Living Knowhere

Research on dementia and architecture
Anežka Prokopová

Tutors:

research tutor
Theo van der Voordt

design tutor
Robert Nottrot

building technology tutor
Ype Cuperus
Preface

With every attempt to start this report and describe the experience with my grandmother’s dementia that led me to this topic, I became more hesitant to share the reason at all. Not because I would be ashamed or sad; just because I could not find the right way to introduce it. Finding a balance between sentiment and cold facts seems impossible. Of course, there are many scars and slashes, many emotions and many sad memories, which invite to present it as a sad touching story but I did not want to do that. It would be unfair because it is not just that. Dealing with the disease has been a whole pallet of experiences with its highs and lows.

It is not easy and it brings many difficult moments to life but at the same time, it also brings many good things. There are many memories I am extremely happy for and altogether, it is just another huge lesson our grandmother has to teach us. Seeing the disease progress makes you reflect upon your life, upon life in general and upon things you consider relevant and important. It has helped me learn to appreciate things I used to neglect and realize the importance of simple, basic things; things which remain present even when all the others are forgotten; things that are natural to us but we tend to rush through them. My grandmother is now no longer able to remember my or her name, she does not recognize where she is but she is still happy when she is outside in the sun, she cheers up when she sees us no matter that she often thinks we are somebody else. She is extremely grateful for any laugh we share, for any warm touch. She is happy when we are all together and in a good mood. She shows us even now what the important things are and what we should learn to enjoy.

Despite all the difficulties and bittersweet feelings, I consider myself lucky to happen to learn from her even now when the disease is progressed. The whole experience has been the motivation and reason that brought me to this topic and although I do not want to call my grandmother a reference or a research method, this experience will naturally be incorporated in the research. Seeing many people including my grandmother struggle and getting lost in many of the nursing homes naturally stirred many thoughts about what really matters in space and what are the simple, essential things people truly enjoy. It has led to thoughts about how space can help us enhance the very basic enjoyments of our true self even when we no longer remember which those are.
Acknowledgments

One page is hardly enough to express my gratitude to each and every person who has inspired or helped me with this report. During the whole year I have met many people who I truly admire for who they are and for what they do. I feel honored to have had a chance to meet people who work by different means to make life of people with dementia better. Some of them are named in the report but those who are not were equally relevant. Each person I talked to, no matter if it was a nurse, designer, director or a caregiver, was an important piece of this whole puzzle. Each one contributed with their insights and knowledge to the overall picture which I could have never made on my own.

Especially, I would like to express my gratitude and admiration to people with dementia who I talked to for sharing their intimate and personal feelings, joys and fears with me. I am humble and truly appreciate their openness and strength with which they live every day.

Meeting people with dementia and learning from them would however not have been possible without the support of directors and managers of elderly homes I could visit. Their openness to my research and the freedom I had has helped significantly to gain important knowledge. Seeing so many people apart from my grandmother struggle with the disease has been a strong learning moment. I am grateful to have had this opportunity because it has opened my eyes not only to how many people there are. It has also opened my eyes to how demanding the work of all nurses and carers is and how strong they need to be both physically and mentally. Thanks to having a chance to peak into the life within a nursing home, my beliefs and intentions could grow stronger.

My deep gratitude belongs also to all my mentors for their encouragements and patience. Theo van der Voordt for always being both kind and critical. Robert Nottrot for his endless humanness and guidance in the design part and last but not least Ype Cuperus for helping me make the design practicable. I feel very honored to have met all three of them and learn from their knowledge.

Very strong base behind this report is my family which although scattered around the world has been a great, unconditioned support. Together with friends and their ways to laugh out of troubles it has been a priceless source of encouragements.

Last and special thank you is devoted to my dearest Jirka for always being there and for reminding me constantly that the world keeps spinning.

2.5.2015
Anežka Prokopová

Delft
How to read

The report is divided into four main parts. First one, Introduction, bears formal information about the research, its goals and means to achieve them. Second part, Theory, introduces a theoretical background to dementias, their relation to society and last but not least to architecture. Third, Reality tests this theory in practice and describes my experience with real dementia care institutions and real people suffering from the disease. Based on all three, the fourth one, Design describes my design principles which I derived from the previous chapters and their application in the design process.

I find it very important to say that this research is focused solely on buildings and spaces they create. By no means it intends to criticize or comment on work of all the committed and good-hearted people that help people with dementia make their lives better everyday. I truly admire their work and although I talk about some elderly homes’ deficiencies, it never includes the people inside. On contrary, by analyzing the buildings and learning by working on this graduation, I hope to one day be able to improve the conditions not only of people with dementia but also of the many people taking care of them.

Within the whole text I will refer to people with dementia differently in order to avoid repetition as well as to follow the way they are called in various elderly homes. Sometimes they are referred to as clients, sometimes as patients or residents. Many times I will also use “they” which however does not express my attitude towards people with dementia. Neither do I see them as a secluded group nor as a homogeneous group of people. Although they have the disease in common, it is a diverse group of people often including our relatives, partners, friends, neighbors and one day maybe even us ourselves.
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1. Part one

Introduction
1.1 Introduction

Due to our aging population, numbers of people with dementia are constantly increasing, while both the cause and cure are still unknown. At the end of a lifetime, after all a person has been through, it is hard to let go. It is hard to let go on home, on memories, on one self. Due to the disease, many things become insecure and one's life falls apart. Moreover, being diagnosed any kind of dementia within our hyper-cognitive society, which values and requires fast adaptation and constant learning, often means bearing a stigma of ineffectualness, disability and uselessness, nevertheless one's previous status. It means being excluded from the society's center not only economically and socially, but also literally by means of being moved from home into a special care unit, dependent on help of others. With no way back and no other place to go, many people spend last years of their lives in such situation. Involuntarily bounded to the institution and the space provided, they experience less and less changes of environments as they no longer have the need or the right to do so. With dementia progressing, life outside of the caring home becomes more demanding and peoples' life sphere gradually shrinks. At a certain point, it shrinks in between walls of the care unit only and continues till the point where it becomes the person himself and his immediate bodily surroundings. In the late stage of dementia, one single room becomes the whole world which tells us how extremely important the direct environment is, as it may contain the whole life of a person at each moment here and now. With so many abilities and certainties slipping away, support from the environment is enormously important as it can be one of the last thing demented people can relate to. There are about 60-70% of people with dementia in most care facilities in developed countries whose abilities to meet their needs independently are lowered or damaged. Due to the consequences of the disease, they gradually become more and more dependent on their surroundings. The more disabled they are, the bigger influence the built environment has, and the less they can modify it. If therefore not designed with care and understanding, quality of peoples' life can be significantly lowered.

In this sense, designs of such places are clearly an extremely sensitive matter to work with. Their importance is immense, yet tremendously fragile to grasp. Because of that, it requires knowledge, attention and apprehension to deal with them correctly. It requires understanding of dementia and its consequences as well as apprehension of demented peoples' perspectives. The latter is especially crucial because people with dementia are very often excluded from the design process, although they know best what is most suitable for them. Learning to understand their experience and difficulties can help avoid unnecessary stress in later stages of the disease when they lose their cognitive faculties and are no longer able to adapt the surrounding environment to their needs. It can help create environments which enhance quality of life of people with dementia.

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2 Ibid.
Such process of learning and improving can not only help people feel more comfortable but it can also help architects broaden their sense of space, its boundaries and its qualities. It can help enlarge their notion of environment when seen through eyes of disability. People with dementia are not the only disabled community and there are many ways of perceiving space and architecture. Approximately 15% of the world’s population live with some disability and therefore with a different perspective and perception of our shared environment. Disabled people form the largest minority in the world and offer a great opportunity to understand and accept different forms of receptions not only to architects. In countries with life expectancies over 70 years, people spend about 8 years of their lives disabled in a certain way. It is therefore worth understanding and accepting various notions of space where disabilities, including dementia, offer a guiding hand.

Learning to design for dementia is also a great chance to take a step back and reflect on the society as a whole. Getting to know the disease and its consequences is an opportunity to shift our focus back towards the basic, sensory experience of architecture which is to provide shelter and enrich our lives at every moment. Coming back to basics through environments which are safe, aesthetically pleasing through materials, lights, sounds or scale and proportions are beneficial to all of us, no matter the diagnosis.

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1.2 Research outline

1.2.1 Problem background

Within our population growing old, many assisted housing and specialized care centres for people with dementias are running short on covering demands of the already high and still increasing numbers of patients. Waiting lists are getting longer and it can take years to get a place in a nursing home. Moreover these care homes are not always succeeding in creating a suitable, sensitive environment for the difficult struggle of people with dementia. Having the background of growing up in the Czech Republic and moving to live and study in the Netherlands, I was lucky to have a chance to see what the difference in general awareness and approach towards dementia can be in different countries. The situation is getting better as many individuals as well as organizations are involved and doing their utmost best to increase the awareness. However, still a lot needs to be done to improve the situation and accept dementias within the society.

1.2.1.a Societal conditions.

While in the Netherlands, still more and more attention is paid to the environment where people with dementia live, how it impacts their state of mind and progression of the disease itself, in the Czech Republic, these concerns have only recently slowly started to arise. Although there are many passionate people doing their best to improve the situation and raise awareness about the disease, influence of the built environment is very often neglected. There is a significant gap between care institutions, caregivers, initiatives, organizations and architects. Mostly, people tend to blame the care organization, lack of finance or lack of people for any inconvenience in care homes but hardly ever they blame the space itself. It is not common that people would consider space a significant factor and consequently, it is very rare that they would ask architects for help. In this research I would therefore like to indicate and show otherwise. I hope to illustrate that architecture of the space plays an important role in the care environment and that it can contribute to people's wellbeing. I do not claim it is the most important aspect and that it can dramatically change the progression of the disease. I fully respect that architecture comes long after the love of family, patience of carers and their devotion. However, I strongly believe that it can have a positive effect on all the mentioned parties and in this report I hope to illustrate how.

1.2.1.b Historical conditions

During my graduation I could visit different elderly homes which mostly proved that the country is still recovering from the Communist regime. During that time, many of today's caring facilities were initially built as a mass and cheap accommodation for workers or students. Not built to be a place for seniors, let alone seniors with dementia, they preserve an impersonal, dull and unfamiliar atmosphere. Many of them are therefore deficient and unable to meet the needs of people with lowered or no cognition, with distorted spatial orientation, and with very frail health and mental condition in general caused by the disease. Each building I visited is described in detail in a chapter 3.1.2 Site descriptions, page 38.
1.2.1.c Legal condition

Further more, due to the inconsistent social and economic system, there are many “unregistered” in-
stitutions. Not being officially registered as a social service they do not have to fulfill requirements of
such institution and often call themselves a hotel or residence. Unlike registered caring homes, they
rarely provide services and help needed specifically for elderly. Due to shortage of places, people how-
ever come anyway and often live in undignified conditions without proper assistance and surroundings.

1.2.1.d „Them”

Despite the growing numbers of people affected with some kind of dementia, people with dementias
themselves are rarely part of a design process. Although their perspectives and experiences are hard to
discover by conventional ways of communication, they are very relevant.

For comparison, we know a lot about people in wheelchairs and their disabilities. We can imagine what
difficulties might occur and based on that, we can compensate for it with a well thought designs. We
can ask and understand what they need and what troubles they experience. We can do the same with
blind or deaf people, with people who have cancer or other fatal disease, but probably due to deceptive
presumptions of demented people being unable to explain their needs we almost never use the same
method with them. However, even though people in late stage of dementia might be unable to describe
what and how they feel, especially in a verbal form, they still react upon their environment. They have
their preferences and they act upon their surroundings. They make their choices and they do act pro-
actively, which is what we can learn from instead of presupposing we know better from the healthy
outsiders’ view. I assume that only by proper knowledge and understanding of what it is like to face
dementia and how confusing it is then to live, one can adjust the design to be more of a help rather than
another obstacle.

1.2.2 Research Goal

The main goal of the research is to get familiar with the complex topic of dementia in order to be able
to design a sensitive environment for people affected. One part of this familiarization process is un-
derstanding the disease on a theoretical level whereas the second part consists of learning more about
perspectives, experience and challenges of people with dementia themselves. By listening to their opin-
ions and working with them, I hope to understand more about what role environment can play in their
lives. I aim to find out, by observations and interaction, how they use the space, how it makes them feel,
what they search for and what calms them down. Visiting different buildings provides a large pallet of
eamples which will hopefully merge in a bigger picture.

One of many theories believes that people with dementia, especially in later stages, spend most of the
time in their memories. The sharp contrast of waking up to an unfamiliar environment very often

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7 Česká televize, «Iva Holmerová, Primářka, Gerontologické Centrum,» in Civilizace, ed. Hyde Park
(Česká televize, 2015).

8 Alzheimer Europe, “The Ethical Issues Linked to the Perceptions and Portrayal of Dementia and People

9 Dementia, Design and Technology : Time to Get Involved, 24.
causes anxiety, stress and even aggression. During my research I therefore aim to find out how such environment can provide safe and sensitive support for people with dementia. It aims on finding out how environment can serve as a strong guard to those who gradually lose their personalities, cognitive faculties, and rely solely on instant feelings, learned motoric, senses and emotions.

### 1.2.3 Research Question

**What deficiencies, challenges and potentials of spaces can understanding of dementia and people who struggle with it reveal, and how can this knowledge help understand their situation, experiences and perspectives in order to design rich and suitable environments which would be a solid support for their fragile condition of personalities, abilities, lives and memories falling apart?**

### 1.2.4 Sub questions

Once I realized how complex and complicated the topic of dementias is, many further questions started to appear. They touch upon different topics but remain connected. I will try to answer some of them by this research but with their broad scope, they will mainly serve as reminders of how extensive this topic is. They will serve as constant triggers of new issues and ideas as well as questions to later reflect on the design part.

#### 1.2.4.a Sensory stimulation

a.1. Can architecture help compensate for people's defects such as loss of cognitive faculties by enhancing the non-cognitive qualities of space?

a.2. How can architecture best help activate people with dementia through triggering their senses and emotions?

a.3. How can space provide enough stimuli for every person while still being clear and understandable?

#### 1.2.4.b Quality of life and familiarity

b.1. Can architecture help enhance people's individual personalities?

b. 2. Can it help continue their normal, familiar lives even during the process of the disease, and contribute thus to their well-being?

b. 3. Can architecture always be there as a support in their scattered and confusing lives?

b. 4. Can it engage people to do various recognizable actions in order to feel at home?

b. 5. How can a place bring back memories and reduce the shock when woken up from one?

b. 6. How can a space feel like home when the home is far away in the past?

b. 7. How can a space be less of an institution, but rather a guarding support to all its inhabitants instead?

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1.2.4.c Overall

c.1 How can we create an environment which appeals to inner, deep emotions and memories, provides enough sensory cues and stimulus while at the same time, creates atmosphere and backdrops to everyday life which is well-known and familiar to its users.

c.2 Would we fear less if we knew we are about to end up in a nice, suitable environment?

1.2.5 Research Methodology

Because dementia with all its consequences touches upon much more than just architecture, various methods of research were used. To grasp the complexity of the disease, I first broadened the scope of interest and explored various fields that deal with dementia in different ways to finally come to common principles related to architecture.

1.2.5.a Personal experience

Spending time with my grandmother and seeing the disease progress has been the most difficult, but the most valid source of ideas and insights. During the many years I have been able to see a lot about how the disease has affected her and what has become difficult. I could see what made her confused or anxious and what she appreciated through time. It is obviously a rather subjective observation and it is just one example out of many but I consider it the biggest inspiration and lesson nevertheless.

1.2.5.b Literature study

Various types of literature were used to give theoretical background to the research as well as to explore opinions of other people interested in this topic. Vast amount of online articles had to be sorted out by asking more precise questions. Initial chaos and overload of data was thus reduced and relevant articles found. I was pleasantly surprised by how many closely or loosely related articles there are and hope to continue reading even after this research is finished.

As I did not want to limit myself with the computer too much, books were used as well. Lucky enough, shortly after I started this graduation year, a book called Lost in Space\textsuperscript{11} was published. This collection of essays, articles, interviews and various project studies gave me a perfect starting position and other books followed naturally. Full list of used literature is attached at the end of this report.

1.2.5.c Documentaries and computer games

Watching documentaries of and about people suffering with dementia sometimes revealed more than an expert article. It might have not provided any precise data but it revealed a lot about the human part of the problem. It gives a better understanding of how sensitive the topic is and how many different people have to face it.

Extreme Love: Dementia

In this British documentary, Louis Theroux follows stories of various families with various backgrounds

\textsuperscript{11} Feddersen, Lost in Space: Architecture and Dementia.
who struggle with dementia. Each of them fights in a different environment but all go through similar
everyday battles. You can see diversity of people as well as diversity of their environments. You can see
strong examples of unconditioned love in home care as well as in institutional settings.

Teepa Snow's videos
With a brilliant dose of humour, love and devotion, Teepa Snow, one of America's leading educators on
dementia, demonstrates and explains the disease with all its highs and lows. She makes many training
videos for professionals and families all of which are very caring and human. She gets into the soul of
people with dementia, acknowledges them as human beings and shares this attitude. Following com-
ments about one of her talks speaks for me.

„I encourage anyone and everyone to go see Teepa in person. She is a fantastic instructor. You will laugh
and feel the pain, but walk away a better person for what you have learned. She is an exceptional woman
with great insight to a scary disease, armed with a wonderful sense of humour lined in compassion. I can’t
wait to see her again when she comes to Minnesota this month."

Ether One
During my search for movies and documentaries, I ran into a computer game aiming to introduce the
fragility of memories and dementia. It is a difficult task to translate such a topic into a computer game,
yet in many ways it works. The whole game tries to show first-hand the slow dissolution of a brain.
Within a futuristic memory-retrieval company your job is to dive into the mind of a woman diagnosed
with dementia, and retrieve a series of lost memories. It however contradicts conventional game prin-
ciples by having no obvious logic and rules. It focuses solely on the world within dementia. It shows a
world of scattered memories, of seemingly random objects and actions gaining importance. It is confus-
ing as much as life with dementia can be. It is disturbing as well as very poetic.

1.2.5.d Interviews and talks
Learning about work and experiences of industrial designers, art and music therapists, nurses and doc-
tors as well as architects related to the topic of dementias was a way to get a bigger picture of the prob-
lematic. To be able to compare the answers, some of the questions and areas were fixed but due to the
variety of people, the rest was left open and always changing with regards to the on-going discussion
and person's lead. Some of the interviews were therefore of a semi standardized nature, some were un-
standardized. Many times the unscheduled part revealed more than the prepared one. It might have
been caused by me being more comfortable with the free conversation as well as by the more relaxed
nature of the talk in general. During most of the interviews I took notes, but only the main ideas rele-
vant to the topic will be introduced in the text.

