

Exploring new means of interaction between dementia patients and their caregivers

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Abstract: This research aims to identify key issues related to the interpersonal relationship between nurses, family members, and patients. One of the greatest nursing challenges is staying vigilant towards someone becoming less attentive with time. This creates an imbalance in the relationship. More is given than can be returned. The present is not the here, and now; it plays in the past or a fictional dream perception. However, this should not result in family members disconnecting from the loved one, even with advanced dementia. Babies and toddlers themselves cannot speak yet can understand a lot – which doesn't prevent us from communicating with them all the time. Instead, caring relatives are slowly distancing themselves from the diagnosed individual. Leaving a family member because of the diagnosis is not the right way to support their loved ones. Particularly focusing on communicational obstacles between the patient and the nurse or family caregiver. The feeling of belonging and emotional exchange is immensely important for their last chapter of life.

Keywords: Care givers, Cognitive Impairment, Dementia consequences, Memory Loss, Prevention, Support

1. Introduction

According to the world dementia research centre, every 3 seconds, someone in the world develops dementia. There were an estimated 50 million people worldwide living with dementia in 2018, and this number is believed to rise immensely over the next decades. This number will almost double every 20 years, reaching 75 million in 2030 and 131.5 million in 2050. (Alzheimer's association, 2020) These alarming numbers threaten people's future, who use their brains as means for communication, processing power, and memory storage that they can access at any stage in everyday life. When a person does not remember anymore: how to walk, talk, interact, speak, and act where there is a difference between a plant and a human being? This is often the case with objectifying demented family members. (see Appendix 2) Caregivers of people with Dementia rarely know what they are facing. Caring for a person with this specific diagnosis is overwhelming. The stresses can range from physical to emotional and economic pressure. (Alzheimer's Association, 2020) The care must be available around the hour, and they have to therefore sacrifice themselves

for the beloved person. This often leads to burnouts and accumulation of stress and frustration. People affected can live their lives many more years, but eventually need help with everyday tasks. (See Appendix 6) They cannot work or drive, go to the supermarket, bathe, or defecate without help. Long-term care is inevitable but not very cost effective, because in most cases, beloved ones have to quit their job and dedicate their lives to the diagnosed person. Moreover, labour intensive for specialized nurses means it is expensive to care for the family member. (Alzheimer's Association, 2020)

1.1 Impact of Alzheimer's caregiving

Alzheimer's takes a devastating toll on caregivers. Reported by the Alzheimer's Association: "Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties". Of the total lifetime cost of caring for someone with dementia, 70% is covered by families — either through out-of-pocket health and long-term care expenses or from unpaid care. (Alzheimer Association, 2020; "Facts and Figures", 2019)

"Caregivers often indicate love and a sense of duty and obligation when describing what motivates them to assume care responsibilities for a relative or friend living with dementia. (Greenwood, Smith, 2019) Individuals with dementia living in the community are more likely to rely on multiple unpaid caregivers (often family members) than older adults without dementia; 30% of older adults with dementia rely on three or more unpaid caregivers, whereas 23% of older adults without dementia rely on three or more unpaid caregivers. (Kasper et al., 2015)" - reveals the Alzheimer's Association.

2. Research background

2.1 Problem statement

The healthcare system faces a sharp increase in the number of Alzheimer's patients who will need 24/7 support over the next several decades. Family members are overwhelmed and cannot cope with the sick family member's stress and workload. Nor can they convey warmth and affection if not reciprocated. There is not enough time for the nursing staff for emotional exchanges, and the patients are left alone with their own lost souls.

2.2 Research Questions

1. How can active emotional care be achieved without a nurse or family member's constant presence?
2. How can family members still actively communicate with the loved one despite their inability to articulate themselves?

2.3 Research Goal

The research tries to understand the relation between Caregiver and Patient. In particular, the research explores the methods used to amuse and help patients from advancing in their

stages gradually. Strategies of conveying warmth and affection for Patients, when feeling left alone at any time by finding the right support. Develop closeness and love through communication and interaction that can be artificially created through technological intervention. Help the patients feel included within their social circles as much as possible; give them a voice in this ever-louder world.

2.4 Research population

The research population group consists of Caregivers and dementia patients.

Who are the caregivers?

All over Europe, women are home carers who quietly do this job within their own four walls.

- About one in three caregivers (33.33%) is age 65 or older
- Approximately two-thirds of caregivers are women; more specifically, over one-third of dementia caregivers are daughters. (Alzheimer's Association, 2020)
- Most caregivers (66%) live with a person with dementia in the community. (Alzheimer's Association, 2020)
- Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers — meaning they care not only for an aging parent but also for children under age 18. (Alzheimer's Association, 2020)

3. Methodology

Before carrying out specific research, a research plan has been designed, including the relevant methodology. Thorough planning of the intended research activities is beneficial to preventing unwanted surprises along the way and handling expectations. This section describes the different research methods used throughout the project and their corresponding research goals, including primary and secondary research population.

3.1 Secondary research online

Reading relevant literature and articles, both on-and off-line, was used to establish a base of knowledge to build upon throughout the project. Topics of interest included Dementia stages, family relations with patients, nursing home environment, Caregivers tasks, Routines throughout the day, and psychological factors of having dementia. Secondary research especially played a role at the beginning of the research phase but has been carried through the project as a tool to back up and complete primary research and gather additional information on questions arising.

3.2 Qualitative Interviews

The interviews tried to establish a positive relationship and basic trust between the participant and the designer to be comfortable working together. It provided a first

impression of the participants' situation and environment (family member, home, relatives) and gathered relevant personal information about the target group. To accomplish an open research approach (semi-structured interview guide) was used to ensure the relevant information was obtained, while also giving the participant enough freedom to lead the conversation in the direction of their own preference.

3.3 Expert consultation

The Expert interviews include visits to specialized dementia homes and a neurology institute. The consultations' main goal is to receive advice from experts in the field. However, there are several variations associated with Alzheimer's disease, which unfortunately cannot be learned about in the time frame.

3.4 Patient Observation

Through observing the patients suffering from a certain form of dementia, behavioural patterns, and routines could be recorded and analysed for further usage. Trying to understand behavioural patterns in an undisturbed environment.

3.5 Obstacles and Bottlenecks

This section describes several situations that slowed down or hindered the research for this project.

Restrictions in personal contact with target group (COVID-19)

Immediate challenges, such as patient safety and direct observation, are at stake. In a global health emergency, these restrictions of contact got even stricter. Therefore, the engagement with various research stakeholders is essential, all while facing the challenge to tackle the spread of COVID-19 and evidence-based healthcare information. The COVID-19 situation is particularly stressful because it is hard to predict how the numbers will develop, and our circumstances are changing rapidly. Although these obstacles might indicate the feeling of being tied and restricted from actively engaging with the research population, there are still many other ways to communicate despite the distance. Switching to online meetings and avoiding the pressure to meet in person made the process faster and more convenient to get information more accessible.

Scheduling of face to face meetings

Due to the lockdown measures, there may be higher restrictions in connecting with the patients directly. Furthermore, entering nursing homes for research purposes and not official family visits, which makes it difficult to interact with potential users at a close distance without being a threat to their health status. By following the official health

guidelines and especially washing my hands regularly, I contributed to the safety of the surroundings and arranged a few more personal interactions.

Entering spaces with high infection risk

A disease that spread efficiently through close contact with people is dangerous for the already with other disease affected patients. The risk of infection within enclosed spaces because of a droplet transmission within a short-range is even higher. Therefore, the few interactions arranged were ongoing outside. As a matter of better protection, this was the instance to be taken to protect the inhabitants of potentially infectious aerosols exchanged to an endangered group.

4. Literature Review

4.1 About Alzheimer's disease:

Translating the word "dementia" from Latin into English, we see how discriminatory and hurtful this word is in its roots. Meaning "without spirit", "spiritless" or "declining understanding". It suggests that people with dementia lead a life without intellectual capacity and triggers panic by being confronted with it in a certain life phase. (see Appendix 5) To understand such a complex disease and connect, the following segment will be analysing the effects, symptoms, and causes of the emergence of this disease. Within the researched literature, there were many different types of dementias. To narrow down the field of focus and better understand the course of the disease, I will mainly focus on Alzheimer's dementia because Alzheimer's disease is "the most common cause of dementia, accounting for 60% to 80% of cases" (Alzheimer's Association, 2020) for older adults. It is a progressive brain disorder that slowly destroys memory and cognitive abilities. It is important to state that Alzheimer's dementia is "not a normal part of aging" explains the Alzheimer's Association (2020). For every individual, the stages and symptoms may differ; therefore, this investigation is based on the most common recurring ones.

The underlying cause for all types of dementia is damage to the brain cells; this damage interferes with the ability to communicate with each other. When brain cells cannot communicate normally, a person's thinking, behaviour, and feelings can be affected. Alzheimer's patients may start rummaging and hiding things. (See Appendix 4) This behaviour can be annoying or even dangerous for the caregiver or family members. Following early symptoms may occur in the first stages: "Difficulty remembering recent conversations, names or events; apathy and depression..." (Alzheimer's Association, 2020). "Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavioural changes and, ultimately, difficulty speaking, swallowing and walking." (Alzheimer's Association, 2020) Dementia can be divided into its primary and secondary forms. The causes of the secondary form include injuries such as traumatic brain injury following an accident or infection. (Alzheimer's Association, 2020) They are partially curable.

The causes of primary dementia are changes in the brain. The best-known form is Alzheimer's disease; there is also vascular dementia, Lewy body dementia, and frontotemporal dementia. (Alzheimer's Association, 2020) The disease is usually divided into three major stages, mild, moderate, and severe dementia. (Alzheimer's Association, 2020)

4.2 Overview of disease progression

The symptoms of Alzheimer's disease worsen over time, although the rate at which the disease progresses varies. On average, a person with Alzheimer's lives four to eight years after the diagnosis, but can live as long as 20 years, depending on other factors. (Alzheimer's Association, 2020; Gaugler et al., 2020)

The stages below provide an overall idea of how abilities change once symptoms appear and are used as a general guide for orientation. They are separated into three categories: mild Alzheimer's disease, moderate Alzheimer's disease, and severe Alzheimer's disease. It is nevertheless very difficult to place a person with Alzheimer's in just one stage as the stages may often overlap. Since Alzheimer's affects people in different ways, each person will experience symptoms – or progress through Alzheimer's stages – differently.

