoe actief bent u? Bijv. sport u nog?

Lopen , maar niet zo actief meer als vroeger.

Hoe zelfstandig bent u in het uitvoeren van alledaagse dingen? Bijv. douchen, aankleden, koken en eten?

Koken kan ik niet, doet mijn partner. Douchen gaat wel alleen als mijn vrouw water aan zet. (partner gaf aan af en toe binnen te lopen om te kijken of alles goed gaat. Aankleden gaat wel zij helpt wel mee.

Heeft u nog hobby's?

Muziek luisteren.

Wat vindt u nog interessant en leuk om doen? (Bijv. dagjes uit, vakantie etc.)

Partner gaf antwoord: vakanties of lang weg gaan lukt niet, mijn partner kan niet te lang in een vliegtuig of auto zitten. Daar word hij heel onrustig van

Thuis situatie:

Zijn er activiteiten die u voorheen deed en nu niet meer kunt uitoefenen thuis?

Partner gaf antwoord: Hij kan niet zo veel, kan hem vragen maar dat werkt niet, want hij onthoud het toch niet.

Zijn er speciale aanpassingen in het huis? (Bijv. gebruik van stickers, beelden op de deuren en kasten)

Ja, plaatjes voor op de kasten en douche en wc.

Heeft u een dagboek of houdt u of uw partner een agenda bij?

Nee.

Zijn er geheugensteunen in en om het huis?

Alleen plaatjes die er op de kasten en deuren zijn geplakt en een analoog klok.

Begeleiding ( dit in geval wanneer er buiten de mantelzorg nog externe begeleiding is)

Hoe vaak is er begeleiding per week/ dag?

Partner gaf antwoord: Niet, hij wil niet naar een dag verblijf.

Krijgen de partners nog speciale adviezen m.b.t. hoe ze met de situatie om moeten gaan?

Partner gaf antwoord: ik heb zelf veel aan de huisarts bij wie ik werkzaam ben. Soms ga ik naar Alzheimer bijeenkomsten.

Zijn er knelpunten voor de patiënten met betrekking tot begeleiding?

Partner gaf antwoord: hij wil geen begeleiding. Is ook niet meer mogelijk in de fase van zijn Dementie. Hij is opstandig geworden en dat werkt tegen.

Zijn er knelpunten voor de partners met betrekking tot begeleiding?

Zie vraag 18

Partner

Wat waren de grootste veranderingen in uw leven? Ik moest mij aanpassen aan heel veel dingen. Doe eigenlijk alles voor twee, daarnaast werk ik als part-time huisartsassistent. Combineren is vaak lastig.

(indien van toepassing) Wat voor effect of impact had de ziekte op kinderen? Wij hebben geen kinderen.

Hoe zijn jullie daarmee omgegaan? N.V.T

Hoe zijn de klachten begonnen? Waar heeft u dat aan gemerkt? Vergeetachtigheid, dingen niet meer weten en kunnen

Wat waren de grote veranderingen in jullie gezamenlijke leven? Dat er een hoop dingen niet meer gezamenlijk waren

Welke vormen van therapie of ondersteuning heeft u geraadpleegd? Huisarts en specialisten

Van welk van eerder genoemde heeft u het meeste steun gehad? specialisten

Partners

Welke momenten van de dag verergeren de klachten?

Blijft gelijk

Welke momenten van de dag is de patiënt scherp?

In de avond is hij scherp.

Waar zou u als partner meeste ondersteuning in kunnen gebruiken?

Algemene dagelijkse leven.

Wie helpt uw partner met het aankleden?

Ik doe dat soms, maar leg alles klaar voor hem, anders werkt het niet.

Hoe begint de dag voor jullie? ( bijv. Moet u kleding klaar leggen voor uw partner?)

ik sta op, maak ontbijt, leg kleding klaar, doe alles klaar zetten.

Wat zijn de knelpunten waar uw tegenaan loopt?

Tijdgebrek en moe zijn, nooit dingen zelf kunnen doen en altijd aanpassen

Hoe zou u dat anders willen hebben, of hoe zou u dat willen oplossen? Zou soms wat meer tijd voor mezelf willen hebben

Aankleden ( vragen 2 t/m 9 zijn gericht naar de patiënt, met evt.. aanvulling door de partner.

Kunt u een korte omschrijving geven van hoe u en uw partner de dag beginnen? Opstaan, douchen, aankleden, ontbijten.

Heeft u en uw partner een vaste ochtend routine? (Bijv. gaat u eerst koffie drinken dan omkleden?)  
Opstaan, douchen, aankleden, ontbijten.

Hoe lang doet u er over om u te kleden?

Als alles mee werkt, 10 minuten.

Is dat anders als voor de diagnose?

Partner gaf antwoord: Ja, was korter.

Hoe is uw kledingkast gesorteerd?

Partner gaf antwoord: broeken bij elkaar, T-shirt en truien bij elkaar, aparte la voor ondergoed.

Is dat speciaal gedaan?