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(California State University: Allyn & Bacon, 2001).
Šárka Karasová - nurse in an elderly home

Talking to a person who has many years of experience reveals lots of practical, everyday problems. It especially shows some organizational as well as spatial complications of existing nursing homes that very often lay in small details and that are hard to anticipate from an outsider’s view.

Henri Snel – Alzheimer architecture architect, haptic designs, multisensory environments

Henri Snel is a passionate and devoted architect working to increase awareness about Alzheimer disease and improve the environments for people suffering from it. His research into haptic designs and multisensory environments emphasizes among other issues the need for accessible stimulation here and now.13

Valentijn Visch - Persuasive Game Design

Having a chance to compare work of industrial designers with the work of architects showed mainly a difference in scale. Whereas architects mostly focus on the entire building, its organization and materialization and get caught up in its complexity, industrial designers very often start with specifics. They focus their work on a particular problem, such as socialization of elderly in moderate stage of the disease or on encouraging the application of humour between informal caregivers and people with dementia14. They state a specific problem first and try to find a solution. Architects, on contrary hardly ever have a chance to get into such details and try to solve the enormous complexity at once.

Another difference became clear after talking to Valentijn. It is much more common, given the smaller scale of their projects, to work with their end-users and test their prototypes with them. Although testing a prototype is clearly difficult with architects who design a whole building, working with end users is often neglected for no obvious reason.

Hester Anderiesen – Industrial design PhD student

Hester has done research into design for motivation and changing behaviour of elderly with dementia and came up with an interactive game that enhances relaxation as well as social interaction. Because of her project, she studied experiences that remain in different stages of dementia. Which those are and how they can be used in relation to architecture will be discussed further in a chapter 2.1.5 What remains.

Alessia Cadamuro – Interaction design for play experiences in dementia

During her project called What remains?15, Alessia decided to spend time and work with dementia patients. Her experience and impressions were very helpful in structuring my own in depth research.

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14 Ilse Blom, “Amarant: Encouraging the Application of Humour between Informal Caregivers and People with Dementia” (Delft University of Technology, 2014).
15 Alessia Cadamuro, “‘What Remains?: A Persuasive Story Telling Game.”
Sara Pabst – music therapist

Because this interview depicts well the irrational, sensual part of human's nature and ways to work with it, it will be attached as an Appendix 1 to this report.

There are many other people who contributed and helped me by sharing their knowledge during the time. Although not officially interviewed, their experience is incorporated in the report as well with great gratitude.

1.2.5.e Site visits

To be able to make better link between the disease and architecture, I decided to have a look at existing buildings. Experiencing the everyday life within, observing the daily routines of the people including the patients, staff as well as visitors was a helpful and powerful tool to see both mistakes and good things.

1.2.5.f Meeting people with dementia

During two occasions I could meet and get to know some people who have dementia in person. Firstly, I volunteered in Het Danspaleis dancing event in the Netherlands. Later, cooperation with Czech Alzheimer fund located in Prague as well as with Centre of social services allowed me to gain platform for working with people who have dementia in Czech. In order to better understand how they perceive their environment, what causes troubles and what on contrary helps, I tried to work with a small group of people in one of the elderly homes. Separate chapter 3.2 Meeting people with dementia describes my experience and methods I used in detail.
2. Part two

*Theory*
2.1 Dementia

2.1.1 What is dementia?

In order to understand complexity of the disease and to learn about how people with dementia deal with its impacts, it is important to know more about the disease itself. Dementia in general is a brain illness due to which cognition and/or behaviour is damaged to the point where everyday life functioning is impaired.\textsuperscript{16} Dementia is however only a so called umbrella term for cluster of disease, out of which Alzheimer’s disease is the most common.\textsuperscript{17} It represents majority of cases, and therefore most of the references used for this research relate to it. Having many aspects in common with other types of dementias, such as vascular dementia, Lewy body dementia or frontotemporal dementia, outcomes of the research are relevant for dementias in general and will not be further subdivided.

There are some accepted medical definitions that describe dementia as a general term, one of which is the following:

“Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. Impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour, or motivation.” \textsuperscript{18}

Shortly, it is a “group of symptoms caused by gradual death of brain cells. The loss of cognitive abilities that occurs with dementia leads to impairments in memory, reasoning, planning, and behaviour”. \textsuperscript{19}

Unfortunately there are more characteristics that all kinds of dementias have in common. They are relentless, irreversible and devastating, as the person suddenly or gradually slips into a state of complete dependence.\textsuperscript{20} Very often accompanied by other disorders such as depression, aggression, sleep disorders or delusion makes it difficult for the person as well as for his or her relatives. Although there is only one person with dementia, it always strikes the whole system and many are influenced.\textsuperscript{21}

2.1.2 Stages

Multiple stages of dementia’s progression are distinguished. Each of them is recognized to have specific symptoms of a person’s cognitive decline. Usually, the stages are referred to as “early stage”, “middle stage” or “late-stage”, but according to the most commonly used staging scale called Global Deterioration Scale for Assessment of Primary Degenerative Dementia there are seven, more exact stages. Such scale is most relevant for people who have Alzheimer’s disease, since some other types of dementia do

\begin{itemize}
  \item \textsuperscript{17} Feddersen, \textit{Lost in Space: Architecture and Dementia}.
  \item \textsuperscript{18} Dementia, Design and Technology : Time to Get Involved, 24.
  \item \textsuperscript{20} Uriel Cohen, \textit{Contemporary Environments for People with Dementia} (Baltimore: Johns Hopkins University Press, 1993).
  \item \textsuperscript{21} Feddersen, \textit{Lost in Space: Architecture and Dementia}.
\end{itemize}
not always include memory loss.\textsuperscript{22} Even for that, there are however no definite boundaries of when a stage starts or ends, mainly because it differs with every person. For better understanding, full table of Global Deterioration Scale for Assessment of Primary Degenerative Dementia, also known as the Reisberg Scale, is attached as an Appendix 2 at the end of this report.

### 2.1.3 Families and homecare

Taking care of a person with such a disease is emotionally as well as physically demanding, especially in later stages of the disease, when a nonstop care is required. With a demented person losing his independence, family members are directly influenced as well. They are under lot of stress and by that they themselves increase risk of developing dementia.\textsuperscript{23} It is stressful and frustrating. For a good reason it is said that with dementia, you see the person die twice, once in mind and then again in the body. Within that time, many difficult situations arise and there are many difficult decisions to make. One of the most difficult ones is to decide that the time has come to move the person to some kind of care institution. In most cases, as the disease progresses, it is unsustainable for the sake of both sides to continue with the homecare. Such decision is however not easy and it is often accompanied by mixed feelings of regrets, blame and failure.\textsuperscript{24} Altogether with certain level of relief, people are often confused, blaming themselves for not succeeding in taking care of their loved ones and for feeling relieved at the same time. There is however researched evidence that people feel less frustrated after moving their loved ones into a place with a great extent of homeyness. Compared to an institutional care, places with a large sense of normal life cause less regrets.\textsuperscript{25}

The current trend in the Netherlands is to keep a person with dementia at home for as long as possible. That way, people remain in their own environment and it is economically more feasible. On the other hand, people at home often lack social contact and variety of activities that they could enjoy in a nursing home. Vice versa, when moved to a nursing home earlier, people are still able to engage in and enjoy activities with others, but they are detached from their own environment. Exactly for this reason, environments of elderly homes should be as normal and home like as possible to lower the difference as much as possible. If it is designed to provide suitable conditions for people in the late stage as well as for those who are still independent, vivid mixture can be created. Furthermore, if also people in the early stage are encouraged and motivated to move in, there is less pressure on the family. I know it very well from my own experience. Although it is difficult, moving a loved one to an elderly home not only provides him or her with better and richer care but it saves time and energy of the family to enjoy the good activities altogether. They can give the best to the person which is sometimes difficult in everyday homecare. Spending a quality time together in a safe environment that offers privacy and richness of activities can often be the best therapy.

\textsuperscript{23} Teepa Snow, Making Visits Valuable and Positive, (Florida 2012).
\textsuperscript{24} Cohen, Contemporary Environments for People with Dementia.
2.1.4 Dementia and society

All these decisions are difficult and so is accepting the disease itself. Nowadays, dementia in general is a topic majority people try to avoid. The devastating irreversibility, together with relentless consequences such as memory loss, changes in behaviour, dependence on others, loss of cognitive functions and many others are considered to be a horrifying experience. We could ask ourselves why we try to maintain our cognitive faculties for as long as possible so desperately, when having to do so constructs a stressful situation both for those still healthy and even more for people with dementia. Due to the consequences, people with dementia gradually become lost in space and time. With only basic abilities remaining, learned motoric, instincts and occasional awakenings, it becomes hard to perform everyday tasks as well as to remember way through a building.

By making environments in which it is not necessary to rely only upon reasoning and cognitive faculties, not only life with dementia would be more relaxed and less stressful. Saying this, there are multiple questions to ask ourselves. Do we build spaces that are too rational and too factitious? What does it say about the way we design our homes if later on they become strange and confusing? May these spaces, to some extent, contribute to and provoke the disease?

Without knowing the answers, shifting our focus towards designing environments where loss of such faculties is not considered a tragedy but rather a transition into something new, dealing with the change might be much easier. For that matter, comparison with less cognitive and more rural societies reveals a different perspective upon the problematic. Although there is only little known about perceiving dementia within societies and nations that are more spiritual and aesthetical, it already tells a lot about how different can an approach to such things like dementia be. It clearly shows that the way we see it is not the only one, and that it just very much corresponds with our modern society's values. It shows that our fear is something we made up together with our life principles and that it can be perceived in a very different way.

Within most American Indian tribes for instance, there is a prevailing idealization of the elderly in general, with common practice of worshipping their wisdom and moral standards. In some cases, the elder with dementia is viewed as a person who is even more honourable and wiser, achieving a high spiritual knowledge. His unclear, incoherent speech and unexpected changes in behaviour are, clearly, equally demanding and hard to understand, but they are generally accepted as a sign of being in a different world, with unknown language and different customs. Within most tribes, although there are slight differences, dementia is a state in which the person is already half way in the next world. It is a state where the spirit has already proceeded into the spiritual, peaceful world while the body remains and prepares to leave. Caring for such a body is therefore considered an honour and represents a sacred work. Dementia is hardly ever considered an obstacle but rather an unquestionable plan and intention of the Creator, given to a person for ultimate learning. As such it does not require any intervention and any form of prolonging this process is considered unnatural since it prevents the spirit from leaving, when its purpose is accomplished.

26 Dementia, Design and Technology: Time to Get Involved, 24.
27 Lori L. Jervis and Spero M. Manson, “American Indians/Alaska Natives and Dementia,” Alzheimer Disease and Associated Disorders 16, no. 2 (2002).
28 MSN Leanne R. Hendrix, RN, GNP, PhD, "Health and Health Care for American Indian and Alaska
Western medicine, on contrary, tries to keep the body alive for as long as possible while the spirit might be already gone. Whether it is correct or not, the fact is that both the spirit and the body, using the dualism of American Indians, naturally need safe and suitable environments to live and leave peacefully. In this light, it no longer matters how modern-looking the space is and whether it follows today’s trends. On contrary, architecture has to strip to its fundamental qualities to provide strong and confident support to this subtle, frail process.

2.1.4.a Transitions

Another comparison with cultures and societies such as American Indians sheds more light upon our understanding of the topic and life in general. Divided into stages as we grow up, life offers discrete challenges and difficulties in each one of them. Whereas within the native Indian tribes, transition into every significant period of life is marked by a certain ritual and celebration, such rituals are slowly disappearing from our rushed society and none of the phases is fully recognized. It is neither celebrated nor clearly marked and as a result, people cannot truly identify with any of them or progress successfully to the next. Because there is no recognition of passing on to the next phase, some of them are neglected and almost feared, especially the last one.

With elderly, the transition is often hard to accept because the old age is, on contrary from the Indians, not recognized as a significant or relevant period of time. It is often underestimated and old people are generally thought of as no longer useful. Their wisdom is very little recognized and their potential is often not taken into account. Already speaking about older people but not to them suggests that they are not seen as active and jointly responsible members of society. Because this phase of life is not given enough recognition within our society, it is hard to deal with. Talking to various elderly showed that moving to a nursing home is usually thought of as an abrupt jump into a terminal stage of life which has no importance. It is often considered as a sign of losing control and influence.

Despite their old age and some disabilities, old people as well as people with dementia have a lot to teach. Not only they know stories we do not and possess valuable experience and knowledge, but they also offer a unique opportunity to think about life and its values. Slowly, people are starting to be interested again in old traditions and crafts where elderly offer a strong link. Few initiatives are arising, trying to bring elderly and young people together. Nursing homes are however not commonly designed to be a place for such sharing. On contrary, they often close old people off from the society with no chance to contribute. It is especially wrong because even in the late stage of the disease, there is a lot to learn from. Be excluding them, dementia becomes something distinct and uncommon to majority of the society while it is an important part of life of many people.

Native Elders,” (San Francisco: University of California).
30 Feddersen, Lost in Space: Architecture and Dementia.
2.1.5 What remains?

Although person’s life is slowly deconstructed with the devastating impacts caused by dementias, there are things that remain till the very late stage of the disease. Based on an interview with Hester Anderiesen, who works on an extensive research on human experiences in different stages of dementias, it became clear that it is the experience of relaxation, reminiscence and sensation that remain the latest. Because they are present and consistent throughout all the stages, they can be worked with and contribute thus to the patients’ well-being. Although described as three different experiences, they always overlap and one links directly to the other.

2.1.5.a Sensation

Sensation, a meaningful sensory experience, is mediated by an area of primary somatosensory cortex. Clinical studies show that sensory systems appear to be relatively intact even in the sever stage of Alzheimer disease and some other types of dementia. There are theories that say we lose our knowledge, memories and abilities in a reverse order from how we acquired them. Our loss of senses is believed to proceed in an inverse pattern as well. Sense of taste and touch in infancy is developed first, earlier than sight and hearing, and most probably they also remain the latest. Sensory stimulation, especially touch is therefore a widely recommended strategy for non-pharmacological interventions. How environment can contribute to such experience is described more in a separate chapter 2.2.2.c Sensory stimulation.

2.1.5.b Relaxation

Through sensory stimulation, relaxation can be achieved. People are very sensitive to what they see around them even when they are no longer able to talk or move. Rear part of a brain, the visual cortex, responsible for processing visual information, is the last part of the brain damaged by dementia. It is one of the very few parts which functions right up to the end. As mentioned above, other sensory experience, especially touch and hearing can trigger feelings of relaxation as well. By processing familiar sensory cues, even memories may be activated.

2.1.5.c Reminiscence

Losing one’s memory is perceived as loosing identity and personality and as such it is greatly feared. Reminiscence however works with the remote memory which is mostly intact till a late point of the disease. It is generally assumed that during reminiscence, patterns of brain activity resembling the areas that were activated during the corresponding experience are reactivated. And because memories play a vital role in preserving individual personality and identity, it is worth evoking them by various means. By being familiar, including well know objects, textures, sounds and smells, environment can trigger memories and increase thus the well-being of people. This is further described in a part 2.2.2.b Non-institutional character.

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34 Shaun Nichols Stanley B. Klein, “Memory and the Sense of Personal Identity” (University of California, University of Arizona).
35 Anderiesen, “Play Experiences for People with Alzheimer's Disease”.
36 Alessia Cadamuro, “What Remains?: A Persuasive Story Telling Game.”
Dementia was officially accepted as a global health challenge in 2012 by the World Health Organisation and all countries were suggested to include it in public health planning. That gives a chance of better understanding and accepting this disease in the society. Nowadays, the topic of dementia and its impacts is still rather feared and not discussed enough. Fear of being diagnosed with dementia has recently overgrown the fear of getting a cancer and much more effort needs to be done to fully understand and accept the complexity of dementias.

It is becoming even more urgent as numbers of people affected are unfortunately constantly increasing, showing no decline. It is predicted that by the year 2050 there will be 135 millions of people with one or another kind of dementia worldwide, while today, there are 44.4 million people with known diagnosis of dementia. One of the reasons why the numbers are so rapidly growing is our aging population. The fastest growing group of our population consists of elderly people and at the same time, chances of having diagnosed dementia start to grow significantly with people above 65 years old. Below this age there is only a very small chance of having diagnosed dementia. If we therefore simplify it and consider only people older than 65 years, around 7% of them are affected with dementia today. These numbers are predicted to double every 20 years from now on, estimated to reach the amount of 135 million by 2050. Combined with estimations of population growth, the percentage will increase to 11.1%.

In 2050, it is a generation of my parents and us, ourselves who is predestined to encounter certain type of dementia directly or indirectly. Big part of us, our friends and relatives is believed to end up dependent on help of others. Already now there are 68% people in UK helping their older relative, friend or neighbour get by and the amount is about to grow. Most of the people will eventually have to be moved to some type of care home, which is a situation healthy people nowadays do not even want to talk about. The need for elderly living will however grow and therefore it is important to accept this societal change as a natural development and try to find solutions. Starting with changing our perception of dementias and disorders in general could help deal with the change better. Shifting our view on dementias, old age and buildings for elderly could significantly reduce fear and stress nowadays placed on the topic.

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41 Ibid.
2.2 Dementia and architecture

What is the reason why numbers of people affected by dementias are still growing is still a matter of research. Many say it is our current life-style, others mention genetic predispositions, and some say it is a mixture of all different aspects. Among others, environment is also officially recognized as a contextual factor by the World Health Organisation (WHO) in the International classification of functioning, disability and health\(^\text{43}\) and should be taken seriously, especially if we take into account the amount of people aging in caring institutions.

Considering the complexity of the topic and the many consequences of dementia, it becomes clear how complicated and sensitive designing of such place is. It expands beyond applying conventional design principles and accessibility norms into the design process. It touches upon more than just safety standards for elderly housing, and if not treated with a great care, it can easily go wrong. As a result of common stereotyping about people with dementia being stolid and no longer noticing their environment\(^\text{44}\), consequent spaces may become cold, unfamiliar and impersonal, closed ecosystems. By lack of knowledge about the disability of their users to justify and reason the built environment, they can cause them even more disability. With so many abilities and certainties slipping away, the support from the environment is enormously important as it can be one of the last thing demented people can relate to.\(^\text{45}\) Despite the stereotyping of being impassive, demented people are strong individuals with feelings, wishes, hopes and reactions. Designs for them should therefore look beyond the disease and acknowledge it just as one single part of a person's identity.\(^\text{46}\) Demented people have the same basic needs as any other person. They need beautiful, diverse, safe and well-designed spaces as well as anyone else. There are needs that start gaining more importance during the development of the disease, but even these are well know to all other people. Feeling independent, engaged and relaxed are just some of the needs environment should be able to adapt to.