Mild Alzheimer's Disease (early stage)

In the early stages of Alzheimer's, a person may still function independently. He or she may still drive, work, and be part of social activities. Despite this, the person may feel as if they have memory lapses, such as forgetting familiar words or everyday objects' locations. (Alzheimer's Association, 2020; Gaugler et al., 2020)

Friends, family, or neighbours notice difficulties. Doctors may detect problems in memory or concentration during a detailed medical interview. Common difficulties include (Alzheimer's Association, 2020):

- Problems coming up with the right word or name
- Trouble remembering names when introduced to new people
- Having greater difficulty performing tasks in social or work settings
- Forgetting material that one has just read
- Losing or misplacing a valuable object
- Increasing trouble with planning or organizing

Moderate Alzheimer's Disease (mid-stage)

Moderate Alzheimer's typically is the longest stage and can last for many years. As the disease progresses, the person with Alzheimer's will require a greater care level. The person affected may confuse words, become frustrated or angry, or act in unexpected ways, such as refusing to bathe. They tend to repeat their messages and actions. Relatives often reach the limit of their patience, and understanding declines. (Alzheimer's Association, 2020) They

want acceptance and have the feeling they are not getting enough of it. Both sides perceive this phase as extremely stressful. (Fenninger et al., 2014) Dementia sufferers change their sleeping habits and start turning day into night and night into day. (See Appendix 3) This means caring relatives, who must do so, can no longer sleep. Besides, it can happen that the diseased person, due to their disorientation, cannot find the toilet or use it and hold objects such as a chair or the garbage can for the toilet. (Litzka et al., 2007) Those affected sometimes forget where they are and ultimately want to go home, even though they are at home. (Fenninger et al., 2014) With short-term memory deteriorating, they want to do what they have just done, again. Major damage to nerve cells in the brain can make it difficult to express thoughts and perform routine tasks. (Alzheimer's Association, 2020)

Symptoms will be noticeable to others and may include (Alzheimer's Association, 2020):

- Forgetfulness of events or about one's own personal history
- Being unable to recall their own address or telephone number or high school or college from which they graduated
- Confused about where they are or what day it is
- Feeling moody or withdrawn, especially in socially or mentally challenging situations
- The need for help choosing proper clothing for the season or the occasion
- Trouble controlling bladder and bowels in some individuals
- Changes in sleep patterns, such as sleeping during the day and becoming restless at night
- An increased risk of wandering and becoming lost
- Personality and behavioural changes, including suspiciousness and delusion

Severe Alzheimer's Disease (late stage)

In the final stage of the disease, individuals lose the ability to respond to their environment, carry on a conversation, and eventually control movement. They may still say words or phrases, but communicating pain becomes difficult. (Alzheimer's Association, 2020) At this point, the ongoing process of brain damage continues to get worse. They need lots of help with daily activities such as getting dressed. Other common symptoms include wandering and getting lost. Patients may lose awareness of their surroundings and recent experiences. While they may distinguish between familiar and unfamiliar faces, they have forgotten their life history and have difficulties remembering their own name. (Alzheimer's Association, 2020)

As memory and cognitive skills continue to worsen, personality changes may occur, and individuals need extensive help with daily activities. (Alzheimer's Association, 2020)

At this stage, individuals may (Alzheimer's Association, 2020):

- Require full-time, around the clock assistance with daily personal care
- Lose awareness of recent experiences and their surroundings

- Require high levels of assistance with daily activities and personal care
- Experience changes in physical abilities, including the ability to walk, sit and, eventually, swallow
- Have increasing difficulty communicating
- Become vulnerable to infections, especially pneumonia

Developing Alzheimer's disease can be frightening both for patients as they grasp their cognitive abilities slipping away, especially for the loved ones helplessly watching them change. It is natural to deny what is happening with the beloved person if possible. (see Appendix 2) It is not called without reason "the long goodbye" because the duration of the disease may vary between 8-12 years from the very first symptom till death, as shown in figure 1. (Teepa Snow "Positive approach to care")

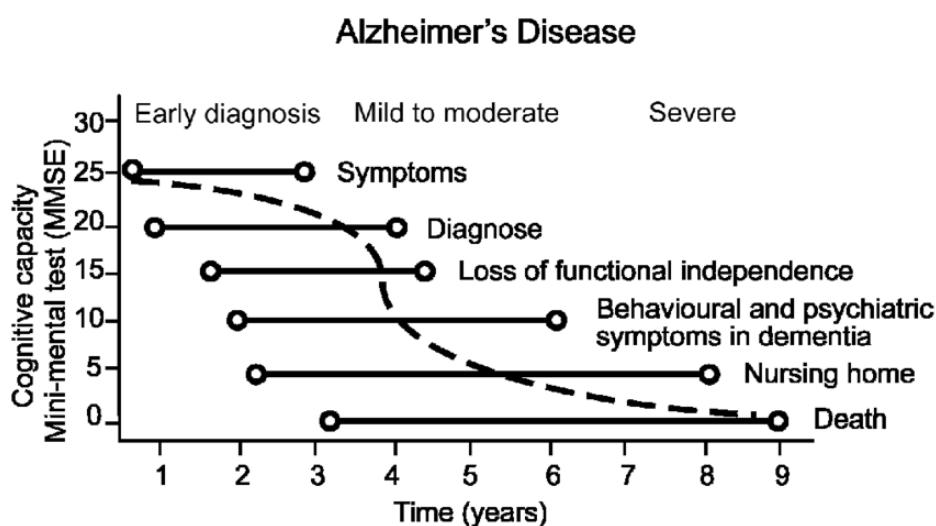


Figure.1 Clinical stages in Alzheimer's Disease. Cognitive capacity measured with MMSE. (Nordberg, Eriksson-Jonhagen, Garling, Gut, Freund-Levi et al., 2006).

There is no medical antidote and, therefore, no cure, but it can be influenced by using drugs. Memory training, activation, and exercise slow down the ongoing process. Exercise, a healthy Mediterranean diet, and sport are advisable. (Fenninger et al., 2014)

„When it comes to dementia, it is noticeable that people think that someone is not one of them.“ – David Sieveking

4.3 Brain changes associated with Alzheimer's

The following segment is a direct excerpt from the Literature used to understand the chemical/ biological process in the brain during the development of Alzheimer's dementia. With a focus on what is being perceived of Alzheimer's dementia initially before first symptoms even start to emerge.

“A healthy adult brain has about 100 billion neurons, each with long, branching extensions. These extensions enable individual neurons to form connections with

other neurons. At such connections, called synapses, information flows in tiny bursts of chemicals that are released by one neuron and detected by another neuron. The brain contains about 100 trillion synapses. They allow signals to travel rapidly through the brain's neural circuits, creating the cellular basis of memories, thoughts, sensations, emotions, movements and skills.” (Alzheimer’s Association, 2020)

“The hallmark pathologies of Alzheimer's disease are the accumulation of the protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons. Plaques and smaller accumulations of beta-amyloid called oligomers may contribute to the damage and death of neurons (neurodegeneration) by interfering with neuron-to-neuron communication at synapses. Tau tangles block the transport of nutrients and other essential molecules inside neurons. Although the complete sequence of events is unclear, beta-amyloid may begin accumulating before abnormal tau, and increasing beta-amyloid accumulation is associated with subsequent increases in tau. These changes are accompanied by the death of neurons and damage to brain tissue. Alzheimer's is a slowly progressive brain disease that begins many years before symptoms emerge.” (Sato et al, 2018; Hanseeuw et al, 2019)

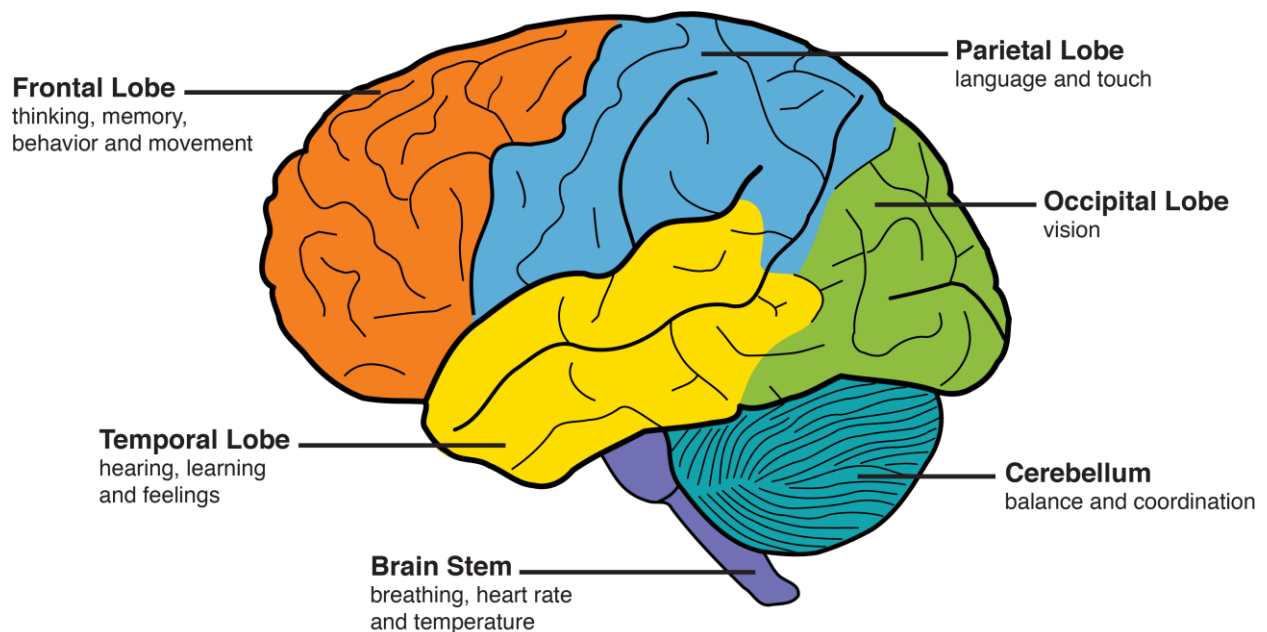


Figure.2 Parts of the brain that can be impacted by Alzheimer’s disease. (UCSF Weill Institute for Neurosciences. (n.d.). *What Happens in Dementia?* Retrieved December 21, 2020, from <https://memory.ucsf.edu/what-dementia>)

4.4 Everything that is gone and kept

Starting to be gone: Vocabulary, Comprehension of speech, Ability to Articulate and say words (Speech production)

Strength kept: Automatic Social chit chat, Rhythm of speech, music, poetry, and prayer, Automatic rhythmic movement

Using rhythm and poses in the speech combined with an immense amount of visual cuing to have a chance to get through to the person. In the Amygdala, the part that allows recognizing of threats: fright (the scary part), Flight (get away from it - the dangerous part) and fight (the drive towards something) is preserved longest because it is developed first and it is the last thing to go. Frontal Prefrontal doesn't reach full maturity until the mid-20s. Decision making is the front part of the brain. Perspective and Empathy are in the frontal part, the last to develop. (Snow,2020) The rest of the brain is a sensory processing system. There are five ways to get information to the brain with our five senses.