Partner gaf antwoord: Nee was voorheen ook zo.

Houd u rekening met het weer?

Partner gaf antwoord: Ja, extra dikke kleding in winter etc

Heeft u moeite met de volgorde van aankleden?

Partner gaf antwoord: ik leg alles klaar en die volgorde moet hij aanhouden.

Wie bepaalt wat uw aantrekt?

Partner gaf antwoord: Ik

## **Applicatie**

In welke activiteit zou u het gebruik van een tool als een ondersteuning zien? In tijdstippen en of taken.

Aan weke eisen moet het voldoen?

zou ik zo niet kunnen zeggen

Wat vindt u van visuele begeleiding ? Bijvoorbeeld Pictogrammen? Zouden kunnen helpen

Wat vindt u van korte informatieve filmpjes in het algemeen?

Nuttig

Denkt u daar baat bij te hebben?

Durf ik niet te zeggen

Wat vindt u van geheugen steuntjes in slaapkamer?

Niet nodig

Bent in bezit van een Smartphone?

Ja

Bent u handig in het gebruik van de eerder genoemde bij vraag 7?

Redelijk

Waar mag een tool volgens u in verwerkt worden?

Het moet simpel zijn. Niet technisch want dat werkt niet.

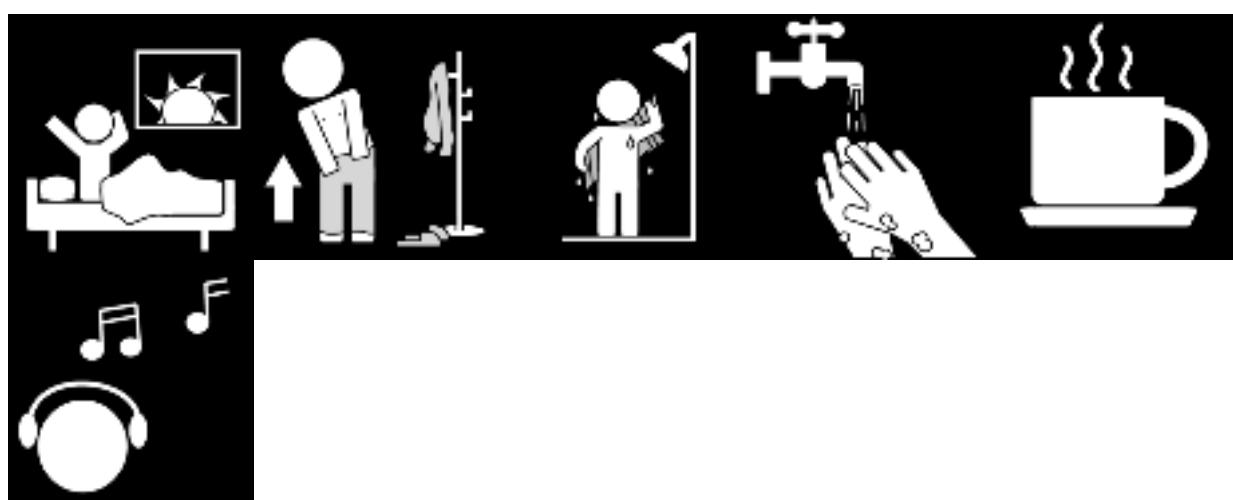
Zou u een ideale apparaat kunnen tekenen of beschrijven?

nee

Denk u dat gebruik van info graphics nuttig is als geheugen steun?

Ja, is wel handig ter ondersteuning. Gebruiken we nu ook voor de kasten en op de deuren

Herkent u de volgende iconen? Ja.



## Appendix 4: Talking mats

# Talking Mats® help involve people with dementia and their carers in decision-making

Findings  
Informing change

April 2010

Recent government guidance recommends that people with dementia should be encouraged to express their views and be included in decisions about their care. This project explores how people with dementia and their family carers can use Talking Mats, a low-tech communication tool, to feel more involved in everyday care decisions.

### Key points

- Talking Mats can help both people with dementia and their family carers feel more involved in discussions about managing their daily lives.
- People with dementia reported that Talking Mats helped them to clarify their thoughts, express them to their family carers, and reach a decision in these discussions.
- Family carers reported that Talking Mats made them feel 'listened to' by the person with dementia. They also felt that their relative could actually 'see' their point of view when using Talking Mats.
- Talking Mats can contribute to the process of negotiation in day-to-day decision-making. They also offer a method for recording joint views to inform later decisions made with members of the wider support community.
- These findings contribute in a practical way to the current debate on how to meaningfully involve people with dementia and family carers in decisions about care. They are also relevant to the assessment of needs.
- The findings have implications for the organisation, delivery, regulation and improvement of services for people with dementia, as their views and those of their family carers can be recorded to clarify and enhance planning. This is essential if personalised services, and user and carer directed outcomes, are to be achieved.

### The research

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[www.jrf.org.uk](http://www.jrf.org.uk)

## Appendix 5: Most used icons