Luckily, people are becoming more informed and interested in this topic. It is more common to realize that also architects are helping and trying to solve the problem. Although it is always a combination of factors that influences the wellbeing of patients, environment is certainly one of them. It cannot cure the disease nor it can stop it but it has means to ease the situation.

Before discussing further particular attributes of the environment that can do it, it is worth thinking about care homes and their role in general. Why these places are often feared and stereotyped about is a crucial starting point for improving the situation. Comparison with the theory of heterotopias offers a guiding hand.


\(^{44}\) Europe, “The Ethical Issues Linked to the Perceptions and Portrayal of Dementia and People with Dementia.”

\(^{45}\) Dementia, Design and Technology: Time to Get Involved, 24.

\(^{46}\) Europe, “The Ethical Issues Linked to the Perceptions and Portrayal of Dementia and People with Dementia.”
2.2.1 Heterotopias

Nowadays, the concept of losing memory of our loved ones and us ourselves makes people very uncomfortable and unless they happen to face dementia directly, they prefer to consider it a problem of someone else.47 The generally accepted idea of a care home, confirmed by people I talked to, is living in a place with no personal context, lost and dependent on others, isolated from the real life, and therefore rather feared.

In this sense, places for people who have dementia can be compared to Michel Foucault’s places of otherness, so called heterotopias of crisis and deviances. Michel Foucault, a French philosopher, gave a lecture to a group of architects in 1967 where he described heterotopias of crisis as places which exist on the edge of every society, temporarily accommodating people who are, in relation to their society’s rules and norms, in a state of certain crisis. These places are privileged, sacred or forbidden. Michel Foucault names adolescents, menstruating or pregnant women as well as elderly as examples of such temporary crisis. As he further explains, old age and its consequences is a crisis in a way, but considered its irreversibility and fatality; it is rather a so called deviation.48 Dementias and people affected can generally be thought of as deviant, with their behaviour diverging from accepted norms and habits. They are, due to the disease, unpredictable, with unexpected changes in moods, consequently hard to take care of and hard to control. As a result, the society excludes them, creating thus the heterotopias of deviance represented by care centres and elderly homes. It is a world in itself, presenting a society turned upside down, society of people who are out of control, not following any kind of rules as described by Michel Foucault. It is a world in itself formed by walls of the care unit and by the dementia. Care centres form a small version of a bigger, everyday life but not always succeed. Many times, they are still separated from the real one even though they are located in cities. If not designed and working well, they cut off almost every relation their users used to have with their former life. The environment can easily be uniform, providing very few opportunities to keep on with people’s hobbies. It can easily fail to offer enough variations for self-realization while being restricting rather than supporting, trying to prevent demented people from doing something, more than enhancing their interests. Because of too many bad examples there are, care centres are often considered a last place to go and never come back.

These presumptions make it difficult for people who have to move in as well as for those who only come to visit their loved ones. With our growing population care institutions are however going to be used more frequently than we might even be willing to admit. Since a significant part of our population will one day become their users49, they deserve to be viewed in a better light. They deserve to be designed and perceived as places for living and not as places for dying as they seem to be now. Although there are many bad examples which only increase this common opinion, there are also good ones. Focusing on them and creating more could slowly change the negative perception.

47 Ibid.
49 International, “Dementia Statistics/ Alzheimer’s Disease International”.

28
2.2.2 General attributes of the environment

Obviously, there still is only little known about what kind of environment positively influences people with dementia, and dementia in general is still not entirely understood. However, every step towards a better understanding is important since poorly designed places are not only unsuitable for people with distorted perception, but also questioned by healthy people. It is important that the environment is supportive towards its main users but also towards relatives and friends who come visit their loved-ones, and equally importantly towards the caring staff.

Fortunately, there are some crucial aspects that the environment can touch upon. Based on literature and own experience, list of such facets is made. It will be further used as a reference to evaluate case studies of the field research. Based on observations and cooperation with dementia patients, the list will later be extended and completed in chapter 3.1.4 Conclusions.

2.2.2.a Safety

Loosing many abilities, certainties and trust in themselves, people with dementia need a strong and solid support from their families, caregivers but also from the environment. Such a space should provide sense of safety and security at any moment. That contributes to greater self-assurance and a better quality of life. Only if a person feels secure in a place, he or she can freely do what they really enjoy. By compensating for defects caused by dementia, it can create a pleasant place to live, eliminate unnecessary stress and enhance the confidence of people. There are many ways environment can contribute to this sense of security which go far beyond using railings and being wheelchair accessible. Some of them are described below.

2.2.2.b Non-institutional character

In relation to dementia, architecture has the power to create a link between the presence and past. By being recognizable even in later stages of the disease, it can provide a sense of familiarity and normality. In that case, people can find familiar aspects of their living environment and the ambiance of how they lived for much of their lives. It is crucial that architecture creates this sense of normality to allow people relate themselves to it and accommodate their everyday routines and habits. Space allowing familiar actions helps people feel at home, although their memories of home vary from places where they had lived to people they had lived with. Many design guidelines therefore call for a home-like, personalized atmosphere. Particularly in case of dementia, achieving a home-like ambiance has been researched to improve peoples’ well-being as well as their mental and physical functionality, and social interaction. Through furnishing and personalization, overall anxiety can be lowered, exit seeking significantly reduced and patients’ agitation decreased. Creating familiar spaces and allowing for personal habits in the building can reduce the amount of confusion by providing cues that are rooted deeply in our memories.

50 Feddersen, Lost in Space: Architecture and Dementia.
51 Ibid.
Potential risk of a homely environment is described in various empirical studies and experiments. In such places, greater assertion of independence can occur. On one hand, it is a desired effect, but on the other hand it can sometimes result into a bigger restlessness.  

\textit{Reminiscence therapy}

\textit{Reminiscence therapy is one of the most popular psychosocial interventions in dementia care. It was introduced in the 1980s, and it is based on evocation and discussion with another person or a group about past activities, events and experiences, using a variety of supporting materials. This treatment is based on the assumption that remote memory remains intact until the later stages of dementia and may be used as a form of communication with the patient.}  

Environment itself can be one of the supporting materials for such a therapy. By being familiar, accommodating familiar actions and objects, local colours and materials, it can bring back memories that may seem to be long gone. Process of such a self-recovery and rediscovery can be very beneficial to people who suffer from dementias, because for that short moment they can be themselves again. In familiar environment, they know what to do and how to react which increases their confidence. Providing space not only for familiar objects and spaces but also for well known actions, their sounds and smells emphasizes memories and habits which they may still remember rather than pointing out things they no longer can.

\subsection*{2.2.2.c Sensory Stimulation}

When due to the disease, cognitive faculties are declined or lost, what remains are direct sensations. Although their interpretation of what they sense may change, people with dementia react to sensory stimulation till very long. \textit{“The primary sensory areas of the brain remain relatively long untouched by the neuropathology of dementias. Experiencing the touches, smells, movement, sights, sounds and tastes of everyday life can serve as an on-going source of pleasure, stimulation and method of communication.”}

Architecture possesses qualities and means to achieve such sensory stimulation. It however has to be done in a modest, comfortable way, as overstimulation very often leads to confusion, aggression, anxiety, distraction or low concentration. Too much distraction in terms of visual inputs, noises or happenings can contribute to even greater level of stress. Right balance between overstimulation and deprivation can offer something to each and every single patient. Although their personalities might seem to

\begin{itemize}
\item 54 Ibid.
\item 55 Maria Cotelli, Rosa Manenti, and Orazio Zanetti, “Reminiscence Therapy in Dementia: A Review,” Maturitas 72, no. 3 (2012).
\item 56 Feddersen, \textit{Lost in Space: Architecture and Dementia}.
\item 57 Day, Carreon, and Stump, “The Therapeutic Design of Environments for People with Dementia: A Review of the Empirical Research.”
\end{itemize}
be long gone, it has been researched and proved that even in very late stages of the disease there are still “islands of the self” left. These are small glimpses of people’s personalities that were crucial to whom they were in earlier life. Normally, they seem to be buried deep down in the dense cover of dementia but with the right trigger they can be brought to surface. Even though such a trigger is very individual and different for every person, they all share a particular quality; all of them appeal to emotions and senses. Being emotionally moved, helps people with dementia remember and be themselves again, even if for a little while. Triggers such as contact with people with a certain charisma or with a particular voice tone, hearing a familiar piece of music, sensing a particular smell, colour or sound, touching a specific material can help people relax to the point where words and memories simply pop out.

Talking to Henri Snel emphasized the importance of stimulation which is accessible here and now, without assistance. Well thought architecture can be a rich source of such accessible and natural triggers. Reducing unnecessary clutter and accentuating places which can engage people in stimulating activities creates a balanced diversity of stimulation.

**Snoezelen**

Multisensory environments, Snoezelen, work on a principle of providing range of visual, auditory, olfactory and tactile stimulation in order to create feelings of safety, relaxation and comfort. They are usually separated rooms where patients are brought to for a certain amount of time. They can then explore their surroundings in a comfortable way. Usually different interactive objects appealing to various senses are placed in the room, such as mirror balls, fibre optic curtains, bubble tubes and many others. Everything can be changed according to individual’s needs and his current mood.

There is a crucial characteristic which makes these rooms successful. It is the fact that they do not require any specific performance and as that they are failure-free. It is an extremely important feature because that is what makes them unique compared to most built environments for dementias. Designs based on rationality and cognition always requires certain level of physical and mental performance. That puts expectations on the patient as he has to achieve something beyond his capacities. Naturally, that leads to stress and embarrassment in case of failure. In multisensory rooms, there is no goal to be achieved and no expectations to fulfil, which reduces the level of stress significantly. Moreover multisensory rooms offer an enormous source of independency, which is much needed in institutional care where people have limited or no control of their environment. Patients can con-

58 Feddersen, *Lost in Space: Architecture and Dementia*.

2.2.2.d Way finding/ readability of the environment

To find a way through a building or through complex of buildings is very often difficult for everybody. If the building is not easy to grasp, each of us can get confused. Architect and environmental psychologist Romedi Passini defines way finding as ‘...a person’s ability, both cognitive and behavioral, to reach spatial destinations.’ With dementia, this ability is significantly lowered, because people are no longer capable of learning and remembering new things. Such loss of orientation in space can be a horrifying experience and people with dementia have to face it on daily basis. Their brain cannot work with cognitive maps anymore and the environment has to take that into account.

Even though it seems to be successful, there are certain aspects that should also be taken into account. As these multisensory rooms are separated, behind a door, they are not freely accessible. There always has to be an assistant, nurse or a carer accompanying the person. That is usually a problem due to the lack of staff in general. Moreover, as the effects and stimulations are of a high tech, artificial matter, they are detached from the natural reality people with dementia are used to. Sometimes it therefore takes time before the patient gets used to it and it can even evoke a completely different reaction from the desired one. People can get confused, stressed and anxious by the strange, unfamiliar environment.

2.2.2.d Way finding/ readability of the environment

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“The walker must commit the environment to memory, must remember the path already trodden, in order not to lose his way in the expanse of space. For people with dementia, this kind of experience of the uncanny can be a near-daily occurrence - the experience of being a stranger in an environment that presents challenges which exceed the powers of one’s memory.”

Some of the principles that help patients find their way and improve their orientation are already known. Empirical studies show that among others, smaller amount of people in one living area is a strong influential factor. The more residents there are the bigger decline in focus and orientation.

61 Benyamin Schwarz, Aging, Autonomy, and Architecture: Advances in Assisted Living.
62 Feddersen, Lost in Space: Architecture and Dementia.
63 Marquardt and Schmieg, “Dementia-Friendly Architecture: Environments That Facilitate Wayfinding in
Following passage from a Pattern language book well explains the problem in general: “The building is easy to grasp if someone can explain the position of his address to you, in a way you can remember easily, and carry in your head while you are looking for it. Straight layouts of circulations, no dead ends and as little changes in direction as possible are proving to be beneficial. Too many options in form of too many doors or too many decorations can cause confusion and loss of attention. On contrary, space with a clear composition which is easy to overlook reduces stress from not knowing where to go.

2.2.2.e Nature

One can never have enough of nature. There is never too much of any of its forms and people have always benefited from its presence. Nature changes during seasons, even during the daytime and never fades. It is also a natural indicator of time. It serves as a reference of what season and time of day it is, and as such it helps position oneself in time and space.

For every human being as well as for people with dementia, nature provides unique source of relaxation and stimulation. Access to nature relieves and freshens up every person and so it does with residents of a care home. Nature provides opportunities for walks, gardening as well as for meditation and contemplation. Well-structured and designed outdoor space which leaves space for all of these and others can enhance the quality of life to a great extent.

2.2.2.f Lightning

In old age, certain level of impairment, such as mobility difficulties or problems with hearing and vision, are natural. To help compensate for the latter, amount of light has to be higher than normal. Ideally, majority of light comes from a natural source as sunshine is not only pleasant but also beneficial. Since people naturally tend to move towards light, changing levels of light can serve as subtle cues for orientation. Creating alternating areas of light and dark within the building can enhance and guide people’s movements.

Enough daylight is important not only because vision in general is mostly impaired. With dementia, the circadian system, which dictates our day and night rhythms is also affected very early. Because it is responsible for regular production of melatonin, the sleep hormone, patients with dementia no longer get their nightly amount. As a result, some of them wake up during the night and wonder around with no rest. According to Dick Swaab, Dutch neuroscientists, even neurons which are affected can be restored with the right stimulation. With a balanced light strategy, biological clock of dementia patients can be enhanced and help them get their lost sleep. Reduce in light pollution during the night is essential but not always thought of. In combination with a healthy amount of sunshine and daylight during the day, sleep disorders may be reduced.

Nursing Homes.”

67 Swaab, “Alzheimer’s Disease.”
2.2.2.g Colour

Use of colour can play a vital role in strengthening an atmosphere of security and well-being. Use of typical local materials and colours helps link the place to its regional context and therefore makes it easier to dwell in and relate oneself to it. Colour however has to be applied in harmony with other forms, materials, textures and surfaces to create a balanced, understandable composition. Colour can enhance contrast between significant elements or softly mark a different zone or area. Such accentuation needs to be done carefully, not to be too overwhelming. Because careful accentuation of individual items and places is equally good as the principle of reduction, balance needs to be found. Reduction is helpful in ensuring that people have a clear overview of where they are but it also has to be used with caution.

2.2.3 Social needs and architectural means

There are needs that gain importance during the disease such as autonomy or dignity. Those that appeared in studied literature and which environment can answer to are described below.

2.2.3.a Autonomy

In well-designed settings, people with dementia can still maintain their independence. Within safe boundaries, it is possible to still use their remaining skills and give them thus a desired piece of autonomy. The environment doesn’t have to be deficit-oriented, preventing from mistakes and damages by not allowing any actions. It can, on contrary, enhance peoples’ remaining skills and inclinations. Except for the very late stages, every person has some remaining skills varying from cleaning, gardening or sweeping to knitting, cooking or serving. Everyone can contribute with his little piece if allowed. Unconditioned acceptance of people’s personalities and skills which looks beyond the disease can reveal other qualities beside the cognitive ones; be it emotional, sensitive or of a practical everyday nature.

Providing spaces for activities that people can still do gives them chances to feel needed and independent.

2.2.3.b Dignity

When having other people helping you with private, daily activities such as getting dressed, having a shower or using a toilet, there is very little dignity left. Very often, personal pride is scarified for the sake of safety and functionality. It is not ideal when already so many abilities, skills and achievements one can be proud of are slipping away. Preserving as much as possible of what is left of the person’s self-respect is important. Within institutional setting, this proves to be a struggle.

It becomes very relevant in bathrooms which are repeatedly marked as most stressful and problematic.

69 Feddersen, Lost in Space: Architecture and Dementia.
70 Benyamin Schwarz, Aging, Autonomy, and Architecture: Advances in Assisted Living.
71 Feddersen, Lost in Space: Architecture and Dementia.
tine, enhanced by the severity of the interior. Balanced designs, that offer calm and relaxed atmosphere, have the power to enhance the overall experience.

2.2.3. C Sense of belongings

If there are activities to join and help with, people will naturally feel more at ease and part of the whole. If everything is fixed and people have no chance to participate, it is much more difficult to develop a sense of belongings. Feeling responsible, needed and valuable in your surroundings is one of the fundamental conditions to feel comfortable and at home. Environment can prepare ground for such therapeutic concept where people are part of daily activities and have options to join or not.

2.2.3. d Privacy

Having a personal, safe space, with own belongings and familiar surroundings is important for everyone. Probably even more important it is for people with dementia living in a care institution. Their room becomes a whole world and the only reminder of how the person used to live. Usually, the modern trend in new care institutions is to accommodate people in single rooms with their own furniture and decorations. That way, they always have a space to return to, space which resembles home and recalls memories.

2.2.3. e Social interaction

Need of human contact is very important for every person. Although with dementia interest in other people gets significantly lowered, interaction with others is a ways to keep challenged and involved. Mutual communication recedes with progression of the disease, but there are means to enhance it. Accommodating people in small groups in which they have better chance to remember one another helps feel more relaxed. Within small group, people are more likely to take the courage and interact whereas in large crowd, they easily get intimidated, frustrated and anxious. Arrangement of rooms and furniture can help and guide people to a certain behaviour and so too it can accommodate an easy interaction. Providing cues for various actions in which people can engage together is a subtle but needed help. Alternating levels of privacy together with semi-public and public spaces creates different environments for different kinds of social activities and therefore everybody can find something suitable.

2.2.4 Conclusions

Fortunately, there is much information on the previously described attributes of environments and numbers of literature references agree on those. Despite the accordance, probably the most difficult thing about designing architecture for people with dementia is that there seems to be no single solution. Although some of the ways environment can provide support might seem rather straightforward, it is not as easy as it might look. There are many contradictions and with every principle there is another one questioning it. Just to illustrate: certain level of stimulation is needed but too much stimulation causes anxiety or confusion. Non-institutional settings create a home like ambiance but also enhance greater sense of independence of people which can sometimes cause problems. Too much freedom questions people’s safety and there are many similar examples.

74 Benyamin Schwarz, Aging, Autonomy, and Architecture: Advances in Assisted Living.
Furthermore, every person with dementia is a different person. That makes it even more difficult to find a common solution. Amount of literature that tries to solve it on various scales shows increasing interest in the problematic in general as well as in its relation to architecture. Following scheme illustrates how double-edged most of the spatial qualities discussed before are. It shows potential benefits as well as possible problems they could cause as described in literature.
However, although there is lot of expert research being done into dementias, this topic is still very much unfamiliar to the general public. People are often unaware of what the disease really is and what its consequences are. Besides the many jokes about Alzheimer’s no further information is commonly spread among the society. Unless people happen to experience the disease themselves, they tend to stereotype. People with dementia are often portrayed as a homogeneous group and many other misinterpretation follow. Because there is very little chance to actually meet and get to know people who have dementia personally, it is difficult to shape a different opinion. Current situation, in which people with dementia stay at home or live in a nursing home, does not provide opportunities for natural process of familiarization. Nursing homes being mostly enclosed institutions do not create opportunities for people to enter. People with dementia cannot freely go outside and because there is nothing of an interest for the rest of the city, these two worlds almost never meet. That way prejudices are created.