Vision: centerfield and edge vision centerfield is well preserved. But less and less able to focus on the edge vision field. The visual field is closing into binoculars. Losing depth, can't judge the distance to an object. Wanting to touch textiles, textures, and being curious, therefore, safety becomes an issue. (Snow, 2020) A full sized brain shrinks in size to just 1/3 of its original. (See Appendix 8) The person is changing chemically and structurally, but emotional memory is kept till the end. The Limbic System is the first part of the brain to develop. "Thrive to Survive" (Snow, 2020)

5 basic physical needs (Snow, 2020)

- 1- Hunger & Thirst
- 2- Wake/ Sleep Cycles & Rest
- 3- Elimination (eliminate waste product, poop, and pee)
- 4- Comfort & Personal Preferences (Temperature, Textures, Movement of Air, Distance, Space to feel Comfortable, Sound type/intensity/familiarity/intensity of light)
- 5- Pain Relief (emotional, spiritual, physical)

Each person is using their remaining skills and abilities. Rhythm anticipatory – learning to use what I've got. Music makes a difference for people living with dementia. This is important in the later stages of dementia. Through music, it is possible to guide and interact. (Snow, 2020)

Music surrounds us; the message counts we want to convey. We are part of the music. There is music everywhere. There is music and nature and within us. Use what you got, doing the best they can do. (Snow, 2020)

4.5 The power of music

Music allows reconnecting to family members; it showed significant agitation reduction. The right playlist can penetrate the behaviour. Even if much of the brain is gone, music can wake it up. Sophisticated language of emotion. A powerful way to restore memory and language through known rhythms. (Snow, 2020)

Oxytocin is called the cuddle chemical it is realised when we cuddle. A German study published in 2014 showed that singing together nearly doubled the oxytocin released as just interacting with family and friends. A powerful physiological effect of music on social

bonding. Music and Movement are connected in the brain. (Snow, 2020) Music is much more potent than words in evoking memories. Emotion and memory are intertwined; it activates both memories and emotions simultaneously. (See Appendix 2) Music is the soundtrack to our lives. (Snow, 2020)

4.6 A devastating disease for families and their loved ones

The disease steals the person from the family. Their personality changes; they become a different person. They grieve the family must go through and seeing their loved one disappear before their eyes.

“Loss of memory defines the disease; it defines who we are as people. Without our memory, we have no past, we can’t plan for the future and we can’t appreciate the present. We fear losing who we are as people.” – Gary Small, MD Director, UCLA Longevity Centre

How can someone be so close and still so important and share so much, but look at this person and get a vacant stare... Out of 5 families dealing with the disease right now, 4 will fall apart—only one will pull together. (Snow, 2020)

4.7 Dementia Caregiving tasks

Following tasks are performed by the main caregiver during the daily routine include:

- Helping with daily activities, such as general household tasks, preparation of meals, arranging doctor’s appointments, transportation in public and private, managing finances, answering calls (Alzheimer’s Association, 2020)
- Helping with the right medication, with reminders or directly administering pills
- Assisting with personal daily activities, such as dressing, grooming, feeding, bathing, transferring from bed to chair and vice versa, usage of toilet, and managing incontinence (Alzheimer’s Association, 2020; Fenninger et al., 2014; Litzka et al., 2007)
- Managing behavioural symptoms, such as aggressive behaviour, night wandering, depressive mood, anxiety, repetitive activity, and night-time disturbances (Alzheimer’s Association, 2020; Fenninger et al., 2014; Litzka et al., 2007)
- Finding and using support services, such as groups and daycare programs (See Appendix 2)
- Managing other health conditions, such as arthritis, diabetes or cancer (Alzheimer’s Association, 2020; Fenninger et al., 2014; Litzka et al., 2007)
- Providing emotional support and a sense of security (Alzheimer’s Association, 2020; Fenninger et al., 2014; Litzka et al., 2007; See Appendix 2)

The caregiver faces many challenging tasks to perform during 24h. Unfortunately, most caregivers are not ready for the difficulties that may arise during caring for a loved one. The expectations do not match the reality, and the body gets more exhausted than what is good for his/her health. Throughout the disease’s progression, many caring family members get

sick themselves, meaning they must consider help from outside and eventually be on the lookout for elderly homes specialized in dementia disease for ideal support of the loved one. Asking for help may be very difficult

4.8 Knowing one persons' core values and needs

The person-centred approach to dementia care is essential to take care of the affected person with dementia and recognizing that it is a part of their life. "person-centered Care is the process by which we maintain the Personhood of those who have dementia" stated by Kitwood, *Dementia Reconsidered* (1997) "Giving the person reassurance, hugs, support, a meaning in life." - Christine Bryden All these effects how a person with dementia behaves, feels and thinks... by understanding their values and optimizing special needs we can help people live well with dementia The person-centered approach based on the enriched model of holistic care includes: Cognitive strengths & needs, Life story, Personality, Physical Fitness, Positive compassionate communication.

Psychological needs in Dementia:

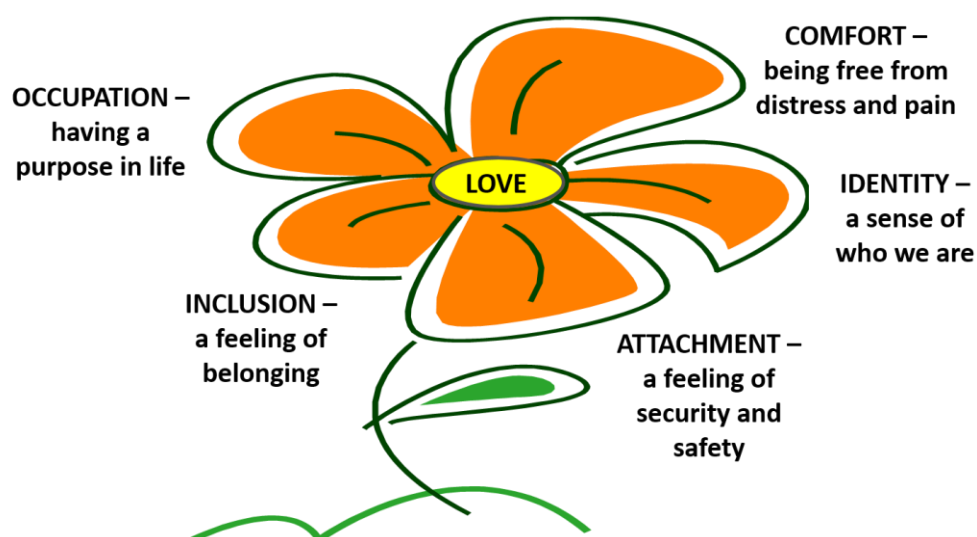


Figure.3 The main psychological needs of people living with dementia. Kitwoods's flower model. (Kitwood, T. M. (2012). *Dementia reconsidered: The person comes first*. Maidenhead: Open University Press)

People with dementia have a particular disability around communication but a major need to feel close to others, especially when verbal skills worsen. As the affected person becomes more emotional and less cognitive over time, the communication shifts to another level. A smile, a simple laugh, and touch are the new words that connect with the person who has Alzheimer's. Empathy heals. The person is still there, but not as they were. There is still a chance to find what has remained the same in emotion and spirit. (Bryden, 2011)

4.9 Empathy

Empathy is the ability to put feelings into other people's positions and actions. She (Empathy) is often introduced with and represents a way to an immediate understanding of other souls' processes. (Litzka et al., 2007) The clearest way is empathy in the relationship between mother and child. (Litzka et al., 2007)

Aged dementia people whose verbal ability to express themselves is reduced and whose planning horizon is shrinking massively can quickly find themselves overwhelmed by daily life demands. The frustration tolerance drops significantly. Moreover, those affected are repeatedly haunted by the neglected (unfulfilled) life tasks, which take their toll on the last stage as violently unannounced.

The struggles that an elderly person faces, especially in the early stages of the disease, aim to maintain personal dignity. (see Appendix 5) In this struggle, compared to the crisis of puberty, old people use all available resources to express themselves. (See Appendix 5) Due to the severe loss of intellectual performance (cognitive abilities), sophisticated options for action and conflict resolution are no longer available to people with dementia. In order to counter the threat posed by dementia in any way, the person affected falls back on fundamental behavioural patterns (so-called basic roles): on roles and behaviours partially learned in early childhood. (See Appendix 5& 6) In the Interview with one family member (see Appendix 2.), we see how we can use empathy to reach even very confused people without treating them as toddlers. In this way, we preserve these people's dignity and become their companions in a threatening time.

5. Results

This section forms the main part of the research paper, summarizing and analyzing the information obtained through secondary and primary research. The information is grouped into topics considered essential to understanding the overall topic and answering the research questions. The aim was to understand the main barriers in communication between different caregivers and the patient and exploring new ways of enhanced care.

Organizing care around the person with Alzheimer's dementia (in advance)

The disoriented person wants to be seen as a subject, as a valuable and unique person, and not to be made an object of welfare and services. It is often a sad reality they are left alone and branded as if they cannot do anything. It can be very offensive and hurtful, not being taken seriously or excluded. The system needs to accept the more vulnerable people and appreciate their existence, rather than ignoring their needs and waiting till it is too late. To plan ahead and relieve the strain on the system Mr. Weinberg is working effortlessly to create a system around the local community where major stakeholders work together to prevent the ever-growing numbers in hospital admissions. With Planetree, he is transitioning to patient centred care possible and stated his vision as: "Health care is social care. Home care is public care. Prevention is key. The geriatric specialist forms a bridge between medical

specialists, district nurses, paramedics, the nursing home, the pharmacy, the community social team and the client's family and caregivers. The great thing is that all of the disciplines around the senior client work together.” (see Appendix 6)

How can active emotional care be achieved without a nurse or family member's constant presence?

Dr Widdershoven states it as follow: “What happens in their brain is: they lose the connection between what they see and what they know (...) they need the outside world to make this connection, while the bridge between what they see and what they know is becoming larger (...) they don’t understand the input they get with what they know.” For example, patients with Alzheimer’s dementia know that their mother was a sweet person. What they see is not like their mother. If I twist it a bit, it can be my mother (See Appendix 5) “They try hard to form new connections. If you’re able to make this bridge for them, then you don’t need a person” (See Appendix 5). For example, a good structure is a bridge. A routine, to know when it’s time breakfast, when is the activity the structure of life is what they can hold on to. While it disappears gradually, they cannot feel it. But we observe it from the outside. For them it’s important to live in the know. (see Appendix 5)

Alzheimer’s patients may as well show anxiety or agitation through fidgety hands. Signs including rubbing at clothes, playing with zippers, twisting buttons, and generally keeping hands in motion. (See Appendix 2) Sensory therapy or fidget toys have proven to be an effective way to reduce anxiety, calm nerves, and provide comfort. The goal is to engage the person with Alzheimer’s in a fun activity and keep their hands happily occupied. (Heltemes, 2018; “Activities for dementia”, 2018) Further keeping them active and engaged in an activity may decry loneliness and anxiety. (Lange et al., 2017)

5.2 Basic Human Needs adapted to Alzheimer’s disease

One area very closely related to our emotions are human needs. Not surprisingly, these are as diverse as it is in our emotional world. (Rosenberg 2001) Most of the time, our needs work, as the American psychologist Marshall B. Rosenberg put it: "If needs are not met, then we automatically think about what other people have done wrong."

People of earlier generations, especially women, have mostly not learned to express their own needs or even take care of their satisfaction. It is no wonder that we hear massive accusations from many older adults about what they have lacked in their marriage and adulthood. (Litzka et al., 2007)

The following tabular overview shows how many needs we have as humans. It is based on Maslow’s hierarchy of needs (see Appendix 10), who analysed human needs more closely in his research, often depicted as the five-tier pyramid of human needs.

Basic Need	Description	ADP Symptoms	Intervention	Source
1. Need for self-preservation or physical existence	Good Health, physical exercise, pure water, fresh food, light, air, sleep, sexuality	lack of energy, memory difficulties, cognitive decline, change in behaviour and cognitive abilities, struggles with intimacy (no affection)	Receive proper diagnosis as early as possible; it is important to know of it because it allows the affected person to plan the future.	Dr. Weinberg; Chemali et al., 2012
2. Need for safety	Protection, security in everyday life, political peace, protection of the family, money, job	forgetting appointments, becoming lost driving to work, difficulties managing finances, loss of attention, insight, judgment, fear of what may happen, strong feelings of loss, fear, and abandonment Effects: Patient may start isolating themselves and feel left alone in the community	Family system model (family dynamic and how those interactions can influence the relationship), Cognitive Behavioural Therapy, social theory approach	Werheid et al., 2009; Robertson et al., 2013; Cox and Pardasani 2013
3. Need for empathy, love, and belonging	Understanding, "being seen and heard", recognition, appreciation, respect, being accepted	feelings such as self-worthlessness, being useless, isolation Effects: becoming an outcast	Involvement in daily activities, art therapy, group work, community programs	Interview with Family member (2) Ortega et al., 2011 Robertson et al., 2013

4. Need for esteem, social contact, and belonging, secureness	Social environment, friendships, neighbourhood, home, love as a “feeling”, part of the team / company / family, closeness, community, togetherness with people with similar interests, consideration, security, respect, support, trust, appreciation, closeness,	Self-esteem issues such as dependency on others, social isolation, difficulty maintaining identity and self-hood, stigma Effects: friends stop visiting and socializing	Music therapy, dance therapy, Alzheimer’s café, community gatherings (enhancing social interaction), lifestyle care	Dr. Widdershoven Dr. Weinberg Robertson et al., 2013 Harris and Keady, 2009
5. Need for rest and play	Relaxation, rest, free time, the possibility of "refuelling" physically and mentally, purposeless activity, games, vacation, being alone, joy, laughing	difficult to understand what the individual feels, needs, and wants due to being unable to express themselves, losing the ability to complete tasks Effects: depression and isolation	Grief facilitation, providing meaningful activities, being in a personalized environment, interaction with beloved ones	Harris and Keady (2009) Interview with a family member (2)

6. Need for integrity	self-expression, personal responsibility, choosing goals, dreams, values, plans to fulfil goals and dreams, freedom of choice, individuality, freedom for creative work, creativity, authenticity, self-worth	Ability to speak declines, nonfulfillment of oneself; a lack of meaning for life	Constructing a life's book (about one's life history, where individuals can reflect on their life), physical therapy, occupational therapy, ability to contribute to the community	Dr. Widdershoven Robertson et al.,2013
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Table 1. Basic human needs adapted to Alzheimer's dementia patients

5.3 Importance of activities

Slowing down the decline

Following the “use it or lose it” phenomenon. (See Appendix 5) Caregivers should be cautious about not doing too much for the affected person, but instead, adapt tasks and allow them to continue doing things and maintaining abilities for as long as possible. (Heltemes, 2017)

Daily Structure

People with dementia do best with a strict daily routine, given predictability when the mind is scattered. By using activities to shape the daily routine can provide important structure. (See Appendix 6)

Feeling Productive & successful

As people with dementia progress in the stages, they do less and feel like a burden to those surrounding them. Helping the elderly person participate in daily tasks and play activities can help their mood and quality of life. (Heltemes, 2017)

Reduction of Dementia caused behaviour

Alzheimer dementia-related behaviours, such as agitation and repeated questions, can be minimized through activities. Discouraging boredom and providing a way to use their energy positively. (Heltemes, 2017)

5.4 Stimulating activities in dementia care

Despite the many Alzheimer patient phase challenges, they still need to participate in activities and do something. Considering the appropriate techniques and support from caregivers for more success. The interest and the background of the person, if an activity is more likely to be done alone or in group setting matters. Moreover, there can coexist different activities to be a success for the individual. ("Activities for dementia,"2018) The table indicates which activities and products might be appropriate at specific stages. Considered as a medium through which the patient may start actively communicating with the caregiver or family member. (See Table 3)

High Activity Level Mild Stage of Alzheimer's dementia	Middle Activity Level Moderate Stage of Alzheimer's dementia	Low Activity level Severe Stage of Alzheimer's dementia
Can keep doing the activities of their typical daily routine, with occasional help	Needs help with the basic steps and details.	Needs physical help with all steps
Understands the goal of the task; uses what is seen as cues for what to do	Doesn't understand the goal but has some awareness of task steps	Doesn't understand the purpose or the task steps
Behavioural changes: Forgetfulness (lack of short term memory), difficulty forming connections, may feel restless	Behavioural changes: Mobility becomes limited, ability to concentrate declines, keeping hands busy	Behavioural changes: Vulnerability to pneumonia; minimal or no speech; severe memory loss; Impaired walk; Passive; Lack of focus
Activities could be: Adapted to the lifestyle of the patient	Activities should be: guided, explained step by step, simple (easy to comprehend)	The activity should be stimulating, but without challenges, repetitive, focus on senses
Awareness: Slower pace of understanding, having patience is key	Awareness: It's about the engagement, not particularly the outcome of the activity	Awareness: May place inappropriate items in their mouths; supervision is necessary
Activities: Cooking or Baking; Read the newspaper; Work on puzzles; Do arts and crafts	Activities: Look at books; Untie knots; Model with play dough; Take a walk; Look at family	Activities: Sensory books & bags (tactile Stimulations); Stuffed toys (cuddle); Hand Massage;

(knitting and maybe painting); Watch family videos; Creating a memory box; Gardening; Exercising/physical activity; Film screening; Crossword puzzle, visit a museum	albums, stress balls; little toys that wind up; Dolls and stuffed toys; Singing (connects with others); having a spa; Tossing balloons, small balls	Sensory Bean bags; Scent stimulation; things with zippers or Velcro closure; Sunshine & fresh air; Playing with dolls
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Table 2. Stimulation Activities by the stage and activity levels of Alzheimer’s dementia patients (Wegerer, 2018; National Institute on Aging, 2017; Alzheimer’s Association, 2020; Golden Careers, 2016)

5.5 Interventions

Music-based therapies and psychological treatment (for example, cognitive behavioural therapy) have been proven to improve depression, anxiety, and quality of life in people with dementia. For example, with the prima ballerina affected with Alzheimer who could recall Swan Lake's dance.

How can family members still actively communicate with the loved one despite the inability to articulate oneself?

Communicating with a beloved person with Alzheimer’s disease or related dementia can be very challenging. Especially a hard time is to understand what they are trying to communicate. There is great potential for misunderstanding, confusion, or frustration in both directions, making it even more difficult. But good communication is an important part of living after the diagnosis of dementia. Keeping a sense of oneself, sustaining relationships, and maintaining their quality of life. Even as communicating becomes more challenging. If the person with dementia cannot express themselves, they can easily lose confidence, feel anxious or depressed, or become withdrawn. They may have trouble finding the right word, repeat words and phrases, or use one word when they actually mean another. As more people nowadays start using smartphones and tablets, there might be a solution to communicate through video calls. (See appendix 2) Seeing a facial expression and body language can nevertheless be much more helpful to a person with dementia than a telephone call or a text message. There are lots of ways to communicate meaningfully together. (See Appendix 2)

- Encourage the individual to talk (See Appendix 5)
- Showing a warm, loving, open mindedness (See Appendix 6)
- Let him/her know that he/she is being loved and that he/she is not a burden
- Reassurance that they are not going to be left alone (Snow, 2020)

The challenges of communication evolve as the disease progresses. Until the point that people with dementia stop talking at all, which is common in the third stage of the disease.

6. Discussion

The disintegration of the family, the disintegration of the neighbourhood, and the promotion of an architecture that exposes unprecedented loneliness make dementia the heavy burden it is. We cannot understand dementia if we do not see it as the backside of a society torn apart by the need to accelerate. During its rapid journey, it necessarily hurls people on the hard waves who are not up to speed. It has a great impact on individuals, families, and communities. The work in many homes, families, and institutions is characterized by doing the best for those affected. But sometimes it becomes too much. It takes one's time, and it can also get caring relatives sick after a certain period. (See Appendix 2) The brain is the stomach of the soul! (See Appendix 5) Perhaps the contents no longer work for dementia patients. But that doesn't mean that the taste of memory that occurs in the soul has disappeared for people with dementia. The character is still inside, the human can not just be forgotten because he forgot who everyone else was. The emotional level is still visible, as research has shown. Relatives and nurses feel a certain connection, despite the lack of memory associated particularly with them.

Fulfilment of basic human needs

Alzheimer's and other dementia types are diseases that affect the ability to comprehend and understand what is going on. Still, it doesn't mean there isn't a person with his/her own needs to feel worthy of living and making choices themselves. The patients quality of the rest of their life should never be determined by their cognitive abilities to understand (Edmund, 2008) Certainly, all Alzheimer's affected patients have areas to be considered strengths, where they can still self- fulfil and they indeed can counteract or compensate for the losses in other areas of functioning (See Appendix 2) Stigma is a huge burden for the caring family members, not knowing how to cope with the diagnosis and the future progress of the disease. (See Appendix 3) When helping and caring for those affected, it is important to respect these individuals still. (See Appendix 5) By integrating them into the care plan, they still obtain an active role in care. Once the diagnosis has been given, it helps the individual cope with it and prepare for the next stages and helps the family gain an early sense of understanding for what this diagnosis may bring. (See Appendix 6) One of life's greatest needs is to feel loved, needed, and respected by others. Therefore, the hierarchy's love and belongingness should be recognized and addressed by those close to the loved one. (Robertson et al., 2013; Appendix 2) it is important to giving the individual with this disease a sense of meaning by providing them with tasks, jobs and especially finding strengths and abilities they can still utilize. This will give the person with Alzheimer's a sense of self-worth and help satisfy their need for the feeling of interdependence. (Edmund, 2008)

How can active emotional care be achieved without a nurse or family member's constant presence?