Importance of elderly in general and of elderly with dementia especially is underestimated and they are often pushed away behind walls of a caring home. No matter the disease or its stage, old people however have a lot to teach. Already a moment spent with a person who has dementia teaches a lesson. It may be an uncomfortable and scary lesson but it makes people reflect upon their own lives and their set

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Europe, “The Ethical Issues Linked to the Perceptions and Portrayal of Dementia and People with Dementia.”

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of values. Especially nowadays, when everybody rushes to catch up with their own and other people's expectations, this is a priceless lesson.

Very few studies I came across however talk about aspect of reversing the exclusion of people with dementia. Focusing on interior, organizational and spatial features, topic of transition from public life to the private sphere of a nursing home is often neglected. Old people need contact with other generations as well as young people benefit from meeting the elderly. Allowing for smooth, natural exchange of experience and knowledge through spatial configuration of nursing homes should therefore be attempted, although it might be hard to achieve. Not being a closed institution but rather a place of learning and understanding life with all its highs and lows, it could help reduce the stigma placed upon the disease and on people who face it.

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3. Part three

*Reality*
3.1 Site visits

3.1.1 Introduction

While in the Netherlands and during three weeks in the Czech Republic, I spent time in various care institutions. The final choice was very much depending on which institutions responded and invited me to come. Some were very positive, some declined, whereas others did not answer at all. In some that were positive about my visit I could spend the whole day to see the daily routines. In some I could only look through the building for a short while. Visited places varied significantly in sizes and organization but also in the general approach. Some of them were exclusively for people with dementia; some of them were a mix of senior housing and dementia care. Some were old, some built recently. Having the possibility to see different places, with different organizations, amount of people and design solutions gave me a chance to compare, and later create my own opinion.

Respecting peoples’ privacy, I was not allowed to take pictures of the interior if there was someone in the snapshot. It was therefore often difficult to document the buildings. In some of the places, I wasn’t allowed to take pictures at all. Amount of visual information will thus differ with each case.

Many times, descriptions of buildings may seem too critical. Noticing and analysing their defects has however helped me realize how complicated it is to create a suitable environment and how double-edged some decisions are. The overall feeling can sometimes seem rather negative but despite the shortcomings of the environments, it is important to say that there are many things to admire. During my visits, I could meet many of the nurses, social workers and even volunteers. Their job is difficult, demanding both physically and mentally and still, they are always positive, always caring and very strong. Every day, they are doing their job for a very low salary, but with a very big amount of love. They are without any doubts more important than the building itself because they are very often not just a caregiver, but also a friend. They provide support at any time and very often they are the only company people have left. They guide the patients through every day, without hesitations, many times all over again.

Unfortunately, with the extremely low amount of money they are paid and both physical and mental demands of the job, there are not enough of them. That means they are very busy each and every day, spending time on unnecessary activities. They are under lot of pressure and often stressed. With buildings being often large in scale and numbers of people, their working conditions are even more difficult.

This research is focused entirely on buildings, their layout and possibilities they offer. None of the comments is meant to criticise work of people involved and all descriptions are detached from the great work people do. Buildings will be described chronologically according to the order of my visits. In order to be able to compare and gain some main principles, I will describe each using the previously mentioned attributes of environment which are the following: Safety; Non-institutional character; Sensory Stimulation; Way finding; Nature; Lighting; Colour; Autonomy; Dignity; Sense of belongings; Privacy and Social Interaction.
3.1.2 Site descriptions

3.1.2.a Senior housing U Kostelička

Located very close to the city centre, next to a small baroque church after which it is named, it is the only institution in the city of Pardubice which offers services to people with dementia. In its function, it mixes a regular senior housing with dementia care unit although spatially these two are separated.

Non-Institutional character

Senior housing u Kostelička differs from home and resembles a hospital in different ways. In order to get inside, one has to enter through an automatic glazed sliding door that leads to a reception. Already such a small thing makes a difference between the essence of a public institution and home. Sliding door evokes everything, ranging from a shopping mall, office building to a hospital, but not home. There are separate departments stacked around a courtyard. They consist of several buildings (Fig. 1) whose units are marked with letters and numbers. One can only enter the unit he is related to.

There is a separate department for people with dementias and like in many other buildings, it is organized in a central corridor and adjusting rooms. Such corridor serves as a substitute for a living room but never succeeds to really do so (Fig. 2). To compensate for the spatial imperfections, there are elements trying to evoke living room like ambiance. There are chairs and sofas scattered along walls, television and an aquarium. It is however impossible to conceal the character of a corridor, where the sofas face an empty opposite wall. Such a setting is neither familiar nor comfortable. When sitting in one of the chairs, there are many disturbing activities around. Other people are passing by, patients are walking back and forth, nurses pulling trolleys, visitors coming and leaving. There are no activities to join at any time but watching a TV.

Small kitchen and a workshop room are located behind a corner, and although they resemble a homely environment the most, almost no one gets there. Because the patients do not have a visual contact.
with these two rooms, because it is hard to remember the way, and because there are many distracting elements along the way, they are almost always empty. Instead, people spend most of their time in the corridor.

![Fig. 2 Corridor as a living room](image)

**Sensory stimulation**

In the corridor, there are many elements but most of them are unfortunately rather confusing than stimulating. The only two things some people seemed really intrigued by is a TV and an aquarium. The sofa facing the aquarium was the one most used and some of the patients stayed for a very long time, silently watching the slow, fluent movement of the fish.

Animal care is generally recognized as having positive influence on people with dementia. Mostly dogs are used for that matter as loyal companions as well as a source of tactile stimulation. In case of a dog, the contact is often limited by time and both parties have to be supervised. Aquariums, on contrary, offer an unlimited source of visual stimulation and interaction. They are safe and cost-effective, with no assistance needed. Although not many studies have been done in this direction, significant decrease in problematic behaviour such as restlessness, aggression or anxiety was discovered in the few carried out. Their results emphasize that animals including fish can have a calming effect on people even in the severe stage of dementia.\(^\text{77}\)

Another significant source of stimulation was a television. This element repeatedly appeared in most of the places I visited. That is why I will elaborate on that more because when recognized and understood, some of its principles such as accessibility and effectiveness may be applied to a design.

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**Television**

Given its accessibility and certain catchiness, many people in care homes spend time watching the television on a daily basis. For many of them, it had been a regular part of their lives before they moved to the care home and provides therefore a certain link with their past habits. 78

In many facilities, it is usually turned on the whole day as an effective diversionary activity when the caregivers are busy with other activities. Very little research has however been done to find out what effects it has on human mind, on the quality of sleep, and whether people with dementia benefit from it. 79 When the television is turned on constantly, different programs are displayed and very little attention is paid to their actual content and its impact on the patients. Although it gives a sense of human contact and social interaction, sometimes it can be misunderstood and the characters thought of as real. There are almost no studies at all showing what such confusion evokes in patients with dementia.

It is an easily accessible source of stimulation with visually attractive pictures and realistic sounds and music. Some of the few studies that were done however show that while watching a TV, most people with dementia doze. As they usually cannot follow the plot, television only serves as a stimulating background. Whether this could be used to improve their sleep during the night or whether, on contrary, these small naps cause night sleeplessness is still a thing to research on. 80 Television is on one hand an effective tool of distraction and occupation in case the nurses are required elsewhere but on the other hand, it prevents people from socializing and participating in other activities.

Its magic however lies in its everlasting attractiveness and availability. It is a never ending source of stimulation, accessible to everyone at any time.

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**Way finding**

Size of each dementia care unit within the complex is rather small. That compactness contributes to better orientation because no long routes have to be walked or remembered. Toilet is safely reachable and labeled with a picture. Unfortunately, almost no further effort is made to make it even easier for the residents to find their way. The many doors leading to rooms, to nurses’ station, to bathroom, to the toilet or to the kitchen all look the same and it is therefore difficult to distinguish the right ones. Patients’ rooms are labeled with their names but written form is only helpful to some of them. There are no signs or pictures that would make it clearer. As a result, people enter each other’s rooms in an endless search for their own.

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80 Ibid.
Nature

Besides the aquarium, there are no natural elements inside. Outside, open to the entire facility, there is a courtyard with small trees but most of the surface is paved and there are cars coming and leaving (Fig. 3). People usually come for a smoke but otherwise it is empty most of the time. From the dementia care unit, there is no direct access to the outside and residents cannot leave without assistance. Because nurses are busy with many daily activities, there is hardly ever time left to walk the patients outside and so they mostly stay in.

Fig. 3 Common courtyard

Lightning

Due to its organization with a corridor in the middle, the unit is rather dark. There are windows only at the end so the amount of daylight is very low. Most of the light is provided artificially which is a poor substitute for the beneficial effects of daily amount of sunshine. Concerning the rooms, each has a window and is therefore well lit.

Colours and materials

As in many other facilities, rooms are toned into yellow/orange colours. Despite the fact that researches often show that people with dementia incline towards white colours with accentuated elements\(^81\), there is a tendency to paint the walls in warm colours in many care homes. With that decision, contrast between single elements is lowered and therefore it is less clear for people with dementia.\(^82\) Floors are very often made of materials which are easy to clean but at the same time, they are reflective. It is well known that reflections on a floor can cause confusion, be thought of as water and feared.

\(^{81}\) Marieke de Boer-Lootens, "Wonen Voor Ouderen Met Dementie" (Graduation report, TU Delft, 2014).
Autonomy
Within the small space of the unit, its residents are free to move around as they like. Some of the door are however locked which often evokes frustration and confusion. No one is allowed to leave as the door is locked with a code. Besides some group activities, there is nothing people could engage in or help with. Meals are brought in on trolleys from a central kitchen. That might save time but it eliminates an opportunity for the people to help with preparation or serving.

Sense of belongings
Because there are no daily routines to help with, people can barely accommodate their habits and routines. They have very few chances to feel needed and responsible for their place. They are taken care of and also the environment is cleaned, prepared and decorated by someone else. There is nothing to do so most of the time people just linger instead of doing something that would make them feel relevant.

Dignity
Given the fact that each room accommodates two or even three people, dignity of each one of them is questioned. Everyday routines such as changing clothes or changing diapers occur in front of the others and that naturally leads to feelings of humiliation, shame and discomfort. Although the nurses do their best, respect each and every one of the residents, spatial conditions are often stronger.
From every unit, there is a staircase leading to another floor. For safety reasons, it is not accessible to the residents. This blockade is however done in form of a grate which is not a very sensitive way to restrict access.

Privacy
Sharing a room with other people causes multiple problems. First of all, in the whole unit there is then no space to be alone. There is no place to be oneself. There is always someone else, be it another patient, nurse or someone`s visit. Being on your own is an important activity in every stage of life for every person and it is equally important for people with dementias.
Furthermore, the shared room itself cannot be personalized to the patient’s liking and character because compromise has to be found. Rooms are therefore generic and each patient can only bring some minor elements, such as pictures or flowers.

Social interaction
Due to high amount of shared space, people are always accompanied by others. That however does not directly lead to their mutual interaction. There is no quality space for people to be together or an activity through which they could meet and get closer. Layout of furniture does not accommodate socialization and there is nothing people could unwittingly do together. As a result people mostly pass by one another in the corridor without engaging in any meaningful activity.
Safety

There are no railings along the walls which can cause problems in case of loss of balance. Together with many loose elements in the way, the space does not provide enough solid support. There are trolleys which move if one leans against them and many loose door wings.
3.1.2.b Hospice Chrudim

Although not designed exclusively for dementia patients, hospice Smíření in Chrudim is a very clear example of how environment and attention to its details matter. With the primary goal to achieve a healing environment through simplicity and functionality, experienced psychiatrist together with her colleague, recognized orthopaedist, started a mission to initiate a new project of a hospice. Thanks to their determination, the building was finished in 2009 after a long struggle to find financial support. Based on their practical knowledge, they both knew what they wanted to achieve, and managed to imprint their experience into the resulting design. Their desire for a functional, well-organized and efficient space paid off. At the first glance, the whole place might seem a little too severe and impersonal, but when the first sunlight enters through the vast openings, very peaceful and calm atmosphere takes over.

Fig. 4 Clear and bright shared space with large openings and a fire place

Non-institutional character
Because of its function of a hospice, medical assistance is often needed. That requires professional equipment which is not usually used in a regular elderly home. For the same reason there is a doctor all the time and in that sense, it resembles a hospital. Although it therefore feels a lot like an institution, it is designed in a very sensitive way. Because it is considered rather a peaceful place to die, lot of attention is placed on creating a calm, quiet atmosphere. The purpose of the environment is not to provide a home but a place for calm conciliation and departure from this world. This aspect is often forgotten in elderly homes despite the fact that as the disease approaches its late stages, spiritual side of life gains importance.

Sensory stimulation
The whole space ingeniously steps back and provides thus enough space for the patients and their conciliation. Stripped off all decorative, unnecessary elements, it emphasizes some fundamental qualities
and brings attention to simple, yet very crucial elements. Above all, it is a fire place in the middle of a spacious hall as well as every single window with a view to the countryside (Fig. 4). There are no obtrusive elements. It is quiet. It is peaceful. One can almost hear the fire in the fire place or the wind outside. Thanks to being very quiet, not disturbing or over stimulating at all, it creates a calm working environment for the doctors and nurses, and that again comes back to the patient. Many reports showed that although designed for people with advanced incurable disease, with a life horizon of no more than few weeks, many of them got better and had to return to a regular nursing home. Although for people with dementia, especially in the early stage, this environment would probably be under stimulating and not challenging enough, some of its principles, such as accentuation of certain elements, framed views are equally relevant in dementia care.

Way finding/ Readability of the environment
Thanks to its size and two major meeting points, it is very easy to find a way. The area for patients only spreads out on one floor which makes it easier for them to accommodate and dwell the space. Because there are mostly patients with cancer, no special steps are taken to distinguish particular door or rooms. There are two spacious meeting points where all the beds and wheelchairs can be brought and where everyone can enjoy the company of others. One is in the interior, winded around the fire place, whereas the other one is located outside in form of a terrace (Fig. 5). Also here, all the beds are often brought to allow the immobile patients enjoy sun and fresh air. These two spacious spaces provide not only a chance to meet with others but they also serve as points of orientation.

Nature
Every room has a balcony with a pleasant view. Windows in the shared space are very large, forming a solid frame around the nature behind. There is a direct access from the common space to the outside. Continuous path leads through the garden where trees are planted in a felly pattern. Each pointing towards a particular vista or landmark, they guide the walker along his stroll.

Fig. 5 Residential floor plan

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Lightning
Due to generous openings and big amount of roof windows, the space is filled with vast amount of natural light. This lightness contributes to the overall clarity and quietness of the place.

Colour
Within a modest pallet of unobtrusive white light colours, core elements are accentuated. Light colours are kept in the patients’ rooms as well to give space to all their personal belongings. Philosophy behind the design is such that patients are those who bring colours and life to the space. According to that, there is almost nothing in the shared space but the patients.

Autonomy
Because in this particular facility, people are still independent and self aware, there are almost no limitation apart from medical ones. Patients are free to move around, leave and come as they like, participate in activities or stay in their rooms. Given their disease, most of them prefer the last option. Vast majority only stays for less than a month so in many aspects in cannot be clearly compared to elderly in care home.

Dignity
Everybody can spend time according to his or her current state of mind and body. There are no restrictions and no obligations. People have their privacy, possibility to be with others, accessible outside space. They can come and go whenever they like if their disease allows. Every room has its own bathrooms and toilet which gives people more privacy and independence.

Sense of belongings
Because the purpose of a hospice is different from the one of an elderly home, its functions differ as well. There are no regular, everyday like activities to participate in which would help people feel at home. The main purpose is to provide people, mostly with cancer, a calm place to reconcile and therefore it cannot be compared to an elderly home.

Privacy
There is a strict division between public and private. While in their rooms, patients can personalize the space to their liking, the shared public space remains clear. In their rooms, patients can accommodate visitors as there is one extra foldable sofa. Having a private space where the family or friends can be together is an important element often missed in elderly homes with shared rooms.

Social interaction
Several “islands” are created around simple objects. The most important one is the central fire place which not only helps heat up the building and saves tremendous amount of costs, but also creates a natural place for gatherings. Spacious windows and their low sills provide favourite places to sit. One is

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located next to a piano and the other one has a library. The two corners are a frequent spot for informal meetings of residents. No one is forced to interact and most residents prefer to stay alone but those who want are provided with subtle cues of where to sit and what to do.

Safety
There are railings along all the walls. The space is well lit which contributes to the overall clarity and safety.

Other impressions
In comparison with senior housing facilities I could see, there is one extra element. The whole space already possesses a high spiritual value in its simplicity, but it also transforms it into specific architectural places. Small chapel and mourning room for families, whose loved ones have just gone, offer a chance for quiet and very private moments. Because there is also a morgue, the whole ceremony can be performed without any inconvenient rush and transportation.

In other visited facilities, the passed away person mostly stays in his or her room which results in problematic coordination of the remaining residents. Usually, people live in two, and therefore the other person has to be moved temporarily. Later, after a doctor and a morgue are arranged, he or she can return. This is obviously quite a sensitive and stressful occasion if there is no proper way to react on it. Because it happens regularly and it is a normal part of nursing homes’ life, spatially smooth and sensitive ways to deal with such situations are needed.
As many of Czech senior housing facilities, this one was also originally built with a different purpose. Constructed in late 70's, it served as a mass and cheap accommodation for workers. Later transformed into a senior housing, it still bears many aspects of its previous function and therefore sometimes stumbles to meet the needs of its new residents. Wrapped around a central courtyard, it offers its services and help both to seniors with lowered mobility and independence as well as to those with lowered cognitive abilities.

Non institutional character
Although there is a reception behind the entrance, the door itself is a regular, heavy door. Some of the residents who are still independent are allowed to leave to the city if they like and the reception is a good way to keep track of that. Because of its size and organization, the building reminds of an apartment block with separate flats and shared circulation. Enormous effort is put into providing as much independence, freedom and respect as possible to every client, but sometimes the size of the building does not complement that. Within the private rooms there is a big homey ambiance. On contrary, long corridors do not provide any sense of home or familiarity at all (Fig. 6).