Sensory therapy or fidget toys have proven to be an effective way to reduce anxiety, calm nerves, and provide comfort. The goal is to engage the person with Alzheimer's in a fun activity and keep their hands happily occupied. (Heltemes, 2018; "Activities for dementia", 2018) Further keeping them active and engaged in an activity may decry loneliness and anxiety. (Lange et al., 2017)

How can family members still actively communicate with the loved one despite the inability to articulate oneself?

During the earlier stages of the disease, the individual still has the cognitive ability to be active and involved in therapies and programs. Whereas, when the disease progresses into later stages, many lose the ability to carry on conversations or not fully participate in activities. These individuals live when they are at a crossroads between their diagnosis and the resources and services available to them. To allow for these individuals to seek a quality of life, we need to direct our practices, services, and resources to more person-centered care, for example, with the model of Planetree (See Appendix 6)

Activities must be dramatically simplified. Through various stimuli input of senses people in the later stages of dementia can comprehend the information one at a time. By focusing on:

- sight
- hearing
- touch
- taste
- smell

Playing music, massaging the hands, and having objects to touch and interact with can support Alzheimer's dementia patients' state of mind.

Communication through a box

The main medium for remote communication is the tablet or the phone. However, an Alzheimer's dementia patient rarely feels connected. Sometimes, even abandons direct communication with the screen. A strange feeling of speaking to a tiny box often creates trouble in times like these with a global pandemic and the next lockdown on the horizon. Physical care is restricted, and affected relatives feel abandoned and lonely. There is still a measurable distance between the individual and the family member on the other side of the screen.

7. Conclusion and Requirements

This research paper introduced the need to connect and care for people with dementia and integrate them back to the surrounding and explore how communication can be enhanced.

The research questions have been answered, revealing the optional stimuli to interact and communicate with the patient on different levels.

Research has also critically examined the specifics of the disease, and how the symptoms develop over the three stages of the disease, further how they can be prolonged as much as possible. Long term care is never cost-effective and almost always labour intensive. Therefore, a means to close this gap and still cut costs will be decisive.

The research results can be translated into requirements to set foundation for the design process. In formulating the criteria, the research population's characteristics, and their demands and desires have been considered.

Considering all research results and consultations with the target population and experts, these requirements have been formulated.

DFV	Requirement	Source
Desirability	Encourage independence (provide guiding instructions)	Dr. Widdershoven Dr. Weinberg
	Should be able to communicate with the patient non verbally	Dr. Widdershoven
	Should be warmth transmitting and actively engaging	Harris and Keady (2009) Interview with Family member (2)
	Practical usage for every day/night routine "constant usage" not temporary	Interview with Family member (2,4) Robertson et al.,2013
	Should be efficient in transmitting care and affection at all time The nurses/caring relatives should be able to communicate through it or send signals	Interview with family member (2,3)
	Should not harm nor make feel a sense of discomfort (targeting family members & patients)	Observation (4)
	Facilitates relaxation	Chemali et al., 2012

	Ease to Use, No learning curve	Wegerer, 2018 Alzheimer's Association, 2020
	Stimulates motoric skills	Alzheimer's Association, 2020
	Improves staff engagement with the patient	Interview with family member (2,3)
	provide different sensory experiences	Golden Careers, 2016
Feasibility	Ease of use: the user should be able to interact with it intuitively, not having to actively or manually activate it (passive input rather than active one)	Alzheimer's Association, 2020
	Material should be water resistant throughout the usage, such as for wetting, the bathroom itself and other splashes	Interview with family member (2)
	Should be as lightweight as possible for the elderly to carry	Golden Careers, 2016
	Material should be impact resistant, be able to fall from a height of 1.5 Meters	Alzheimer's Association, 2020
	Material choice should be scratch resistant to certain aggression outbreaks The design should be modular for the ease of replacing faulty or damaged parts	Litzska, 2007
	The production and use of the product/service should avoid having a negative impact on the environment, therefore the materials and production methods used should be environmentally and human friendly	Self-evident

Safety	Should not harm nor make feel a sense of discomfort (targeting family members & patients)	Interview with family member (2)
	Avoiding the usage of rare earth materials	Self-evident
	The production and use of the product/service should avoid having a negative impact on the surrounding, therefore the safety measures for elders have to be strictly taken into account	Wegerer, 2018; National Institute on Aging, 2017
Viability	Profit by selling/renting the service/product to health insurance companies, institutions, private households, nursing homes	Dr. Weinberg
	Minimum viable product (Start-up approach)	Self-evident
	Created Customer value provided should equal the pricing and how much the user is willing to spend (empathy-gathering session)	Empathy mapping
	Incentive for stakeholders clear mapped	Dr. Weinberg
	Has to sustain itself over a period of one year (be profitable)	Self-evident, Business Model Canvas (proving, testing)
	Price-performance ration should be focused on the target group	Harris and Keady, 2009
	Should be Applying the Lean Start-up methodology (Build- measure- learn)	Ries, E., 2019

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Appendix 1

Interview with Nurse

DATE AND TIME: 22.09.2020 AT 3PM

These interview questions will help dive deeper into my research and specifically indicate difficulties in Care that will be targeted in the design process. There is no wrong or right answers, just honest ones.

What is your name and how old are you? *(optional)*

Susi – gender: woman; age:24

Me: How long have you been working in this profession?

Susi: For 8 years now, previously I was working in the hospital but eventually it got to stressful and my shifts couldn't be combined with my private life especially kids. So I decided to change the branch and as it turned out dementia care was one of my few choices so I got the job and now I am here. Definitely the best decision, concerning my nurse-life balance as we like to call it.

Me: How does your daily routine look like in the nursing home? *(Starting with the first interaction of the patient)*

Susi: I usually have 7-10 patients to care for, so depending on my shift. I usually first greet them and go in each room and ask if they need something and how I can be of good help. Usually I stay for a quick chat and then move to the next. We also organize events to make sense of the community and play with them if possible also for various national holidays we have a choir that sings to cheer them up. Then I help them dress, go with them to the toilet and Sometimes they start remembering the past and start telling stories, which are heart-warming and lovely to listen to. Afterward I give them the pills, preferably with some milk. Then I let them alone for a while. They can call me anytime with just a button. Depending if it's a good or a bad day, some patients like to be left alone and want their privacy. Therefore, it's important to talk to the relatives upfront how they behave what their routine looks like and what we shall be careful about. Next up is preparing food and helping them all arrive at the dining room. We sit down and eat all together, we support the ones having troubles and talk to others wanting some companionship. There are also some friends and relationships in our group, which are interesting to follow along, because they merely know each other but still truly love one another. Afterwards we go to the community/lounge area and give them freedom or read them some stories. Again pills and then some like to rest a bit so we help them get to their "right" beds (it happens that they confuse the neighbours bed for theirs). Afterward the routine repeats until the time to go to bed where we shower

and prepare them, not all shower every evening so we have a schedule for that too. That would be a short summary of what we do on a daily basis.

Me: Do you have major obstacles with patients that suffer from cognitive impairment? If yes, which? *Please name a few:*

Susi: The majority of our patients are in the second stage, they cannot walk very well they need assistance with eating and support while going to the toilet and elsewhere. So there is care needed around the hour. We have to repeat ourselves multiple times an hour, but it is part of our routine... Not communicating well, what they truly need rather say words which don't make sense in that particular order.

Me: Is there any help provided by technological assistance that support the daily routine? And is the patient in direct interaction with them? *(In form of devices or machines...)*

Susi: Indeed, the bed itself, the nudging system and in the surrounding often radios and televisions in the common area.

Me: Are there specific actions the patient takes on daily basis that challenge you? If YES: How do you cope with them?

Susi: Well these challenges are part of my job, I wish I had more time for the patients individually. Unfortunately, we do not have the capacities to ensure personal care at that level... challenges would be resulting in a lack of time, they fell left out and sometimes often confused about their location so in the beginning it was not usual form me to repeat things every 5 min, but now I got used to it. They are wholehearted beings and still have their emotions so I really feel a lot of love when talking or interacting with them.

Me: Do you find ways which help the patience be more relaxed instead of anxious and distorted?

Susi: We try to calm them down best as possible, especially before some of the inhabitants moved in here they had difficulties with aggression and anger outbreaks. So it can happen, but it doesn't very often because their medication is working against those symptoms.

Me: Does the interaction with other patients benefit a better mood? And through which domain are they interacting with each other, any hobbies? *Options: verbally, games, exercises, motion*

Susi: Most of the times yes, but often they tend to have a fight. Luckily it is forgotten after a short period. It depends some barely speak so are not able to do verbal activity but we do play cards and yam boo also sometimes to keep them counting. Their hobbies have faded out and they don't really read much anymore.

Me: Are there objects/products that residents often hold on to?

Susi: Yes, indeed, many female residents own and keep old dolls and stuffed animals with them.

Appendix 2

Interview with family member (daughter)

DATE AND TIME: 16.11.2020 AT 12PM VIA MT

This Interviewee (age: 55) wants to stay anonymous out of personal reasons. Her father was 72 when he got the first diagnosis. It was an 8-year process of the disease since the first symptoms appeared. This interview was conducted over Microsoft Teams and was transcribed afterwards.

Me: Who was the main caregiver or did your father spend most of the time in a nursing home?

Her: My mother, she did everything herself. We, my brother and I helped from time to time but until he got into the nursing home just 9 months before he passed away she was there to care for him and took over all the responsibilities in the household.

Me: When did your mother (the main caregiver) realize the first symptoms?

Her: She got very irritated, by him thinking he lost his wallet and therefore calling the bank every time in order to block his bank account over and over again. She would then explain them that he had just replaced him and apologize for any inconveniences. My mother found that very strange so she urged him to go to a medical check-up to see if everything was well.

Me: What were the main obstacles during the care process for your mother?

Her: It was a **social problem**; she was very embarrassed about it. She didn't want to tell anybody. She kept mentioning that it was a special kind of vascular dementia (cerebrovascular disease) so she wouldn't have to say dementia. She was **very ashamed**, because her husband my father did everything and was responsible to manage and guide the family throughout the decades. Suddenly he was gone and she had to turn around her life and be the main figure. As a caregiver she **crossed all borders**, she couldn't be sick. For eight years she did everything! She was like a hero and beyond.

Side note: 20 years ago people used to call cancer K, now dementia is similar to it.

My Father had the symptom of aphasia he lost the ability to speak, it becomes harder to remember words and assemble them in sentence. **Words wouldn't work anymore**, but we found a way to **communicate** with him **through singing**. Suddenly he started singing - whole songs whole sentences came out of him, we all couldn't believe what we heard.

Me: How was your mother coping with the around the clock care?

Her: Well it was very much an *"old fashioned marriage"* they had, she would kill herself for caring after him. During these years she would be neglecting herself and ignoring her needs. For her this is the ultimate definition of love... to give it all until the last second. We were

very concerned about the risk of [her getting sick or seriously injured](#). She wouldn't be able to care for him anymore if something had happened, but she did it anyways.

Me: Was there an apparent personality change that you realized after the diagnosis?

Her: My father was a very rational, analytical [mathematical guy](#), not much emotions where part of his life. Anyways he didn't use to show them very often. But suddenly [he became very loving](#), emotional and [enjoyed hugging people](#) - so that was indeed very surprising.

Me: Was there any help provided by technological assistance that supported the daily routine?

Her: A small button tracker, that would ring when my father left the marked territory. So my mother would be alarmed quickly and could easily find him wherever he was.

Me: Did he perceive the nursing home as a safe place and were there objects/products that he would often hold on to?

Her: In the nursing home he lived with very similar dementia patients, who were also very friendly and calm people to be around - so he fit very well into the setting.

My mother always saw him as the strong man in the family and also had the ideology of him being a main pillar for all these years. So in order to keep it that way [she didn't allow him to cuddle with fluffy stuff](#), nevertheless he had a [stuffed dog](#) in the nursing home and [he kept twisting his eye](#). Which I found very interesting, because it matched his engineering background to have the need to repair, analyse and modify objects. My mother found it very embarrassing that he had a stuffed animal to cuddle. He [liked to play with buttons, little ropes attached pillows and especially zippers](#). Once I bought a stuffed soccer ball, because there is a way of [communicating through movement and play rather than words](#). So we were just throwing the ball and catching it without words, still he made jokes where he would act as if he was going to throw the ball but not actually doing so. There was still something there... Additionally the ball can be seen as something for grown-ups, it's not a pig or a dog it's a ball, he could still touch and hug and my mother would be ok with that as well. A Win-Win situation.

Me: Did your mother find a proper solution to cope with the stress and anxiety connected to the diagnosis of your father?

Her: The very beginning was hard for her, she didn't know how to cope with it and was overwhelmed further didn't tell anyone. But as the stages gradually progressed she couldn't do it all alone so there was a nurse coming to bath and dress him once in a few days. It was particularly difficult for her to perceive that she had to [see him become a kid](#). Leaving him behind in the nursing home was as well a difficult decision she had to make. First it was only over the weekend, where she had time to pamper herself all day or go out with her friends. Gradually the days increased and he was there full time. But seeing him having fun with other inhabitants in the nursing home, [playing with the balloons, balls and games](#) together warmed her heart once again.

There were more people living there, another woman invited my father to be with her in the room. Like children can often do. And my mother got really jealous, but later we figured out the older woman perceived him as her son and just wanted to take care of him.

There was also a platform we could login to see updates and pictures from him, comparable to Facebook where you can post messages and share picture in a safe environment where you can only see your family member. Still it is a lot of effort, putting a picture on it for nurses and they don't have a lot of time.

Me: Previously you said he was very active; could he still walk or exercise?

Her: We were walking with him as much as possible. A major advantage was that the nursing home he was living in was in a kind of big park so we would have enough space to wonder around together.

Me: What would you have wished for him to have existed back then that wasn't there?

Her: A comforting thing that he could carry around. Sleep with it, play with it may be a little maid or a doggy that he could cuddle and feel good about.

Side note: A friend's mother also has dementia now during the pandemic they tried to call her on facetime, but her mother didn't understand to talk to the phone. Instead she was looking at the nurse and talking to her instead looking at the screen. She didn't understand that she could talk to this flat thing in a box.

Extras: In the Netherlands there is an elderly home where people can walk around and borrow a pet. Smart solution for dementia patients.

A city to work well, to wonder around and open the door and see what's behind the corner would be very helpful. Dementia patients are very curious and they love to discover.

Often people really don't know how to cope with the diagnosis itself, a friend of mine also had her father suffering from dementia. She would say things like: "It sits in a chair"- also those people exist. Pure separation from the living being, seeing "it" as an object

Appendix 3

Interview with caring family member

DATE AND TIME: 23.11.2020 AT 10AM

Natalia is a mother of two already in pension, previously she worked in the kindergarten for 17 years. Her father got diagnosed right after her mother died. She immigrated with her children to Vienna during the war in the Balkan states. Long before the dementia of her father was starting to evolve. In total it was a 5-year regressive process, her siblings and her would share the responsibility of caring for him. The interview was conducted over the phone. Interesting information is highlighted in bold.

Me: Who was the main caregiver or did your father spend most of the time in a nursing home?

Natalia: We are 3 sisters and one brother, we all agreed upon having him for one year at our own locations. So it would be fair for all. We tried also registering him in a **nursing home** but he **flew many times** and so we decided to take him out once again. There were many obstacles considering his care, especially when having two kids running around grandpa and caring for the family and having a part time job.

Me: When did you first realize that something was wrong?

Natalia: In the **middle of the night he would go out** to the driveway and in order to wait for his friends to pick him up for work (back then a sugar can factory), he would say they called him that they are approaching. We tried several techniques to get him back to bed, the one that worked best was through telling him they just called, because their having a delay so it's best to get back in bed and get some rest before you go. When he woke up everything was gone. He **couldn't remember even going outside**. Later he would do the same with the animals at the farm. Long before my mother died we had cows, pigs, chickens and rabbits. So he would go up to the barn with a bucket to feed the animals, when he got there they were gone and blamed the neighbour for stealing all of them.

Me: How where you coping with the around the clock care?

Natalia: It was a tuff time, my sisters and I couldn't handle him alone. I mean he is a big man and also quite heavy when lifting. Doing this routine **everyday would exhaust us** and eventually my brother and his wife learned and practiced the best way to cope with the situation. He stayed there for 3 years and they allowed him to go to the city, even though it was very unknown to him of course accompanied by him or his wife. My father even once said that she was 3 times better than his own daughters. Haha. We came from time to time to visit him, but the stages gradually progressed and at some point he couldn't talk anymore nor hear very well. So we would **use gesticulations and pantomime to playfully talk to him**.

Me: Was there any help provided by technological assistance that supported the daily routine?

Natalia: Far from that, there wasn't any assistance near and far. We could not afford such luxury to be honest, my parents were farmer and they wanted us to be educated, go to universities and have a better life. Which eventually did come true, but still all the machinery was still very expensive and therefore we were not able to poses nor rent one special bed for regulating the height. Everything we did was manually.

Me: Did your siblings find a proper solution to cope with the stress and anxiety connected to the diagnosis of your father?

Natalia: Yes, gradually it faded away... The years of the disease progression where by far the most challenging ones I have experienced. Nevertheless, we were [living in the momentum](#) back then, it was important for us to be there for him. He is also coming from a working family also farmers who sacrificed their whole life just have an education for their children. So by caring we could return the love they have been giving us our lifetimes.

Appendix 4

Home Observation elderly with moderate Alzheimer's disease

DATE AND TIME: 25.09.2020 AT 11:24

The observation took place at my aunts' house, in Belgrade. I wasn't there myself, but instead monitored a camera and the recorded for 2,5 hours. The participant was Branko (the affected family member, Age: 67) He has moderate Alzheimer's disease and is in a much worse condition, compared to when the first symptoms started to showcase two years ago (2018). The purpose of this observation was to see the behavioural pattern and gain insight in his daily routine. MMSE scores: First test was at 16 points the second one reached only 6.

Sitting on the couch and sorting cigarettes into a bulb packaging box. After realizing 2 cigarettes are missing, starting to look in the kitchen for the missing ones. In the sink, in various cups and containers. No luck, he continues looking in his closet. He takes out all the cigarettes out of the light bulb box and places them into the cigarette case. After a few minutes pass...he goes again to the closet and changes the clothes he has on with a completely new outfit and puts the ones he previously had in the dirty laundry basket.

In the next few moments he goes out to smoke in the garden. When he comes back he is looking for the lighter he previously had in his hand. Which is gone. He hid it in the garden (I found it later on) My aunt brings him lunch and he barely tries it, just eating the crust from the sandwiches she made him. Smokes two cigarettes inside and afterwards starts putting

the rest of the cigarettes in the bulb packaging again. Which is trying to hide in television case.

Appendix 5

Expert Interview Dr. Widdershoven

DATE AND TIME: 29.11.2020 AT 11AM

Dr. Widdershoven is a Geriatrician, nursing doctor, manger in hospitals for daily care based in The Hague. Besides that, she is also giving lectures around Europe in Health Sciences and later in her career has worked in the psychiatry department as well. She is organising working groups on residential facilities for older adults with mental disorders. Next to being a doctor she is also a sculptor, lecturer, web designer and Artist. The main goal of this interview was to prioritize between cognitive and emotional development needs. Once one was chosen, the fundamental needs that drive it and how to be able to fulfil it where explored. The conversation was audio recorded and later transcribed see below.

Me: During the years you have been working closely with patients suffering from dementia how did you?

Expert: When people get a diagnose and become a patient, everybody start to **treat a person as a possession**. He has a very special life in front of you.

Working **for** the patient **not with** the patient. When I say with it is very possessive. On television they talk about my patient and make it therefore their possession. Try to analyse videos and see where they use the possessive form.

Me: How does the communication differ between working for or with them?

Expert: Always try to talk to the patient, through that communicate with the carer. I **ask the permission of the patient to talk to the carer**. Older nurses try to put the patient in the middle, but their pressed by time course and everything they have to do. It needs time to process and automatically switch to the one that has the fastest brain.

Me: For the nurses besides the communication obstacles, where there any other challenges they faced with the work for the patients?

Expert: Well, it's not difficult to communicate with a person with dementia, it just asks other skills. But they are trained in other skills, that the main part. **As a community we represent people with dementia as unable**, but they **are very able**. They lack certain things in some areas, but in other areas they are very able., until a certain point. Un Decisiveness. They need guidance, it is different from the approach we are used to. How we as a community think about different people, not only dementia but also schizophrenia. Also people with another colored skin. How we treat people that are **different from ourselves**. It is a very very deep problem in the society. We even do it with the language we call people with dementia

“demented” suddenly not people anymore. Also with Jewish people or Turkish people, Jews or Turks. You have to be aware of [the fears you express in your language](#). In our old brain we are afraid of what is different.

Me: What do you think that we have to change inside the societal structure in order to reverse the numbers in Alzheimer’s patients? Is the lifestyle and the system we live in the cause of dementia?

Expert: Partly it is, I am a very strong believer of “what we eat, we are” and the majority nowadays lives very unhealthy. There is more and more research how your lifestyle influences your brain. As well as how the microbiomes in our bowels influence our brain. We can see it especially now with corona, it is a very nice example. All the people are overweighed, and have disease that are connected with the overweightness. they are more vulnerable to corona viruses. And this is the same with any disease. The moment you take good care of your body instead of expecting anything your brain wishes. Than we can expect to lower the number of dementia. [Prof Erik Scherder](#) has very interesting programs about the brain on television, about his [vision on taking good care about your brain](#). How to prevent or influence the progress of dementia.

Our brain isn’t made for this kind of life. A part of it we can’t influence it. We get too old for what the body is made of. It gets older and older and the muscle isn’t made for getting this old. With all kinds of health, medication we get people to become eighty. Raise our children and help our children to raise their children and that’s enough., It has an in-built mechanism of destroying itself. Lots of people are surprised if they get ill. They are surprised that they can die.