Sensory stimulation
These long corridors, facing a courtyard on one side, hold access to many private rooms on the other. Despite the efforts put into their differentiation by colour stripes, the corridors all look the same. Because there is nothing of an interest directly accessible, people tend to spend as little time in the hallways as possible. There is no stimulation and people only happen to be there when they travel to the canteen on the ground floor or exceptionally, when they want to go for a short stroll. No stimulation is directly accessible and the corridor does not engage people in any action. As a result, all the available stimulation in form of an art workshop, chapel or a small cafe are not used on daily basis. They are far away, scattered along floors, out of reach and therefore only used by minority of the residents.
Regular and walk-along interviews described in a chapter 3.2.3. Extended research in the Czech Republic showed lack of interest in what is going on in the floor. The same happens with little sitting places in the middle of each hallway (Fig. 7). Although prepared for people to gather and chat, these spots are almost always empty. They merge with the corridor by means of the same floor pattern, wall colour and atmosphere. Decorated with artificial flowers and random pieces of old furniture, it is a very tangible proof that it is not enough and that even though with dementia, people still recognize what is pleasant and what is not.

![Fig. 7 Sitting alcoves in the corridor](image)

During my visits I was asked to come up with small interventions which would improve these alcoves and make them more popular among the clients. It is now in process and first one should be realized in summer. I am extremely happy to have this opportunity not only to test my research in practice but mainly to see that people are interested in this topic. It is very encouraging to see that they are positive about changing the environment to better serve the people.

Way finding/readability

The biggest downfall of the building is its organization within floors. Single floors do not form an independent unit but are interconnected by various activity rooms. On every floor there is a different one, art workshop, library or a chapel. In order to participate in particular activities in each of these rooms, one has to set on a journey beyond his or her capacities. Having to remember a way to another floor proved to be extremely difficult if not impossible during my walk along interviews. Starting with the long corridor where there is an endless amount of the same looking door, through an elevator with numbers, towards another, identically looking corridor. Doors are not significantly marked which makes it hard to find them among the many others.

Even if people took the courage and managed to arrive to the right place, their way back is equally difficult. Door to the rooms all look the same, labeled only with a name (Fig. 8). This can work for people with lowered mobility but less for people with lowered cognition. However, even people who are still independent and healthy in mind often do not dare to go out of their room on their own. No one of the elderly I talked to visits other floors unless he or she has someone to visit there, which unfortunately happens very rarely. People therefore do not have an access to stimulation and activity almost of the time they stay in their rooms.
Privacy

No matter the diagnosis, everyone has his or her own room (Fig. 9). For married couples or newly found partners there are few rooms that offer a possibility to live in two, but most of the clients deliberately remain living alone. Based on an extended research that is further described in a chapter xxxx I had a chance to see that with every door, it is as if you entered a little world. Whole life of a particular person is packed into one room in its miniature form. Some are flooded with objects; pictures, calendars, flowers, clocks, books, while others are very modest. Some are messy while others perfectly clean. Some smell of coffee or flowers, some do not. With every single person there is a unique and a very personal kingdom; kingdom of memories and a reminder of how the person used to live. There, they feel safe, surrounded with all their belongings. When asked about the environment, they are usually extremely happy to live alone in their personal surroundings, with the possibility to do whatever they want. However, very few of them are happy. When asked about what is missing to feel at home, all of them, without knowing the answers of others, said it was the company of people.
Social interaction

Although very personal and safe, every single room is also a kingdom of solitude. All the people I had the chance to talk to and work with spend most of their time in their room. Except for the meal time, they hardly ever go out. They are too scared and very little motivated to go outside and seek for activities. Because these activities are concentrated in specific rooms and hard to find as described earlier, very few people dare to go. There is nothing appealing directly behind the door, in the corridor, which makes people stay in their rooms. Their ability to initiate an action is lowered or lost due to the disease and if the nurse or environment does not start the interaction, they remain inactive. As a result, they lack social interaction which is a valid source of stimulation.

Nature

Inside the building, real plants are sometimes supplemented by artificial ones because of safety reasons. There are however plants that can be implemented safely and contribute to a nicer environment. On contrary, there is a garden behind the building with many herbs, various flowers and a stream providing auditory stimulation. Place for a barbecue, or a small quiet corner, all is there, accessible to everyone. In the middle of the building there is a courtyard with a rather calmer environment (Fig. 10). Despite the diversity and quality of the outside spaces, few people go out. Because of the layout of the building and its many floors, outside nature is difficult to access.

Lightning

Thanks to the courtyard in the middle, all the long corridors are mostly well lit. Also each room has a sufficient amount of daylight.

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86 M. Arch. Margaret P. Calkins, Design for Dementia; Planning Environments for the Elderly and the Confused (Maryland: National Health Publishing, 1988).
Colour and materials

During my visits and time spent with the patients, many times I could see their confusion and difficulties when colour of the floor changed. They treaded very lightly, with sudden caution as if they expected a step or a gap. With every change of material, colour or reflection on the ground, I could see their hesitation. Mostly they couldn’t explain what they are scared of but many of them reacted the same way. The same happened here where the floor pattern changes with almost every step. Furthermore, the floor reflects a lot of light, resulting in a water-like surface (Fig. 11).

Fig. 11 Floor pattern and reflection

Autonomy

Most of the people are still capable of independent life as they only have difficulties with mobility. That means they can leave any time they want. They can go shopping, visit their families or just go for a walk. Because there is a guided entrance, no one can leave without being seen.

Although there is a small kitchenette in every room (Fig. 12), almost no one uses it for cooking. There is a central canteen on the ground floor but meals are prepared in a separate kitchen. The small kitchenette however gives people a chance to welcome visitors with a cup of coffee. It might seem as a small unimportant detail, but the fact, that people can be in charge of something and that they have something to offer means a lot to them.

Fig. 12 Kitchenette
Dignity

Thanks to living alone in a very personal space, people feel secure and quite independent. They have their own toilet and bathroom which reduces feelings of humiliation. The whole complex works rather as an apartment block where everybody is responsible for his or her own flat. People are given as much freedom as possible and are not pushed to do anything they would not like. If they do not feel like having a breakfast with others in the common canteen, they can eat it alone in their room. If they do not want to participate in group activities, they do not have to.

Sense of belongings

Because their private rooms are very personalized, people feel like at home. Talking to few of them proved how much they appreciate this individual space of theirs. While in their privacy they can dwell and accommodate their habits and interests, in the shared place it is more difficult. There are no activities to join or daily tasks to help with. The corridor space is uniform offering no opportunities to meaningfully live in. As a result there is a sharp contrast between a very personal private space and an impersonal shared one.

Other impressions

On the highest floor, Christian chapel is located. Lit by roof windows, it holds a very strong atmosphere. It was therefore surprising how very few people use it. Talking to a group of residents revealed some reasons why. Due to the large distances within the building and its floors, some people did not even know there was a chapel. The rest felt inappropriate using it because of not being Christian. Although Czech Republic is believed to be one of the most atheist countries in Europe, people have their beliefs. Some spiritual place to contemplate and calm down the mind would be welcomed by the residents but is missing in most elderly homes.

*Extended research was done in a senior house in Praha 9. I could see the whole space, its everyday life as well as meet and work with some of its residents. This part of the research will be discussed in a separate chapter 3.2.3 Extended research in the Czech Republic*
3.1.2.d Day care centres, Prosek and Delft

Atmosphere in day care centres that I saw felt more relaxed compared to normal care institutions. The function is slightly different, both carers and people with dementia come in the morning and everyone, including the staff, leaves again around 5pm. The fact that everyone goes back home to retreat and recharge seems to reduce the amount of tension and stress. People are in small groups and because of that, there is enough time to spend with each and every client. Because both day care centres I could see were very similar, I will describe them together.

Non-institutional character

Both day care centres were formed by one main space which constitutes for a living room together with a kitchen and a dining area (Fig. 13, 14). That way it is very familiar to all the clients, they know what to do and it is comfortable. In both cases, people were encouraged to bring some pieces of furniture, decorations or something of their own to make the space even more familiar.
Sensory stimulation
Thanks to the informal character, daily activities take place with the help of people. Through cooking, baking, painting and many other activities, motoric is trained and senses are stimulated. Natural smells occur during the day and form a familiar reference. Thanks to regular everyday activities, people are constantly reminded of their past lives and habits, and are helped to maintain them.

Way finding/readability
Given the small, compact size of the space, it is very easy to live in. There is no other destination to remember as people spend their day together in the living room. This one space is easy to overlook both which helps both the clients as well as the personnel.

Nature
Both centres had a direct access outside (Fig. 15). Various types of pot gardening, walks, sunbathing and even fishing (Fig. 16) offer a diversity of outdoor activities to choose from. Because of the small amount of people, it is easier to go for a walk and people get enough of physical exercise.

Lightning
Thanks to big openings, access to the outside, both spaces were well lit with daylight.

Colour and materials
Light colours and modern furniture were prominent in both centres. Bright colours gave space to decorations and to people themselves, and made it easier to contrast and accentuate important elements. What was mentioned by nurses was the need for more contrast between floor and furniture as well as less reflective floor materials.
Autonomy
Because people are in small groups, gathered in one common space, there is time and space to talk to each one of them, play games, train memory, go for a walk etc. No one is in a hurry and everything is rather informal. If a person doesn't want to participate, no one will force him. Everyone can decide if they want to be part of the activity group or not.

Dignity
With this freedom, people can still feel independent and responsible for their own decisions. Everyday practice in daily activities enforces their confidence.

Sense of belongings
Although not living there, people can engage in all the daily activities (Fig. 17). They can help cooking, grooming, gardening which is both a therapy as well as a way to make one familiar with the space. People are given space to decorate the place, to adjust it and live in it as they like which makes them feel at ease. Inhabiting the space through actions and decorations makes people feel as if it was theirs.

Privacy
In a day care, people are together the whole day. They can decide to join activities or not but they still remain in the space together. There are sleeping rooms where people can get some rest if they like or they can just walk outside to the terrace. What is however very important is that at the end of the day, everybody returns back home to their private zone. Everyone returns to their personal territory where he or she can relax and recharge. This change of surroundings, atmospheres and environments is extremely important but very hard to achieve in a purpose made settings of an elderly home. There, although every person with dementia has his or her private territory in form of a room, it is still within one building, with the same people, with the same atmosphere.
Social interaction

When everybody comes from their real homes, there is plenty of time to enjoy the company of others while doing various activities. People told me they are looking forward because they have the option to do so. They are looking forward because it is something special which they cannot experience at home. They prefer to go and be with others because they also have the possibility to compare it with the option of being home alone. All of the people I talked to said they prefer to come because they get to interact with others through many different activities which they never could at home.

Safety

Small size of the space helps the nurses to comfortably watch over everyone (Fig. 18). Thanks to that, people have quite a high level of freedom while still being safely guarded. Both centres I saw were wheelchair accessible. Because there were no long distances to be walked, no railings was used. Solid furniture served as a support in both cases.
Today's Home for the elderly in Zahradní město in Prague, formerly known as a Department of Social Welfare - Retirement Home, consists of three buildings and forms a big complex. The oldest and biggest part built in 1969 is a representative example of mass care complexes, announced and built to be available to every citizen of a Soviet Union. According to the communist regime's policy to provide social service to everyone, first clients lived crowded in two or four bed rooms. To save money and space, these rooms were unfortunately very small and not at all corresponding to today's standards. Luckily in 2007, the capacity of this building was reduced from four to three beds per room and nowadays, with new health standards for elderly housing, all the rooms are doubles. New part was built in 2010 and nowadays third one is almost finished. There are 93 places for elderly and 146 for elderly with special needs, mostly with dementia.

Fig. 19 Main entrance

Non institutional character

Because of its age, history and size, the oldest building looks rather scary from the outside. It definitely does not give an impression of being welcoming and homely (Fig. 19).

Fig. 20 Facade of old part

It is a five-story high building (Fig. 20) still organized into a simple layout of a central corridor with clients' rooms on one side and service and common rooms on the other. Staircase is located in the middle and joins all five floors. Extremely long corridors have nothing to do with a comfortable atmosphere
and enhance thus the unfamiliar, institutional feeling. Rooms are shared in two and therefore not completely personal.

Way finding

Because of the many rooms on one floor, the corridor is extremely long, which was proving to be frustrating both for clients and nurses (Fig. 21). Clients are wandering back and forth, forgetting where their room was. Nurses reported to get anxious when literary having to see how much work is ahead of them. Everything is far away and out of reach, some clients have to walk quite far to reach their destination or to enjoy company of others. In this building, a separate floor was established for clients with a need of intensive care and support in 1996, but no changes were made so far to improve the environment. As a result, patients find it hard to orientate themselves in the long, indifferent space and are therefore often frustrated and wandering. The end of the corridor is almost invisible with no precise destination at the end.

Second building is a new one, finished in 2010, and the difference is clearly visible. Rooms are bigger, corridors wider and shorter. It is in general more spacious and less frustrating but still, the corridor possesses no meaningful value (Fig. 22).

Despite the unfortunate length of the main corridor there is one thing that seems to work quite well. Alongside, there are few places left out, with no rooms. Therefore, the corridor becomes wider and
provides space for informal meetings (Fig. 23). Social activities and various therapies take place in these places. Everyone who passes by can thus freely join without having to search for the correct door. They can be seen while walking around and therefore easy to find. As such these niches serve as points of reference and provide a source of stimulation.

![Fig. 23 Shared space in a corridor](image1)

**Sensory stimulation**

In order to make the shared space of the corridor more appealing, walls are decorated with various elements. This was a common approach in most of the elderly homes but almost never successful. Depending on the nature of decoration, it was mostly either confusing or hard to understand. Boards with notifications, schedules of activities and different reminders are only relevant to people in the early stage of dementia who usually form a minority in elderly homes (Fig. 24). Most of the patients come in the moderate or severe phase when reading and understanding of the written text is nearly impossible.

![Fig. 24 Decorations and notifications in a corridor](image2)

When there is no therapy, people spontaneously tend to gather in the niches during their walks, especially in the one with a TV (Fig. 25). Unfortunately, there are no more stimulating objects which people could constantly be engaged with without assistance of the caring staff.
Privacy

As in all of the other facilities, there is almost no private space. All of the rooms are for two and their layout does not allow any partitions so the two patients share everything. They share the good things as well as the bad ones. They share their visits, their troubles as well as each other’s annoying habits. At the end, they even share the other one’s death. They have to find a compromise in many daily rituals and when they can no longer communicate, others have to find it for them. There is no escape because behind the door there is a long corridor full of another people. No place to hide, no place to relax alone.

Lighting

Located on top of a hill, each room has a balcony and a spacious window. Natural light is certainly an advantage, making the room seem bigger and brighter. Corridors are however very dark as the only windows that bring daylight are in the niches. The rest of the corridor remains blocked with rooms aside and with only a narrow light stripe below the ceiling (Fig. 26).
Nature

The vast view from patients’ rooms seems to be successful at the first sight but while talking to the them it became clear that with the nearest objects located far away on the opposite hill, everything behind the window is too distant. Nothing is at comfortable visible reach and furthermore, there is no nature, only a far too distant view of apartment houses which was said to not be satisfying (Fig. 27).

![Fig. 27 Distant view from a balcony](image)

Garden around the building is now being reconstructed (Fig. 28) but as in other facilities organized in floors, very few rooms have direct access to it.

![Fig. 28 Sloping garden](image)

The rest requires assistance to reach the garden. Unfortunately, there is usually lack of time and human power to help people get there on daily basis and therefore very few people get out. More over the garden is moulded in a slope which makes some of its parts unreachable by the elderly with lowered mobility. There is one spacious terrace (Fig. 29) that offers a place to enjoy the fresh air and sun. It is frequently used during summer.
Colours and materials

Corridors as well as rooms are painted. In the old building corridors are painted yellow while in the newer one, they are light green. With the whole space painted in one colour, everything becomes rather blurred and nothing is clearly accentuated.

Autonomy

Although people are free to move around and do what they want, there are not many activities they could join outside of an assisted therapy. Apart from watching a TV or reading a book, there are no normal, well-known activities to participate in. People have no responsibility and are given no tasks to feel needed.

Dignity

In the new part, there is a shared bathroom for every two rooms whereas in the old part, the bathroom is located in the corridor, accessible to everyone. That obviously makes people feel more anxious, especially if they are not able to move anymore and have to be brought to the bathroom across the whole corridor in front of the others.

Sense of belongings

As already described before, if there are no familiar, stimulating activities to join at any moment, it becomes more difficult to dwell in the space. Here, people are not given the opportunity to actively contribute with their remaining skills and that is why they cannot fully identify themselves with the space.

Social interaction

On every floor there is a small common room for therapies or informal meetings (Fig. 30). Because it is out of visible reach, not many people go. Usually those who use it are still capable of remembering the way and because their cognitive faculties are still relatively untouched, they can also fully use the room in terms of reading a book or listening to a radio. Because it is rather hidden from the numbers of people, it offers a chance to have a calm, relaxed time.
In many elderly homes including this one, there are canteens designed to accommodate as many people as possible (Fig. 31). With so many people not knowing what to do with the meal, it quickly becomes a chaos. The atmosphere is rather stressful, despite the effort of nurses to help everyone. Many people get anxious and want to leave which disturbs the others and so it becomes even worse. With too much distraction people quickly lose their focus. On contrary, small groups of people are generally recognized as having a positive influence on people’s concentration, orientation as well as social interaction. 

Safety

There are railings in all the corridors and each floor is wheelchair accessible. Unfortunately, corridors are rather dark which makes it less clear for the clients. Enhanced by a reflective floor material (Fig. 32), people can often feel insecure.

87 Ibid.
Building of the Alzheimer centre in Průhonice is one of few designed specifically to accommodate people with dementia and it is one of six buildings operating under private Alzheimer centre organization in the Czech Republic. Although originally it was built as a luxurious residence for elderly, later it was transformed into an Alzheimer centre. The luxurious atmosphere remains and it is promoted as a high standard care institution. Although shiny on the surface, it was not always like that underneath.

Non institutional character

Early in the morning, when the clients are still asleep, the architecture itself is a very confident, persuasive, object. Despite its size, it has many homely aspects and is fine tuned into details. It is very welcoming through warm colours, decorative wallpapers, reminiscence corners, lightning, installed aromas or through pair of doves at the entrance.

There are many elements resembling home. Reminiscence corners (Fig. 32) are decorated in harmonious combination of pictures, old items, wall papers and books (Fig. 34, 35). It feels very much like a little living room.
Also in the rest of the building, much effort is put into creating a comfortable, familiar environment. There is one bathroom which is designed to reduce the stress and feelings of humiliation by providing a relaxed atmosphere (Fig. 36). More than a regular bathroom, it looks like a place in a spa and evokes sense of sensation and comfort.