Me: How did you convey the message of death as a positive side-effect of life?

Expert: I always said that you won’t notice it. When I die, it’s very sad for the people that stay behind. It wasn’t that itself, but how they are going to die. We know our conscious life. I’m 65 now, I know this for 50 years, why not cope with it then. [Simone de Bouveret](#), she wrote a book about a person who took immortality pill and didn’t die. A very interesting book how life is when you don’t die. We should like that we are dying, give space to other person’s other ideas. If you look at it from another way, geocentric not from me but I am a little sport on the earth. Then you realize that the energy that is geotic put together. The energy diverse to all kind of things and it gives form. Energy is something we can transform into things. We should be happy to go back to the state of energy. I am agnostic, I don’t know. Every theory of it is an invention of my brain. Why not just don’t know. Enjoy the consciousness I have now. Why not worry about when I’m dead am my energy returns to my pool of energy. Why worry about coming back as chaotic form of life.

Why not be who you are at this moment? People try to look ahead. That why we advance, there is always a balance between looking ahead and being in the now. It is perceived in our culture as difficult. We think that we moan for the person that has left, but instead we

actually are pitying ourselves. We pretend we are sad for the person we lost. Mourning for the loss I endure afterwards.

To get back to the subject: When people get the [diagnosis dementia, they get a death sentence](#). Even how can they help them with death. Sometimes very strange.

Me: Rumours are there in order to calm the patient who escape the nursing home or appear to be very aggressive that are given various pills to calm down?

Expert: Not to keep him in bed, but keep him enclosed. It is discussed often and there are two kinds of medication. There is a medication to change the brain and the other to change the behaviour. Both medication have different functions. I see them try to look at people and try to understand why the people act as they do and try to understand the behaviour. It is normal to give people Oxazepam three times a day so they just sit in a chair. Rehabilitation and Vision in nursing for the future, for patient in already advanced stages to keep them steady in the progress. There is [medication](#) that is supposed to do that. In [1 out of 16 cases it works](#). In my experience I saw it 2—3 times it really worked. I they slope you have to stop the medication and they need constant care in the nursing home.

Me: What is your advice for the caring family member to live a more balance live?

Expert: It is very sad to see first before they see the diagnosis, statistically more woman get dementia. Suddenly men get the caregivers role and their not prepared for it at all. Because [it goes gradually](#), they have to pick up things. It is very sad to see how a person of 80 struggles with doing the household and other responsibilities. They can get help from outside, and when the care comes they [start treating them both as children](#). Suddenly they cannot do certain things anymore. There is attention for this problem. There is special training for nurses and caregivers how to cope with situations like this. [Client orientated psychology](#) and still there are only a few places that understand it and use it. It is very difficult to change a society in the way we think. That's why there are all kind of initiative that will change it. Why doesn't a person address himself/herself it is not they didn't want to but the you'll understand what to do.

Me: Nurses interacting with the patients, especially dementia patients need the time to be with them?

Expert: I am not sure if they need guidance, I am [not sure if it's a person who need to be with them](#). What happens in their brain is that they [lose the connection between what they see and what they know](#). They need the outside world to make this connection. The bridge between what they see and what they experience., What they see and what they know is becoming larger. They don't understand the input they get with what they know. They know that their mother was a sweet person. What they see is not really like their mother. If I twist it a bit, it can be my mother. They [try to form new connections](#). If you're able to [make this bridge](#) for them, then you don't need a person. For example, a good structure is a bridge. A routine, know when it's breakfast, when is the activity the structure of life is what they can

hold on to. It disappears gradually, they cannot see it we observe it from the outside. For them it's important to [live in the know](#).

If you look at the progress; the film Benjamin Button is a good way to visualize the process. This is the way it should go. Nobody knows it for real. If you look at people how they behave. The earliest brains are the ones that are still capable of coping with world. With steps they come closer to the stage of beginning, their brain loses the other things and they come closer to the earliest time. *"The first thing in is the last time out"*

For different types of dementia, it is different, we all call it dementia but there are different types of dementia. In the nursing home there are all kinds of dementia. As a society we did a really strange thing, when a person has [dementia it is a very complex disease](#), as a society we decided to let that be helped by the least trained people. The highest trained nurses are the ones in intensive care. We choose the people with not the best intellectual capabilities, to take care of such a complex disease as dementia is. Which needs a lot of flexibility, a lot of [ability to think ahead to understand with less information](#). In Finland they educate the basic school people, with the very best educated teachers. You have to be outstanding to educate the basic school people. You want your best people to train the most vulnerable people. You want your best abled people to help and support the persons with dementia. The first 26 years around me were very intelligent people and suddenly I started working and I wasn't aware of the lack of intellectual capabilities. What we do, this is not discriminating. I love people because of what they are and not because of their intellectual capabilities. It is not only intellectual capabilities you need, also emotional and social capabilities. Why do we ask people with less intellectual capabilities to take care of the most vulnerable people? There are enough people who have and instincts to care for people. There are people that after my doctor degree said nurse to me, because it was a common thing to call men doctors and women nurses. It did hurt a bit, why they didn't say doctor why because as a doctor I am more appreciated I am better listened to. These are more the things that are in our society. The better educated nurses often don't go working in the nursing home, because on the [society view it is a less worthy job](#). We are so focused on "normal" (without any disease, without any wrinkle) that's normal that's our measure point.

There is a picture of a baby that crawls up on the stairs then the person is on the top of it celebrating and then the stairs start going downwards again, an elderly is crawling down again. It takes me much longer to do things. For people like you I am too slow, that is the state of mind-set. My experience has grown in my time. My parents and the elderly before me, gave me the space to have my experience in my time. We have to give your generation to experience things in your time. It's not knowledge that makes you a wise person, it's the experience. I have to step aside if you need anything. You have to figure it out myself. You're now going upstairs, if you stay healthy and don't die you will have the same way downstairs.

Me: Where there still any hobbies for the dementia patients?

Expert: Yes, sure! if they are acknowledged they get the space to do certain things. I knew a painter that was still painting, who made self-portraits while he was more and more demented. You see him disappear. But very abstract ways. When I give the people the diagnose dementia in the second appointment we have. I always advise them to [start a life book](#), we talk with them they loose with time more and more memory. We advise them all the things they do still know to put into a book. Pictures of the family, what they loved, the work. It [helps the nurse connect](#) with them by talking with them about the work they did. People with Alzheimer, don't realize and the partner neither. Often the children realize it first, they push them to go to the doctor. They're used to a certain structure that they have been living it. They [can't realize what is changing](#). Their brain can't do it anymore. What does this mean for their lives? Then we go and train you to put the keys always on the same spot, then you ask the partner to do the same to help. That is the person that had most of the responsibilities and suddenly I have to learn him to put his keys always on the same place.

Me: Was there any specific need you realized during the time working in the nursing home that the patient made you aware of?

Expert: Their [main need is to be seen as a person](#), every person with dementia is hurt by the ways they are treated by the surrounding. Once I was on a convention in nice at a lecture given by Steven Sabbath he asked somebody to come to the stage. There was a third person on the stage., He asked him to take the blouse out of the trouser, he was talking to the other person while he was putting the other person the blouse back inside the trousers. That stuck with me.

Me: What would your advice be for the family members that they still be capable of connecting with them, if a patient is in a nursing home especially in corona times where only one visit per week is possible?

Expert: I am really waiting for [augmented reality](#), because you can place the person in the room. It is really odd to have a small box to talk to you. If you could [replace the nurse for the person itself with augmented reality](#), then they talk to the person itself. I think there is a lot of augmented reality in place. We don't use it for the low technology nursing homes but rather for the high technology equipped department. We use it in the high tech environment instead of the nursing home. If I can sit here and talk with this person in real live. But we unfortunately don't use the technology for these kind of situation.

Me: Are there any specific wishes for the future that you would like to become reality?

Partially already answered...We have the technology; we just have to find places where to use it as well. It is very [rudimental today](#). For people with dementia it is not important. Everybody can be their mother or their daughter. It doesn't have to be a high great technology to work for dementia patients.

Advice: Visit Alzheimer café to talk to more patients and get their perspective as well

Try to **approach it as can't instead of won't** that's just one letter difference but a whole world apart.

Appendix 6

Interview with Dr. Amnon Weinberg

DATE AND TIME: 04.12.2020 AT 10AM

Dr. Amnon Weinberg is a Palliative* doctor with 25 years of experience in the hospital, supporting clients and loved ones facing many challenges of living with a serious illness. He has worked over many decades as a doctor in the nursing home, organising the system around individual help. His main emphasis today while he is in pension is work on building networks and integrating various health workers into collaborative environments. By spreading his vision around the Netherlands he urges to change the system for the better. The main goal of the interview was to explore the treatments and planning around dementia care. However, his focus is more on connecting valuable stakeholders, therefore very little information on the matter of treatments is provided. More so the diagnosis and Patient-centered care which also play an important role in caring for Alzheimer's dementia patients.

*Since 1986 in elderly care

Me: Well, tell me more about your vision in Geriatrics in the future Healthcare system...

Amnon: I recently won a Planetree award for it. Leadership, responsibility and the right mind-set to achieve things. **Keep the caregivers learning** and keep them better. Local situation arrangement and a valuable contribution from the government. The aim of integrating regional geriatric care into a network organization. Which essentially depends on the **right care in the right place at the right time**. This means small networks of experts around the elderly and their relatives. One electronic system GP where all the information is readily accessible. It doesn't matter who does the work, to one who does it best will do it. We don't recognize vulnerability in palliative care at the right time it takes more in advance. The system needs change, now we are in **a momentum with people at home**, nobody comes, the treatment is stopped, the family members don't come they don't want to affect other. Good care, low cost and change the mentality in society. **Health care is social care. Home care is public care**. Prevention is also key. The geriatric specialist forms a bridge between medical specialists, district nurses, paramedics, the nursing home, the pharmacy, the community social team and the client's family and caregivers. The great thing is that all of the disciplines around the senior client work together. Professionals must take the leads.

Me: You mention that ideal care depends on the right care in the right place at the right time how does one know when the time is, often they are not aware of their state and that's why they often don't ask for help?

Amnon: I am in a government group about the GP, but there is a taboo about it. The doctor says when someone is 80 and has no problems we don't have to worry about them. GPs want to do everything themselves. Elderly proof GP practice. Everybody must realize that there is a vulnerability, [the health system](#) has to get the centre more [elderly proof](#). [The earlier the better](#). If they have a partner, they discuss that as well. Give information in the society about the third phase of life. Create a system that people know about it, give them valuable information. Case finding from the elderly proof GP system. How can we get the information at the right time? GP centres, [work together](#) from one standing point. In the general education system palliative and elderly care is not included.

Me: How can you assure a productive work together with various different disciplines?