![Relaxing bathroom](image1.png)

**Fig. 36 Relaxing bathroom**

**Sensory stimulation**

Attention is paid to all of the senses. Aromas of different kinds are installed in each floor, ranging from lavender to cinnamon. That way it smells nice when you enter the building which makes a big difference in how one perceives the environment. Moreover, it subtly helps distinguish separate floors.

Next to the entrance there are two small cages with doves (Fig. 37) that constantly provide a subtle coo sound in the background. Due to the safety cover, it can be difficult for people to recognize the birds and therefore it was mostly used as an auditory source of stimulation and not as a thing to watch.

![Doves](image2.png)

**Fig. 37 Doves**
Radio is on with a light music or news and to provide accessible tactile stimulation, some of the safety railings are made of timber (Fig. 38).

Way finding/ Readability

The building is divided in floors, each of which with a different theme (Fig. 39, 40). That helps patients better orientate in the building. The differentiation is enhanced not only by colours but also by different wallpaper topics that are exposed in front of elevators and staircase. Together with the topics, each floor has its own signature aroma.

Despite this differentiation, the corridors on each floor are hard to walk through. Because of their non-linear shape, the end is not visible. That makes it extremely hard to find a point of reference of where one is at the moment (Fig. 41).
The end destination is not visible and there is nothing to reach for. Furthermore, with the staircase and elevators in the middle of the corridors, there is nothing at their ends (Fig. 42). Dead ends are known to be difficult for people with dementia. When they finally arrive at the end, it is difficult for them to understand why it is suddenly not possible to continue walking.

To provide some daylight as well as to improve the dead end, there are doors in each one of them (Fig. 43). That is however even more confusing for dementia patients. Seeing the door and the outside behind but not being able to open it is a stressful situation. Many times there were people pulling the handle, trying to continue their way (Fig. 44).

Rooms are not differentiated and without any point of reference it is nearly impossible to find the correct one (Fig. 45).

Therefore even that people are able to recognize better which floor is theirs, thanks to colours, smells and themes; within a particular floor they can become lost.

Fig. 45 No significant room differentiation

Nature

There is a large garden with various elements ranging from a smoke-room to a kids playground. Path is design in a loop circuit winding around all these landmarks. In upper floors which cannot directly reach the garden, there are small private balconies.
Lightning

Common space where people spend most of their time is open to the garden and therefore receives a lot of daylight. Private rooms are equally well lit. The only problem is the corridor as in many other buildings. Because of its length and shape, most of the light has to be provided artificially.

Colours and materials

Colours are used to distinguish floors as well as to give a recognizable atmosphere to a certain space. Wallpapers are also used in a balanced way to enhance the homey feeling at some places. Sometimes, materials on the floor are however confusing. They are either reflective or uneven. Just a small change in height such as one in the canteen caused many troubles (Fig. 46). It got people out of balance or it made them stumble. There are also many changes in the floor pattern without any significant reason (Fig. 47).

![Fig. 46 Complicated height difference in floors](image1)

![Fig. 47 Confusing changes of floor materials](image2)

Autonomy

In this case, I experienced a big disappointment. Although advertised as a very modern, human institution, it lacks easiness, freedom and sense of a normal life. Despite the generosity of decorations and comfort of the environment, daily processes contradict all that. People have no freedom to choose where to go or what to do. After the morning hygiene everyone is brought to breakfast which takes place on the ground floor. (Fig. 48). Everybody then stays there for morning therapies and further for lunch. After the meal, all the 200 patients are brought back to their rooms to rest. The same repeats in the afternoon when everybody has to return to the canteen and attend the therapies until dinner. After dinner, they go back to their rooms.

Because of this schedule, not only their autonomy and dignity is seriously questioned but there is also no time and no chance to use the special rooms. No one is there in the reminiscence corner or in the bathroom. No one is in the art workshop, because things are brought to the canteen. People have no time to just wander around and find their place of interest and relaxation. They spend their days in the canteen altogether.
Social interaction
With so many people in one space, it is a chaos. It is not suitable for meals and even less for the therapies. Even that they are divided into small groups and each does something else, spatially they remain together. The dining space is divided in zones by columns and atmospheres, but there is no proper barrier to stop the sounds. There is therefore a lot of distraction; the level of noise is high, mixed together with the doves and a radio. Such an environment makes people restless, anxious or very distracted. It makes it harder to keep their attention and focus and almost impossible to enhance their socialization. At the end, such a big space is very counter-productive (Fig. 49).

Dignity
Having no chance to decide about their daily routines, people become generic. Their personal pride and dignity is lowered if all of them are treated the same way. They all have to wake up at the same time, even though some might be natural early birds, some the opposite. Breakfast is served at one precise time with no exceptions and it continues this way during the whole day. There is no possibility to find your own interest or to just linger for a while.

Sense of belongings
Because everything is planned and fixed, people cannot dwell in the space as they would like to. That makes it difficult to feel at home. With the huge numbers of residents spending most of the day together, it becomes even harder.

Privacy
Rooms are arranged for two or more people. The rest of the day, people are in bigger groups with no chance to be alone. Although not used during the day, therapy and reminiscence rooms are a welcomed place for visitors and families because they offer a calm oasis in the rushed atmosphere and a semiprivate space to be with relatives.

Safety
The whole building is wheelchair accessible, sometimes made a little more difficult by the different levels of floor. There are railings along the corridors providing support.
Articulated in three wings, multistory building of an elderly home in Přelouč has been offering its services to seniors for already fifty years. It provides help for people with dementia as well as to others who need it due to their old age. After a reconstruction it has a capacity of 230 inhabitants.

Non/institutional character
As in many other facilities I visited, this one too has its wings organized in corridors with rooms alongside. Because life happens at the corridor and there is nothing like a living room or a kitchen, the overall ambiance is rather institutional. The atmosphere is however pleasant and welcoming. Patients’ rooms are clean and modern looking but due to their size, there is no space left for personal furniture.

Sensory stimulation
Main source of stimulation are other people as it is in many nursing homes. This can however quickly turn into a very unpleasant element which is hard to escape. Many decorations on the corridors make the space homier on one hand but on the other they can sometimes create confusion and overstimulation. No natural sources of smells or tactility are present.

Way-finding/readability of the environment
Each wing works as an independent unit with its own nurses’ station. Their size is moderate and still easy to overlook which contributes to better orientation. With the organization of a corridor in the middle, it faces a terrace on one end and a door to a bigger hall with staircase on the other. This door is camouflaged with posters of different themes. Some fit the environment such as a bookshelf, others do not. Walking along the hallway and suddenly arriving into a sunflower field can only increase feelings of anxiety and confusion.

Canteen, outside space, reminiscence room, rehabilitation and some other specialized places within the building are located out of reach and sight of the residents. Some people are still capable of finding their way there and back, but most need help and cannot therefore benefit from the spaces on their own.

Nature
At the end of each corridor, there is an outside terrace. Its location directly at the end allows for smooth organization in case of outdoor activities. It is easily accessible and can be therefore used effortlessly. Besides that, the building has a vast park garden. By system and articulation of its path it leads the walker through different experiences and offers ground to various activities and stimulations.

Lightning
Rather short corridors are well lit as well as private rooms with windows.
Colours and materials
Yellow and orange are two dominating colours throughout most of the corridors. Although they give a certain sense of warmth, they blur everything together. Nothing is accentuated and as a result, the whole corridor is just one colourful mash. It is hard to distinguish any element and hard to find peace within the vivid space.

Autonomy
People are allowed to move freely within the building. Those who still can, may even walk outside on their own. Nevertheless, most people stay in their own part of the building.

Dignity
Thanks to the rather small size of one unit, people are more relaxed. There is a private bathroom and a toilet for every room which provides a discrete settings. One extra bathroom in the corridor serves better in cases where complete assistance is needed.

Sense of belongings
Although the atmosphere is quite homey, there are no proper activities that people could participate in. Besides organized therapies, people cannot engage in any meaningful action as in many previously described cases.

Privacy
All rooms are double with no alcoves or comers to create at least little bit of privacy. Two beds are facing each other and there is not much space left for additional, personal furniture. Sharing a room is double edged as many design decisions. On one hand, it deprives people from privacy. On the other hand, talking to two women in this senior house showed how it helps them stay active. They support and help each other, they make each other happy or mad but they are constantly stimulating one another. They can laugh about their troubles which is incredibly important.

Social interaction
Because people live in two, there is always somebody else to interact with. That way each and every person is stimulated but at the same time, they can never be alone. There is no semi-private space to relax and to not be part of the overall hustle. Furthermore, there are no opportunities to do something together which makes people mostly just linger.

Safety
The building is wheelchair accessible with railings along the walls. Small size of the unit makes it easier for nurses to overlook the space and therefore safer for clients to move around freely.
The Hogewey is a very often mentioned example of a successful concept where care meets with spatial organization. There are 23 houses for 152 people with dementia organized in a village like settings. It has its main street with various facilities as well as gardens and backyards. Much effort is put into creating a home rather than a care institution. All the houses are designed based on 7 different lifestyles: Goois (upper class), homey, Christian, artisan, Indonesian and cultural. That gives each person a better chance to accommodate his individual life within the new environment.

Non/institutional character

Big emphasis is placed on creating a home-like ambiance through the environment as well as through actions. Residential units are designed according to different life-styles and provide thus less generic backdrop. Each works as an independent home with own kitchen, living room and private bedrooms. Toilets as well as bathrooms are shared the same way as they are in regular family house. Within the whole complex, seeming of a normal life is visible. Familiar environments such as a café, restaurant, small shop or a theatre are accessible and provide therapeutic stimulation. The whole area works as a little village with private homes and public facilities (Fig. 50).

Fig. 50 Main street with stimulating public facilities

Sensory stimulation

Stimulation comes from natural sources and daily activities. In each home, there is a kitchen where meals are prepared with the help of residents. They also help with cleaning and with many other daily activities, which provide different kinds of familiar tactile, auditory as well as olfactory stimulation.

Way-finding/readability of the environment

The whole complex is closed with a reception at the entrance. All the residents are therefore free to move around without being able to escape. Through different courtyards, landmarks and public functions, people always have some point of reference (Fig. 51). Moreover the staff is trained to help any time they see someone wandering a searching for their homes. Homes themselves are rather small, accommodating 6 to 8 person which makes the space easy to understand and overlook.
Nature

Different kinds of therapeutic courtyards are designed in the small village (Fig. 52,53). They provide various stimulation as well as points of orientation. Each home has access outside and thanks to the enclosed character of the whole complex, everybody is free to walk around.

Lightning

Daylight is well managed thanks to openings to courtyards and gardens.

Colours and materials

Colours, wallpapers and decorations range from modest to very decorative depending on the life style group. In cooperation with a research company, it was established what each group is used to and what it needs. That way, the change of environments when moving from home is not so abrupt and people can better accustomed themselves in the new space.
Autonomy
Since the whole space is safely closed, everybody is free to move around. On their way people happen to bump into a shop or a barber where they are treated as a regular customer. Although being fake, it gives people sense of responsibility and importance. In their homes they are involved in all the activities if they like and are free to choose what they like to do.

Dignity
People are treated as if they really lived in a city and are given lot of freedom. There is always someone to help which prevents them from feeling lost or confused. They are naturally engaged in well-known activities and through that they gain the precious feeling of independence and respect.

Sense of belongings
Integration into normal settings, although unreal and fake, helps feel as part of a regular life. Thanks to variety of actions people can engage in, it becomes easier to familiarize the whole space and to feel as a relevant part of it.

Privacy
Privacy in homes is strictly guarded. Because the whole project is very popular, many people come to have a look. No one, besides the carers and relatives is however allowed to enter and interfere with the daily life. On contrary, visitors are welcome in the city-life within the complex.

Social interaction
Thanks to the variety of activities that one can find, people are constantly engaged in interactions with others. The casual environment is designed in such a way that is gives spaces and opportunities for familiar, everyday topics.

Safety
Thanks to the enclosed character with a reception, people can safely walk outside. The whole complex is wheelchair accessible.
3.1.3 Cross site analysis

To have a clear analysis of all the cases, table with multiple categories was made. That way comparison is easier and many relevant relations stand out. Results which were positive are marked with green colour, whereas those that were rather negative are red. White ones stand for neutral or not clear cut outcomes. The whole table can be found as an Appendix 3.

3.1.4 Conclusions

Having a chance to experience life in different nursing homes, be with the people, talk to nurses and carers was a lesson no money can buy. It helped reveal further aspects of how environment can shape the way people live in a building but also and mainly, it revealed very much of the problematic in general. It clearly showed how big the problem is and how many people struggling with dementia there are. I could see how much they have in common but also how much they differ. Their symptoms are often similar, but the way they deal with them is very individual. Sadly, existing buildings often treat them generically despite the enormous determination and effort of the carers.

I could see many times how people struggle in specific situations and how they react upon certain elements. I could see how theory often clashes with lack of people, lack of space, or lack of money. The table shown in Appendix 3 shows how certain aspects are missing very often. It also very well illustrates how building layout influences many other elements or how some other categories determine each other. Some of the main findings from all the site visits are described below. Their order will follow the previously discussed categories and complement them by new findings.

3.1.4.a Non-institutional character

As tempting and appealing such designs are, there is a great danger behind their beauty. The appearance alone is of no importance, unless it works in symbiosis with functionality. Space with a great homely atmosphere which doesn't work well, was repeatedly described as a space wasted during observations. Talking to nurses and carers revealed the tremendous importance of these two aspects working together. Too many decorations and furniture standing in a way of smooth daily operations can increase the anxiety instead of creating a calm atmosphere. Cosy place with no storage space is equally useless and many other examples follow.

Functionality

Providing suitable and comfortable working conditions for the caring staff often seemed neglected for the sake of the patients. Not only there are usually too many people to care for but too often, the space is making it even more difficult. By being too small, too big, hard to overlook, too noisy, too crowded etc., the frustration grows. If carers waste energy to struggle with insufficient space capacities or frequent spots being too distant from each other, there is no energy left for the patients.

It is very common that there is not enough storage space. Just the amount of diapers and wheelchairs is overwhelming. Having to constantly search for places to store those because the building does not offer them, is time and energy consuming. Building which allows for smooth, daily actions saves both for the good of the patients.
3.1.4.b Sensory stimulation

There was very often no accessible stimulation besides TV or other people. Apart from some decorations, there is usually no source of natural tactility, smell or sound. This resolves mostly from lack of stimulating activities. Because there are no natural daily activities to join, the environment lacks richness. Generally, much stimulation comes from sources we do not consider important or relevant and these are often forgotten in nursing homes as well. Simple laundry hanging already represents an activity during which many senses are stimulated but is hardly ever done in elderly homes. The same happens with cooking, grooming or gardening which provide natural, familiar stimulation at any moment. Unfortunately, they are often done excluding the residents for time, economic and safety reasons. Besides more everyday stimulating activities, there is a need for self entertaining, cost effective sources of stimulation. In this sense, television is effective because no assistance is needed. There should however be a wider pallet of such accessible stimulation. Although this freedom sometimes clashes with safety, with a good strategy all these activities can become a casual therapy where the personnel is included.

What was often lacking is a quiet space. High level of activity and noise is very common due to small diversity of spaces and big amount of people. Being constantly part of such a hustle and having no place to hide makes people restless, anxious or even aggressive.

3.1.4.c Wayfinding/ Readability of the environment

Most difficulties people had with orientation derived from layouts of the buildings. Their size, capacity and disposition were often causing troubles. Some of the most frequent problems are described below.

*Corridors*

Too often buildings I saw were organized in long corridors with private rooms alongside. It obviously saves space, accommodates the most people and reduces costs of the building. But at the same time, it lowers the quality of life significantly. Long corridors repeatedly proved to cause troubles. Most of all, they provide no stimulation and no natural activity to join. On contrary, they are discouraging and demotivating. With the many doors leading to other peoples' rooms, they can be very confusing, lacking any point of reference. Without a visual contact with an end destination, corridors offer no chance to relate oneself to something in space. One has to remember where he wants to go and how to get there which can often be difficult. Vice versa, finding the right door to a person's room is difficult without any significant distinction.

Corridors are not suitable for many other reasons. Sound is usually echoed and does not create a comfortable atmosphere. Due to their common location in the middle of the building, they often lack proper amount of daylight. They sometimes lead to dead ends or turns which are both situations hard to handle with dementia.
Floors

The same occurs because of distribution of places in multiple floors. If one floor cannot work as an independent unit, it becomes hard for people to grasp it. Having to remember a way through a building during which there are many distracting elements seemed to be very difficult even for some people with early dementia that I talked to. Because of the difficulty, many people are discouraged from going and therefore lack the activity’s benefits. It needs human power and help of carers to get people to places of interests if these are not at reach and comfortably found.

Barriers

Majority of buildings are based on commonly known barriers taken for granted; barriers that are visible and reasonably explainable – walls, ceilings, floors or furniture. They can however be questioned by people with dementias, because in later stages of the disease people are no longer capable of reasoning and analyzing, and thus no longer capable of categorizing the space formed by these elements. They do not cognitively think but instinctively rely upon senses and intuitive motoric and their space is then formed by entirely different barriers. While healthy person might conceive certain space as one whole, it might be three different spaces for disabled person. Strong shadow on the ground for instance can easily be thought of as an object or mistaken for something completely different. Very common barrier during my visits were reflective floors. Despite the fact that they are easy to clean and hygienic, they often resemble a liquid surface and can therefore be an obstacle. The same proved to happen with changes of patterns on the floor. Every change of colour or material was perceived as a step or a gap by some of the patients. That made them hesitant and insecure about their movements and it often disturbed their balance.

Because it is perceived so strongly, change of colour or floor material can be used as a simple way to mark a zone, something of an importance or higher level of caution. It should however be used wisely and only when necessary because otherwise it causes unnecessary hesitations and confusion.

3.1.4.d Nature

Organization in floors leads to another inconvenience. Besides ground floor, no other floor has access outside. Sometimes, elderly homes have balconies but there is no easy way to reach a garden. Very often, people are therefore deprived of this priceless source of relaxation.

Nature was many times described as a desired element and preferred as a view from window. Because it is so variable, it constantly provides something to look at, it is a reference of time and a source of diverse stimulations.

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90 Ibid.
3.1.4.e Lightning

The only problem with lighting was repeatedly found in corridors. Because of their length and location, they do not have enough daylight. Lack of light only worsens their overall inadvisability. Rooms and shared spaces mostly had enough daylight coming from windows or balconies. What became an obstacle was however operating of the window itself. People with dementia usually did not think of opening it and as a result, there was very often no fresh air. Nurses do not have the time to operate each window in each rooms and therefore windows only serve as a light source but remain closed.

3.1.4.f Color

In many cases walls were painted with expressive colors. Yellow or orange often dominated the space, especially in the corridors. Unfortunately, despite the good intentions, final result was rather confusing, blurring everything together. When everything is already colored, it is hard to emphasize important elements or places. The overall contrast is lowered and it becomes more difficult for orientation.

3.1.4.g Autonomy

Unfortunately, in most cases people had very few opportunities to participate or contribute to the living flow. Meals are usually prepared elsewhere, brought to the people. Plates are then also washed somewhere else. Laundry is washed and dried outside of people’s reach and the same happens with many other things. As a result people are detached from these routines which form a significant part of a normal life. They are often given no responsibility and no chance to help. Because everything is usually arranged for them, they cannot make any decisions and have therefore almost no chance to feel at home.

3.1.4.h Dignity

Besides the element of toilets and mainly bathrooms being shared, aspect of dignity mostly depends on the care concept and personnel. Environment can provide privacy and space for dignified routines, but it is mainly the people who can give others respect.

3.1.4.i Sense of belongings

Lack of possibilities to engage in familiar, stimulating activities not only cuts short on stimulation but also prevents people from feeling engaged and needed. Without having a possibility to participate, people can never feel like at home. If the space does not provide opportunities for daily activities or cues for participation, people are only left with wandering. If there is nothing to do and everything is arranged centrally, people have no chance to develop sense of belongings. Very clear example repeatedly appeared during my visits. To reduce costs, time and work, there is usually a central canteen. Meals are prepared elsewhere without any possibility to join. All meals are being prepared, brought to and later taken away from the patients. Such a process is neither familiar nor homely and it detaches people from normal daily life.
3.1.4.j Social interaction

There are usually many opportunities to interact with others as there are many people in the nursing homes. With those numbers it however often has a negative effect. With only a few chances to be alone, people can quickly become frustrated by the amount of other people. Furthermore there are usually not enough activities people could enjoy together without assistance and not enough places of different qualities and levels of privacy.

Size

For example, in canteens, many people gather at the same time. Lots of them need assistance with eating and may feel ashamed for that. With so many people in one big space, it quickly becomes a loud, crowded, and stressful place. People can get anxious and many of them try to leave. Altogether it is just spiraling up the noise and frustration level. Big activity rooms are often enhanced by colouring, usually by red which is generally believed to embrace interaction and it is recommended for high activity areas. Despite the colours and materials, their size sometimes unfortunately plays against it by not incorporating deeper knowledge of demented people's perspectives. It is of a huge importance to avoid patients with dementia feel embarrassed, especially among many other people. They already have to face many failures every day because of the disease and its consequences, that they are often afraid to act freely in order to avoid another. Being in an open space, watched, with endless eventual risks of embarrassment, is not an atmosphere for casual, unintentional socialization. Instead, it creates feelings of fear of failure and that is where open space rooms fail. Smaller rooms on contrary can provide calmer environment which is, in general, better for relaxation, mainly because people do not feel so exposed. Smaller places offer more freedom and less stress. Social interaction can therefore happen more naturally. Such rooms can vary in sizes, materials, lightning and sounds so that there is a wide range of possibilities to find one's individual preference.

3.1.4.k Privacy

The issue of privacy is one of the most important, yet also one of the most complicated ones. Obviously it is preferred that everybody has a piece of space for him or herself. Place of their own, a territory to retreat to and to be oneself.

Nevertheless, when people lived alone I could see very well how this can also become a downside. Regarding old people's common fear to engage in new, unknown activities, they very often felt demotivated to leave the room without assistance. Especially with dementia, people are afraid of failure and embarrassment, and they are very often inclined to stay safely in their room. That however leads to a different negative effect which is solitude. All the people I had a chance to talk to felt a very strong urge to mention that as the main negative factor. They were alone. There are nurses and social workers who come by but hardly ever they have time to talk to people for individually. There is not enough people and not enough time to sit and listen to every single patient. The fact that people stay isolated and do not participate in group activities deprives them from most social contact.

On contrary, most care institutions in Czech that I could see are designed to accommodate two or more people in one room. Living with others seriously questions dignity, individuality and privacy of each one of the people and causes many troubles. Certain level of sharing however seems beneficial.  

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91 Benson, “The Use of Colour in Dementia Specific Design “.
Talking to various nurses revealed that when living in two, people often help each other and keep each other busy. Sharing some quality space while still having a personal space to retreat seems to be a good balance.

3.1.4.1 Transition

Some people were discouraged because there was an abrupt transition between the private space and public one. Right behind the door of a room, there is a public space mostly in form of a long corridor. That leads either to a common space or represents a common space itself. There is commonly no transition or a semi-private space to adjust to the amount of people and level of activity. The public space is usually quite featureless, offering no different levels of privacy. There are often no semi-private spaces to just watch the activity or to be with family. There are no spaces to escape the rush and to just relax. That can lead to a restless behaviour, constant searching for some calmer place or to anxiety.

There is often an abrupt change not only between private and public but also between inside and outside. Visiting a person with dementia can be very difficult and so is entering a nursing home in general. Entrance is usually equally abrupt and there is no sensitive transition for people to calm down, relax and enter the world of dementia.

3.1.4.m Flexibility

It may not be visible from the outside but spending time in elderly homes shows how dynamic these environments are. There are many people and sometimes even animals involved. There are people with dementia, personnel, families and friends. Many changes happen within the space but unfortunately, current spaces are not able to react upon them. Not only life sphere and interests of each person changes during the progression of the disease, but there are more things that constantly shape the atmosphere. It was a pleasant surprise to learn that it is not uncommon that new couples are formed and new friendships created. There are new people coming and as sad as it may seem, also death is a natural part of every elderly home. Layouts of elderly homes are however rather rigid, often not flexible to react upon all these changes.

3.1.4.n Spirituality

As the disease progresses, cognitive functions are lowered while sensual and emotional receptions remain. Many of the spaces I saw however only appeal to the rational part of our self. Creating places for contemplation or relaxation is not very common although it could bring many benefits. It became clear that such a space would have to be neutral, without any religious context. If not, it is difficult to accept by local people and therefore less used.
3.2 Meeting people with dementia

3.2.1 Introduction

Besides the previous site visits and informal talks with nurses and care givers, I was lucky to have two opportunities to spend some quality time with people with dementia. Firstly, I was invited to participate as a volunteer in a dancing event organized by Het Danspaleis\(^9\) and secondly, I could spend some time with a small group of people in one of the elderly homes I visited in Czech. Because the two experiences differed significantly in their content, I will describe each one individually.

![Fig. 56 Het Danspaleis](image)

3.2.2 Het Danspaleis

Het Danspaleis is an initiative organizing dancing events throughout various elderly homes in the Netherlands. With great amount of joy and devotion, they not only bring music to elderly but mainly, they bring happiness. As much cliché as it might sound, they manage to wash away all people's troubles and differences. During the two hours, they bring people closer to each other; they cheer them up no matter their disease or its stage and allow them to forget about it for a while. I participated as a volunteer in one of their regular visits to Antonius Binnenweg in Rotterdam and would not hesitate to do that again.

While the organizers were setting up a room, decorating it as well as each other in order to create a comfortable, cheerful atmosphere, I could take a stroll throughout the building. Within that short time, I saw glimpses of many different individual struggles and everyday battles. I saw a man walking in rounds, putting on and off his yellow jacket. I saw a woman repeatedly trying to pull a handle of a locked door. I saw a young man in a swimming suit and his mother pretending to go swimming with him in order to evoke atmosphere of his formerly favourite activity. I saw people sleeping almost innocently, bundled up in chairs with warm blankets. I saw some others looking absently into distance. Everyone was in his own world of thoughts and memories, almost never sharing them together.

Most of the people and many others were then gathered downstairs when the music and dancing started. With familiar songs, many people started moving their feet or noddle to the rhythm. Naturally, most of them were shy or scared to stand up and dance. However, with the help of us, volunteers, they did not hesitate and cheered up instantly (Fig. 56). Dancing allowed them to express and enjoy them-
selves. They woke up with the rhythms and some never wanted to stop. Many of them continued dancing by themselves or with others the whole time. Most men I danced with still remembered the steps and were extremely happy to be able to be the lead once again. Suddenly they could be certain and confident again. Sharing such a powerful moment with a person was very touching and their happiness was incredibly contagious. Each person I danced with gave me a feeling that what we were doing mattered and although I could not talk to the people because of my insufficient level of Dutch language, dance was a strong and very personal tool to communicate. No words were necessary because the dance itself allows people get closer in a natural way. During dance people hold hands and exchange smiles which is already more than words can sometimes do. Through dancing, nurses and their patients could share a very personal, emotional moment and so could relatives and visitors (Fig. 57).

It was a unique experience I am extremely grateful for. It was not tightly related to the topic of my research but it proved me that although sometimes buried deep down, there are still emotions, hopes and feelings in each person. Enhancing them gives people their lost confidence and joy which they do not hesitate to share.

Fig. 57 Het Danspaleis
3.2.3 Extended research in the Czech Republic

My second experience was possible thanks to kind assistance of Centre of social services (Středisko sociálních služeb městské části Prahy 9). I was given freedom to talk to five women who have dementia in their elderly home in Prague. This building and its aspects is described earlier in a separate chapter 3.1.2 Site descriptions. This part of the research is its continuation, extended by collaboration with the women.

3.2.3.a Preparations

In advance, I tried to find out what qualitative methods are used to work with people with dementia in order to learn from them. Unfortunately, there are very few examples as many qualitative research methods rely on subjects who are still capable of reasoning. That can however only relate to people in a very early stage of dementia. For the progressed cases of the disease I could find only few empirical research methods. The same shows a review studying environments for people with dementia. It reported only two empirical studies out of their many references. Vast majority of designs were based on an expert opinion alone, while only two of them worked closely with demented people.93 Because it is not common to work with opinion of people with dementia, they are rarely included in discussion. Interview with Alessia Cadamuro, a social designer who has been working with Alzheimer patients, however helped me realize that there might be no perfect way. Since every person with dementia is different, methods to approach them have to be unique as well. So although I tried to prepare methods based on scientific theories and examples in advance, I also had to improvise a lot during the process. All the methods were sometimes slightly adjusted to make it relevant for me as well as suitable and enjoyable for people participating. I will describe each method that I found in literature and which I consider relevant to my research and reflect on each of them separately. Later, I will describe common conclusions.

3.2.3.b Unexpected situations

Thanks to the experience with my grandmother, I was not scared to work with people who have dementia and I knew what to expect. I know how difficult it can be and that helped me keep my mind open. Therefore, I was not surprised to be once mistaken for a granddaughter or that sometimes sentences did not make sense. I consider this an advantage because I knew how to react to people's difficulties and that hopefully created a pleasant atmosphere. What was however surprising to me was how open all the women were. Although I was a complete stranger to them, they all were very friendly and did not hesitate to share their experiences with me. All of them were happy to have someone to talk to and revealed many of their opinions.

3.2.3.c Limitations

Unfortunately, mostly due to time limitations, I could not use all the methods. I only had three weeks to visit all the sites and unfortunately there was not enough time left for all parts of this research. That is why some of the methods could not be tested.

93 Dementia, Design and Technology : Time to Get Involved, 24.
3.2.3.d Researched Methods

Field Observations

To get familiar with the environment of a care home or any other environment, initial observations are commonly used. Watching what happens during the day, where people go and what they do prepares ground for further activities. Talking to people in the meantime is an opportunity to gain some informal insight. I used this method in every building that I visited and supported it by sketching and taking pictures.

“Field observation (sometimes termed "naturalistic observation") refers to a researcher entering into a natural setting, such as a neighborhood, to observe (and ultimately learn) about the social life of this environment. This method is ideal for a researcher interested in familiarizing her/himself first-hand with a location being studied. Thus, some key strengths or advantages of field observation are that it provides a natural way for the researcher to acclimate her/ himself with a particular locality, raise research questions in an inductive manner, and observe phenomena that may often escape awareness of people who inhabit a particular setting. Nevertheless, field observation is limited by the researcher’s own interpretive framework, accounting primarily for what the researcher sees and hears. Thus, field observations are limited in examining residents’ perceptions and experiences of the environment.”

For the later mentioned reason and to get to know perspectives of the people with dementia who I could talk to, I researched on the following activities.

Go-along interviews

“The go-along method is a form of in-depth qualitative interview method that, as the name implies, is conducted by researchers accompanying individual informants on outings in their familiar environments, such as a neighborhood or larger local area. [...] all go-alongs involve interviewing a participant while receiving a tour of their neighbourhood or other local contexts. In this regard, the researcher is ‘walked through’ people’s lived experiences of the neighbourhood.”

Walking along like this with people in care homes is a way to explore their perception and experience of the environment. It is a very personal way to get to know what people go through every day and how it makes them feel. Letting people with dementia be the tour guide and talk freely about what they choose to be important dissolves the conventional power inequality of a regular interview.

This aspect of equality and independence made the method very suitable for people with dementia. They could feel more relaxed and important when given the leading role. The fact that during a walk, people were constantly exposed to various elements of their everyday environment and could spontaneously share their feelings about it made it very easy. During a go-along interview, people can react in an instance which does not require memory. Most of the women were enthusiastic to show me around but never wanted to walk far. Because of the corridor, some were demotivated to take a stroll with me at all. Their arguments that there is nothing to see and their questions why I would want to go there

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95 Ibid.
96 Ibid.
clearly showed how discouraging such corridors are. Only with one of the women I took an elevator to a different floor. Differentiation of floors by colors proved to be very important because otherwise all the floors look the same when a person enters.

**Diary keeping**

This method is based on an example of modified diary keeping developed by Ruth Bartlett who used it to find out about lives of people with dementia. Asking people to keep regular notes about a certain experience is a rather unobtrusive way to collect personal data and perspectives. Because many people with dementia use notes to keep track of things they want or have to do, writing an extensive version in form of a diary only expands the activity they are already familiar with. That, together with the freedom of choosing when and what to write, gives people a high level of independence and autonomy, which is very important in case of dementia. Engaging in the writing activity has in general proven to be beneficial as well. However, not everyone feels comfortable writing and therefore other methods were introduced in her research. Ruth Bartlett modified the traditional form of a diary to accommodate different personal approaches of people with dementia, and allowed other means of documentation, audio recording and picture taking. Each participant had the freedom to choose which means he or she felt most comfortable to use. In her report, she notes that audio records as well as pictures taken revealed potential opportunities for further use. Photo diaries unintentionally generated some useful visual data of the environment of the person, while audio diary showed a potential of recording their emotional experiences.

Downside of this method is that it can only be used with people in the early stage of dementia which is a limited target group. There are more factors that have to be taken into consideration such as assistance, length of diary keeping period, amount of data to analyse, ethical issues etc. Ruth Bartlett also noticed that it might be demotivating for people who keep the diary because during the whole month of writing, they could see a visible proof of their abilities slipping away.

Asking people to keep record of spaces they go through the day, while focusing on how they make them feel could show some interesting data. Not only I would see where each person spends most of the time but mainly it would show what they like, what they don’t, and why. Unfortunately, diary keeping method is one of those that had to be left behind quite early as it requires lot of time and assistance. Although it might have brought many interesting data, there was not enough time to organize and pursue the experiment.

**Photo voice technique**

Photovoice is a qualitative research methodology which provides participants with a camera to record and document their personal experiences. With dementia, this method is very relevant as it gives people who might have difficulties in verbal or written communication a chance to express themselves.

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Taking a picture can be done in a second and as such it can be a very fast way to document an instant feeling. There is no need to keep the thought for a long time. Difficulties can occur with the actual picture taking action and some assistance might be needed. Later discussions about pictures taken would be necessary to fully understand. In such case, having the pictures during the interview helps people remember and start the conversation, although according to some studies, it might happen that people no longer know why they had taken it.

For the same reason as the diary keeping method, also this one was not realized at the end. Lack of time did not allow proper preparation, camera collecting and sufficient assistance.

**Picture associations**

In her project called “What remains?” Alessia Cadamuro used biographical pictures of Alzheimer patients in order to make them play, move and combine them to tell a story. Strong visual elements enhanced by a spherical magnifying glass attracted attention and evoked memories. Seeing combinations and pictures chosen by the patient made it then easier for the care givers to understand patient’s actual needs.

For people with later stage of dementia, it might be hard to keep a diary or to take a picture. Therefore, based on field observation and insights of other patients, it was me who brought different pictures to talk about. Use of pictures was essential as it kept attention of people and in many cases helped remember various feelings. It was interesting to see what each picture evokes in every person and how it differed. There were however two pictures which received many positive comments from all the participating women. All of them reported that the spaces shown in the photos reminded them of their childhood. They reminded them of times when they were happy, safe and relaxed. Both spaces were usually associated with visiting a grandmother’s house (Fig. 58) or a summer cottage (Fig. 59).

Alessia Cadamuro, “‘What Remains?:’ A Persuasive Story Telling Game.”
Although people with dementia experience decline in memory, it brings interesting data to ask them to describe their care home. Seeing which elements they remember and why shows what is most intriguing in their environment. This can be done in various ways, such as verbal description, drawing a map, putting together a collage etc.

What proved to be the most effective was talking to the people in person. It was interesting to ask them to describe the building and tell me where they go and why. Seeing what places they mention and for what reasons clearly shows how people relate themselves to the building. Vice versa, noticing which places they do not talk about reveals equally relevant information.

**3.2.3.e Difficulties**

What became the biggest struggle was keeping the women's focus on a desired topic. They seemed to be excited and grateful that there was someone who has the time to listen and they often started talking about personal topics. Because they wanted to share everything that was on their mind, many times we happened to talk about their grandchildren or kids. Keeping their attention on one specific topic was difficult and I decided not to force it. Although it was not related to my graduation topic, their stories were important to them and I would feel bad for stopping them. At the end it did not bring any closely related data to the research but it showed how much people stick to their lives, relationships and memories. They are difficult to lose and people struggle to keep them for as long as possible because it preserves their sense of identity.

It also showed how company of other people is important, especially in the early stage of the disease. All the women I met mentioned their solitude as the biggest concern. Due to the layout of the building, its long corridors, organization in floors and long distances, all of them preferred to stay safely in their room despite their solitude. The building and its configuration made it difficult for them to meet other people easily and therefore each one of them was alone. Some had friends in other floors which gave them a reason to leave but some are lonely without a chance to engage with others.

*Fig. 59 One of the two favorite pictures*
3.2.4 Conclusions

Talking to people about the building and about their life within the building very often slipped to talking about food they are served, nurses and their help or families and frequency of their visits. We often arrived to talking about what they do or what they would like to do but cannot. It was a great lesson to learn about architecture. It is not space that matters in the first place. It is not space that people remember the most. On contrary, it is the people within, the time they share and things they do together. Architecture can however help enhance these moments by providing suitable and pleasant spaces for them to happen. It can help people meet by creating less confusing environments, it can help them engage in actions by making them visible and accessible.