Amnon: Well, Holland is not big. Those initiatives are already going on. One of the problem is still paining the people. There is no integrated financing system. The nursing home, says they don't have time and so the specialist doesn't come. A lot of programs, a lot of learning from what is going on in the country, lot of monitoring. The care standard in dementia: that is about the journey when the first symptoms appear until the moment we say goodbye after the funeral. How do we efficiently divide the task so we can avoid the hospital? In the right time, with the right expertise. There can be done so much more for the client at home.

Me: Most of the caregivers are relatives or the so called "sandwich generation" which care for a minor and an elderly at the same time. They are very overwhelmed and often cannot cope with the amount of work and love that has to be provided. They get exhausted and eventually get sick themselves. Do you have an advice for them?

Amnon: There is a lot of burden for the caregiver. They have a big risk and to get health problems themselves or lose their job. We work with insurance packages, the package 5 is the so called dementia intensive. But you can get the money also in PGB (Persoonsgebonden budget) They need guidance who is going to take care. Are there [behaviour problems](#), are there any other difficulties? Admission to the nursing home is inevitable close to the later stages, it is [too much of a burden](#) how much the caregiver can bare.

Me: What can improve in the home environment to be more accessible for the elderly, if they wish to stay at home during the last period of their lives?

Amnon: Give them good information about the diseases. Get it out of the taboo with help of the government. On a local level there must be intercultural groups that can reach those groups. Social system. Case finding, try to find them earlier. Which makes it easier for Palliative care. Regional and local organisation of various stakeholder. Working together analyse what are the needs, how does the future look like for them. There are people who are care avoiding, they don't want to let you in. People don't have only one disease it is often a combination a many others. At the diagnosis it is often too late.

Me: On the other hand, patients or clients do not realize the situation as serious as it might be. When does the planning usually start?

Amnon: Advance planning of care is really at the heart of the geriatric specialist's work. We are **too busy with postponing dying instead of giving a good say goodbye**. Older people need to be able to take stock of their life beforehand and know what it will mean for them when they get sick. What the future will look like and what consequences this will have for your quality of life and independence. In this way they can decide for themselves what to do and what not. What kind of care would you like? Who would you like to represent if you can no longer do it yourself? What treatments add something? Where do you want to end. This is not a single conversation, but a series of conversations that are very important in the chain and in networks. It starts at home, and an elderly person's life often ends at home.

Me: How do you apply the Planetree User-Centered care in a context with time pressure of nurses and difficult personalities?

Amnon: It changes the culture, the care and process. **Facilitation of bringing people together**, teaching them, arranging accommodation. In caregiver everybody is an ambassador for that. What about this system? What are the needs? The special is normal. Social health care everybody has the same worth, but still everybody is different. Do it together. The attitude and culture makes a big change in an environment.

Me: How could the family members still be capable of connecting with loved ones, if a patient is in a nursing home especially in corona times where only one visit per week is possible?

Amnon: The reversed child development. When children are growing up in the first stages they get all the senses, but the **senses do not work together**. Over time the integration of sense is evolving. On the other hand, I believe with Dementia patients the opposite is happening they **suffer a disintegration of their senses**. They have problems with all these stimuli coming from outside to reduce those stimuli.

Life story is very important, so you can understand things better. How is the team/the stuff doing? Support the teams in homecare and in nursing homes because it is a very tuff job.

I was surprised in The Hague in Mariahoeve there is a nursing home they have a **Life style differentiation**, when dementia sets in, the patient falls back into all patterns of the past. Early childhood. Integrated personal care, where lifestyle is a very important thing for it. The stuff has to understand **different values** even if they don't match.

Me: Which therapies do you apply for dementia patients especial Alzheimer's patients?

Amnon: First of all, we analyse the needs, how can we get day-care organize around their lifestyle. Keep them steady as long as possible.

“What counts is not the issue, but what's the matter for you”

Me: There are rather many stigmas around elderly care which doesn't make it the most popular area to work in for young health workers, what could trigger change?

Amnon: Elderly care is not trendy. It's mostly the hospital for the young people. It's a momentum to change the things. Elderly care for good and share prices we must support the home situation. The hospital gets so many elderly with all kinds of disease. I don't believe in first aid for elderly.

Me: What do you wish for the educational and health system in the future and how can your system be applied worldwide?

Amnon: Prevent, prevent complications, prevent hospital admission, prevent that the hospital gets overloaded. That must be the basis of our health care system. It's also about world government play. In Holland there is a growing solidarity/socialism. Dividing people is the biggest problem. By dividing the people there is even more trouble. We must protect the young people who will take over in the future and respect the elderly who paved the way for us. Using the social system in the interest of people, not the government.

Appendix 7



Figure. 2 Three parts three pounds. Cerebrum; Cerebellum; Brain stem (Alzheimer's association, 2019)

Appendix 8

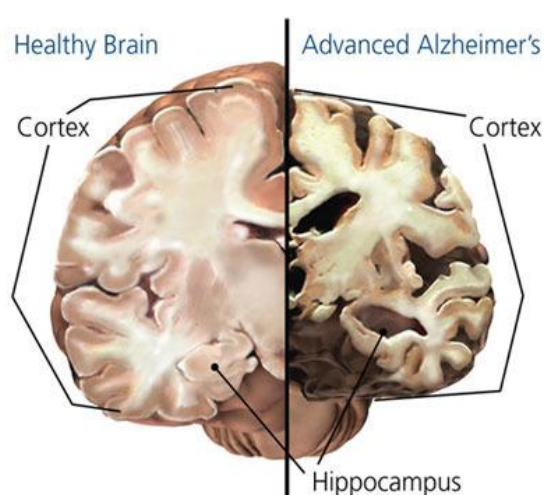


Figure. 3 Cerebral slice of a healthy brain and a brain in advanced Alzheimer's disease: strong shrinkage, especially in the hippocampus, can be observed in AD. Image credit: ©2015 Alzheimer's Association. Illustrations by Stacy Jannis.

Appendix 9

Basic Need	Description	ADP Symptoms	Intervention	Source
1. Need for self-preservation or physical existence	Good Health, physical exercise, pure water, fresh food, light, air, sleep, sexuality	lack of energy, memory difficulties, cognitive decline, change in behaviour and cognitive abilities, struggles with	Receive proper diagnosis as early as possible, it is important to know of it, because this	Dr. Weinberg; Chemali et al., 2012

		intimacy (no affection)	allows the affected person to take part in planning of the future.	
2. Need for safety	Protection, security in everyday life, political peace, protection of the family, money, job	forgetting appointments, becoming lost driving to work, difficulties managing finances, loss of attention, insight, judgment, fear of what may happen, strong feelings of loss, fear and abandonment Effects: Patient may start isolating themselves and feel left alone in the community	Family system model (family dynamic and how those interactions can influence the relationship), Cognitive Behavioural Therapy, social theory approach	Werheid et al., 2009; Robertson et al., 2013; Cox and Pardasani 2013
3. Need for empathy, love and belonging	Understanding, "being seen and heard", recognition, appreciation, respect, being accepted	feelings such as self-worthlessness, being useless, isolation Effects: becoming an outcast	Involvement in daily activities, art therapy, group work, community programs	Interview with Family member (2) Ortega et al., 2011 Robertson et al., 2013
4. Need for esteem, social contact and belonging, secureness	Social environment, friendships, neighbourhood, home, love as a "feeling", part of the team / company / family,	Self-esteem issues such as dependency on others, social isolation, difficulty maintaining	Music therapy, dance therapy, Alzheimer's café, community gatherings	Dr. Widdershoven Dr. Weinberg Robertson et al., 2013

	closeness, community, togetherness with people who have similar interests, consideration, security, respect, support, trust, appreciation, closeness,	identity and self-hood, stigma Effects: friends stop visiting and socializing	(enhancing social interaction), lifestyle care	Harris and Keady, 2009
5. Need for rest and play	Relaxation, rest, free time, the possibility of "refuelling" physically and mentally, purposeless activity, games, vacation, being alone, joy, laughing	difficult to understand what the individual feels, needs and wants due to being unable to express themselves, losing the ability to complete tasks Effects: depression and isolation	Grief facilitation, providing meaningful activities, being in a personalized environment, interaction with beloved ones	Harris and Keady (2009) Interview with a family member (2)
6. Need for integrity	self-expression, personal responsibility, choosing goals, dreams, values, plans to fulfil goals and dreams, freedom of choice, individuality, freedom for creative work, creativity, authenticity, self-worth	Ability to speak declines, nonfulfillment of oneself ; Lack of meaning for life	Constructing a life's book (about one's life history, where individuals can reflect on their life), physical therapy, occupational therapy, provide the ability to contribute to the community	Dr. Widdershoven Robertson et al.,2013

Table 1. Basic human needs adapted to Alzheimer's dementia patients

Appendix 10



Figure 4. Maslow's five tier hierarchy of human needs. Starting from the bottom of the pyramid: physiological, safety, love, esteem and self-actualization

Appendix 11

High Activity Level Mild Stage of Alzheimer's dementia	Middle Activity Level Moderate Stage of Alzheimer's dementia	Low Activity level Severe Stage of Alzheimer's dementia
Can keep doing the activities of their typical daily routine, with occasional help	Needs help with the basic steps and details.	Needs physical help with all steps
Understands the goal of the task; uses what is seen as cues for what to do	Doesn't understand the goal but has some awareness of task steps	Doesn't understand the purpose or the task steps
Behavioural changes: Forgetfulness (lack of short term memory), difficulty forming connections, may feel restless	Behavioural changes: Mobility becomes limited, ability to concentrate declines, keeping hands busy	Behavioural changes: Vulnerability to pneumonia; minimal or no speech; severe memory loss; Impaired walk; Passive; Lack of focus

Activities could be: Adapted to the lifestyle of the patient	Activities should be: guided, explained step by step, simple (easy to comprehend)	Activity should be stimulating, but without challenges, repetitive, focus on senses
Awareness: Slower pace of understanding, having patients is key	Awareness: It's about the engagement not particularly the outcome of the activity	Awareness: May place inappropriate items in their mouths; supervision is necessary
Activities: Cooking or Baking; Read the newspaper; Work on puzzles; Do arts and crafts (knitting and maybe painting); Watch family videos; Creating a memory box; Gardening	Activities: Look at books; Untie knots; Model with play dough; Take a walk; Look at family albums, stress balls; little toys that wind up; Tossing balloons, small balls; Singing (connects with others); having a spa	Activities: Sensory books & bags (tactile Stimulations); Stuffed toys (cuddle) ; Hand Massage; Sensory Bean bags; Scent stimulation; things with zippers or Velcro closure; Sunshine & fresh air; Playing with dolls

Table 2. *Stimulation Activities by the stage and activity levels of Alzheimer's dementia patients (Wegerer, 2018; National Institute on Aging, 2017; Alzheimer's Association, 2020; Golden Careers, 2016)*