What also became very evident is that, as already mentioned earlier, each and every single person with dementia is different. It is well demonstrated by diversity of their private rooms I could see. Each and every one is different, revealing a lot about the person him or herself. They all have been through a very different lives, different struggles and joys and the fact so many times repeated in various literatures that dementia is the only thing people in care homes have in common proved to be very true.

What they however also have in common is their lack of social contact resulting in solitude. Because they spend most of their time alone in their room, they are not challenged, not motivated and sometimes bored. Such situation only contributes to the development of the disease because the brain is not trained and the person is not happy. They lack interest and curiosity and the environment does not offer a guiding hand.

Although they sometimes remain apathetic, when given attention or stimulation they cheer up. They start talking and are happy to share what they know and remember. Before I left each women, I was given many warm hearted advices. Their life experiences gave them an advantage and also thanks to the disease, they know what matters in life. It is a pity that nowadays there are still very few opportunities to pass on this wisdom.
4. Part four

*Design*
4.1 Design principles

Based on all the previously described work, literature study, site visits as well as on talking to different people, including people with dementia, I condensed my findings into a form of design principles. These I intend to use further during my design process. They will serve as main starting points as well as overlapping themes throughout the design. Following and using them later to reflect upon the design will hopefully help me create potentially suitable environment. Inspired by the way spaces and their qualities are described in Christopher Alexander’s book Pattern language\textsuperscript{102}, similar list is made. Although not directly named after the categories elaborated earlier, all of them are a synthesis of qualities that the spatial attributes provide.

\textsuperscript{102} Alexander, Ishikawa, and Silverstein, \textit{A Pattern Language: Towns, Buildings, Construction}.
Compact building layout

Small building or small independent units within one building eliminate the need to remember directions. When everything is at reach and preferably also visible, people can react and decide at a moment without having to memorize and find their way. Compact layouts with short distances offer clear overview which is beneficial both to people with dementia as well as to their care givers. Resulting elimination of corridors and dead ends contributes to the overall easiness.
Having visual contact with main points of the building reduces stress from having to search for a particular place. Seeing the possibilities eliminates the cognitive, decision making process. Once a person has eye contact with a destination, he or she does not have to seek for it anymore. Opening spaces one to another for better visual connections also allows sounds and smells to spread. These are valuable cues for people with dementia, evoking feelings and making it easier to arrive to a desired destination.
Clear distinction of spaces and mainly of their functions gives people comprehensive indications of what to do and how to behave. Basic spaces such as kitchen, dining area or a living room are inscribed deep in people’s memories and create a familiar environment. Unlike „day rooms“, „therapy rooms“ or corridors, these core spaces indicate well what they are for. Knowing what to do, feeling relaxed and calm is equally beneficial to people with dementia as well as to their carers and visitors.
Differentiation of spaces for people with dementia can be marked by various means. Less obtrusive barriers than a physical wall such as changes of materials, colors, columns, ceiling heights or levels of light allow for smooth orientation within a building. Besides signings and pictures, these are more natural, subtle cues which can be used to guide people through the space. Creating various patterns of light and dark spaces enhances people’s movements and so does changing heights of ceilings. Transitioning from a lower space to a higher, brighter one is accompanied by curiosity and therefore it can help people initiate their journey. Vice versa, retreating to a more enclosed space can be enhanced by lowering the ceiling.
Activities

Providing space and allowing for various daily activities is extremely important. Activities of everyday nature are familiar to people and as such they offer a chance to keep up with what they had been doing their whole life. Cooking, grooming, watering plants and many other activities that people can engage in give them a sense of responsibility and belongings. Moreover such activities provide natural source of many stimulation. They are both a therapy as well as part of a normal life. Through actions, sounds, smells and various tactile stimulation can be achieved. Creating spaces for these activities and their cues gives life to the building as well as to the people.
Sensory stimulation brings relaxation even at a late stage of dementia and very often it is one of the things people have left. Because it is processed by a part of brain which remains intact the latest, sensations have the power to trigger memories and emotions till very long. For that reason, it is important that a building itself is a rich source of diverse sensory experiences ranging from materials and atmospheres to activities. Providing stimulation which is natural, coming from everyday activities makes people stimulated in a pleasant and familiar way. Designing the space in such a way that it is possible to hang the laundry or sit in an evening sun brings in a seemingly simple but very valuable quality.
It is important to offer different levels of privacy so that everybody can find where he or she feels best. If there are places to be alone, to be with others, places to just watch the others or to be with a family, the whole place becomes a rich pallet of possible experiences. Variety of semi private spaces offers possibilities for different activities to enjoy with others as well as alone.
Transitions

Creating transitions between different spaces and levels of privacy gives people the time to settle and adjust to the change. Small in-between spaces can link places with different functions, noise and activity levels. Such gradual flow between spaces is important on various levels. Helping people deal with a change between private and public is equally important as providing a calm transition for visitors between outside and inside.
Flexibility

Environments of elderly homes are surprisingly dynamic. As a natural part of their ever changing nature, people die and are exchanged by new ones regularly. Moreover, the disease progress with different speed with each person and every person deals with it his or her own way. In each stage, people have different needs and their life sphere gets smaller. Meanwhile, there are couples formed and new friendships discovered. Families come and spend time in the space as well as therapist and sometimes animals. Buildings should therefore be able to adapt to all these situations by being flexible and vivid.
One can never have enough of nature. Nature changes during seasons, even during the daytime and as such it is a natural indicator of time. It serves as a reference and helps position oneself in time and space. For every human being as well as for people with dementia, nature provides unique source of relaxation and stimulation. Access to nature relieves and freshens up, it provides opportunities for walks, gardening as well as for meditation and contemplation. Well-structured and designed outdoor space which leaves space for all of these activities and others can enhance the quality of life to a great extent. Equally important is bringing nature inside in form of plants or animals.
Use of materials which are not only pleasant to look at but also tactile and stimulating contributes to the overall richness of the environment. Without being offensive, natural, well-known materials are easy to understand for people with dementia. In balance with furniture and colors, materials can help accentuate and distinguish certain spaces. Unlike materials that are reflective, slippery or difficult to clean, well chosen materials can increase the overall experience of both people with dementia as well as their carers.
Enough storage space, short distances or clear overview all contribute to easiness of the care home. Smooth work of nurses saves their time and energy which can then be given to people with dementia.
4.2 Design

With all these guidelines in mind, I set out to come up with a design which would merge them together in a harmonious environment. The resulting care center is a conjunction of desired qualities, relations and atmospheres. Starting with requirements on the experience of a person with dementia, the building naturally started developing itself from the innermost place. Conventional approach of starting from a bigger scale proved to be inappropriate and the only natural way to think about the building was the one of a perspective of a person inside. Given the period of graduation, none of the drawings is completely finished but they already illustrate the main ideas of the design.

Thinking about everyday routines and challenges I slowly developed the plan from a small scale of private rooms to shared and outside spaces. Resulting design is a cluster of buildings and variety of outside spaces their articulation creates. The entrance as well as the most public functions are located in the center of this configuration and the further a person goes, the more private the spaces become.

Each building is a small assembly of spaces with different levels of privacy and activity. Each is naturally leading to another enhanced by cues of transition. Permanently accommodating eight people with dementia and their caregivers, each building also serves as a partial day care center. During the day, the most public part of every building welcomes a few temporary inhabitants. It allows people with dementia who still live at home but need some assistance to come, enjoy the activities and get used to the space. They are welcome to help and participate in daily life withing the building so that later if they need to move in, the change is not abrupt.

This most public space in the home takes a form of a shared living room with kitchen and dining area with access to a garden. It is a source of natural, stimulating activities, well-known to the residents. Divided in clear zones by ceiling heights, light levels and activities, it is easy to understand. Its core, central space of the building represents a recognizable landmark. It shelters a fireplace and serves as a hearth of the whole space. Visible from each important place in the building, it is a crucial point of reference. It is a shelter always to be found and always to provide security. Giving a feeling of being enclosed, it still opens up to the rest of the building by wide straddled arches.

The further from the core, the higher the level of privacy. Each step towards this intimacy is guided and emphasized by lowering both ceiling heights and levels of activity. Changing heights of ceilings simultaneously allows more daylight to enter the space and creates thus different light patterns.
Adjacent to a courtyard, two spaces running from the living room create a calm zone for relaxation and contemplation on each of its side. Each creates a link between the busy central space and private rooms, and offers a quiet place for small group of neighbours to meet. The courtyard with trees and flowers serves as an indicator of time as well as source of encouragements, sensations and relaxation. It is the first thing people see when they step out of their rooms. As that, it has the power to softly catch their attention and help them continue their way. Lowered window sill welcomes everyone to sit and enjoy the atmosphere. Important view lines are connected to this place and lead both to rooms as well as to the central space. Through the open sequence of spaces, smells and sounds can spread from the living room which further invites people to engage and go forward on their journey.

From the opposite end, the plan develops from a very private bedroom with easy access to a garden followed by a living room like space shared with another person. This is a place for being alone with a family, for being with a friend or for having a cup of tea at home alone. Leaving the private realm behind, one finds himself in a space which lays on a border. It is already open to the shared space with the courtyard but still remains personal, reassuring the person on his or her way. It is a place to sit and watch what is happening in the rest of the building while still being protected in a safe territory. It works as a support to engage with the public life and higher level of activity and at the same time, it marks clearly where the person’s room is. That makes it easier to locate it on the way back because various recognizable elements can be placed here such as a small chair, shoes, jackets or other relevant elements.
Zoning is enhanced by structure and materials. Permanent and core parts are made of concrete, covered by different roofs. The rest of the building is made of bricks, allowing for changes and different infill. There are few important aspects reappearing on different scales in the whole design. Creating smooth transitions from one space to another happens between rooms as well as between the building and its outside spaces. Subtle cues are used both inside and outside the building, the latter in a form of natural barriers. Providing security and freedom at the same time resulted in enclosing the garden and outside spaces by barriers which are not perceived as forceful but rather natural, such as a slope or a small stone wall.

In-between the buildings, various spaces come to life. People from the neighbourhood are welcome to continue working on their existing gardens while passing by an entrance. Restaurant with a refreshing beer, home made cakes and meals as well as different kinds of workshops and happenings mediate an informal meeting between generations. Because people with dementia cannot freely visit the city, the city has to come to them. At the edge of the site, there is a natural viewing point over the whole city of Prague and a way to it leads either through a ring around or directly through the care center, passing by the restaurant and small workshops. Relatives and friends are allowed to continue further inside, progressing from the center public life towards the more private, outer spaces.
Reflections

Although it was often difficult, I enjoyed working on this graduation very much. Because I could have chosen the topic and had a lot of freedom thanks to Explore Lab studio and my mentors, I could find my own way to do it. Having a personal experience with dementia was very helpful but double edged at the same time. On one hand, being involved in the problematic on an academic as well as personal level can sometimes be difficult and contra-productive. Dealing personally with the amount of new expert information about the disease itself and about ways to deal with it can sometimes be overwhelming. It is then easy to get bogged down by sensitivity of the problem and be less objective. On the other hand, it was very helpful because it gave me a strong motivation to start the report as well as to finish it. During the process, it also helped me better understand the problematic I was researching about. It gave me a good starting position and it helped me very much while working with people who have dementia as well as during all the site visits.

The following process of combining an academic research with a practical outcome has been a learning process as well. Defining themes and design principles for the design was certainly very helpful but the design process itself showed how double edged most of them really are. Already during the site visits I could see how some well intended measures did not work well or failed completely. On contrary, experiencing life within different nursing homes revealed things which were very relevant and which I would have never considered as such. That made me question some of the design steps and making decisions was sometimes difficult knowing dementia and its consequences. The design process also triggered further questions which I initially omitted in the research so the resulting work was developing itself in continuous circles. It was not at all a linear process which was sometimes hard to process in the written form. However, both in the report as well as in the design, I tried to do my best. I learned a lot myself and hopefully I will be able to use this knowledge further in my work.
Saying that there is nothing particularly special about designing for people with dementia and that the same spatial qualities would be equally pleasant to every other person at the end of this report might seem as depreciation of my own work. It is however the contrary. Because dementia, as sad and difficult it is, has the power to strip us, humans, from all our roles, statuses and expectations, it can clearly show what truly matters in life as well as in space. Learning from the disease brings us back to basic qualities we all share as human beings and which are equally beneficial to all of us. Unfortunately, what we have in common is very often hidden behind our lifestyles, expected behaviour or prejudices. As a consequence, we tend to forget about it and neglect the simple enjoyments of everyday life. We rush through them in order to catch up with something we might one day forget.

If there is something I have learned thanks to this graduation, it is that neither medicine nor architecture or other people alone can change or heal our lives. Architecture cannot do it now and it will not be able to do it once we have dementia or other disease. It can help us along the way but in the end, it is us ourselves who have the power. Architecture can open up to an evening sun, to nature, it can provide warmth and safety but we have to find the joy from these things ourselves.

So although our current lifestyle often suggest otherwise, learn to stop. Learn to feel good. Wear comfortable materials, touch pleasant things, listen to sounds that make you feel nice, smell new books more often. Eat good food with friends and family, sit in the sun and enjoy the breeze. Even if it sounds pathetic, learn to enjoy whatever else makes you happy. Learn to pay attention. Learn already now to enjoy even the smallest things and learn to be a better person because that is what one day we might have left.
Appendices

Appendix 1

Interview with Sara Pabst, music therapist

Interview with Sara Pabst, music therapist working in Graz was done in a written form due to the distance. Her answers were left in their original form with only minor changes.

Could you tell me a little bit more about your work? What exactly does your work consist of?

I’m a “Music therapist” in Austria. I work 10 hours a week in a memory clinic in Graz. In each department, there is a doctor and together with her/his team they ask me to work with certain patients. The most common reason for that is usually a big compliance difficulty (the patient doesn’t accept the treatment and shows aggressive, defensive or antisoial behaviour). In many cases, the person is not able to communicate verbally as this ability is already very often lowered or damaged. Verbal language is however only one form of contact out of many, and the nice thing about music therapy is that it does not have a problem communicating in other ways. So for example, playing instruments (rattles, drums, chimes, glockenspiel, lyre ...) is also one kind of a dialogue. To communicate in such other ways, as a music therapist, you should have a very keen sensorium to react on patients’ (musical) expressions - we call this ability “to go in resonance”.

What specific principles do you use related to people with dementia?

Basic principle of a music therapy is the factor of a relationship. That means that the relationship between me and the patient is part of the therapy and its fundamental aspect. In other words, I don’t assess the character of the patient but instead, I give him or her the feeling that he or she is accepted the way he or she really is. In music there is no “rating” - there is no good or bad music. Each human senses music and sound in a different ways, and each has different feelings and emotions. So I look carefully and “go into resonance” to see what kind of music or sound is suitable for the moment.

An important factor is also the TIME. In the “everyday-clinical flow” there is too much stress and little time for the nurses and doctors to sit next to the patients and spend time with them. So my therapy requires that patients have the impression that I have a lot of time for them. “I have no time to have stress”.

As a result I often have the experience that my “waiting” and giving people the time to sense their own feelings opens an inner, deeper and emotional process.

Furthermore, music and sound is vibration. We know that music, sound and vibration can stimulate the nerves. For that reason I also use specific instruments, which give a strong vibration and place them on patient’s body. When I play them, the patient can feel these vibrations and has the possibility to “feel his or her own body”, to feel the bodily boundaries. A lot of my patients have a hemiparesis (they had an apoplectic stroke) and cannot move parts of their body.

So it is true that with the help of music, people can relax to the point that certain aspects of their life can be reviewed?

Absolutely! I have specific instruments (monochord, hapi but also singing), which facilitate relaxation
- often combined with guided thoughts (focussing on the body, on relaxing thoughts, on feeling caring from the ground). Of course singing is also a “remembering” factor. Melodies and old texts (songs from childhood), can help to remember, can help to speak and tell about the nice and difficult parts of people's life.

**What makes music such a powerful tool?**

Music is one of the earliest elements in human life. Already the foetuses can hear the environment (in the 16th week of pregnancy), the sounds in the body of the mother, the rhythm of the heart beat.... so we are in contact with music much earlier than we start, for example, seeing things. The ear, the acuesthesia is one of the first working senses of humans.

**Do you think relaxation and reminiscence could also be achieved through other senses?**

Yes, the human has emotions, mind and the body. And working with the body - touch, body contact etc. can also help to remember thoughts. It can help to feel loved and protected. But music has - in my opinion - the widest range. Music does touch everybody!!! Music is never unaffecting. And to come in contact with sound, music doesn't require a special cognition, mind or intellect.

**How do you find out what kind of music each person likes?**

There are multiple ways to do so:

- By knowing something about the personal biography: each patient has a map, where relatives answer questions about the life of their loved one. But in most cases I don't need such information.
- By intuition and resonance
- By speaking with the patients
- By “trial and error”, and always with the important aspect of empathy, resonance and appreciation. If the patient is not able to “tell me” how he/she feels, I’m very intent in reactions (face, mimic, the rhythm of the breath, body movements). Humans “can speak” with me, without using the “normal” mediums of communications. I can feel if somebody is on the brink of weeping and I give time and space to express these inner processes.

**Where does the therapy that you do take place? Is there a special room for that or is it better if it takes places in a regular common room for instance?**

Many patients are too ill to stand up - so they are lying in the bed in a room of two patients maximum. This is very good. So I have a small carriage with all my instruments and I visit patients in their rooms. Three times a week I make a “Music therapy Group” - so 5-8 patients (who can go themselves or are sitting in a wheelchair) are brought to a bigger room, where we sit in a circle and have music therapy for an hour. There the focus is on getting contact with other humans, to interact, to be active, to experience community and to being secure.
# Appendix 2

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<tr>
<th>Level</th>
<th>Clinical Characteristics</th>
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<tr>
<td>1</td>
<td>No cognitive decline No subjective complaints of memory deficit. No memory deficit evident on clinical interview.</td>
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<tr>
<td>2</td>
<td>Very mild cognitive decline Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.</td>
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<td>(Age Associated Memory Impairment)</td>
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<td>3</td>
<td>Mild cognitive decline Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient's relatively poor performance; (c) word and name finding deficit becomes evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.</td>
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<td>(Mild Cognitive Impairment)</td>
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<td>4</td>
<td>Moderate cognitive decline Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of ones personal history; (c) concentration deficit elicited on serial subtractions; (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and place; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flatting of affect and withdrawal from challenging situations frequently occur.</td>
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<td>(Mild Dementia)</td>
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<td>5</td>
<td>Moderately severe cognitive decline Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives, e.g., an address or telephone number of many years, the names of close family members (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses' and children's names. They require no assistance with toileting and eating, but may have some difficulty choosing the proper clothing to wear.</td>
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<td>(Moderate Dementia)</td>
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<td>6</td>
<td>Severe cognitive decline May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and, sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will be able to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behavior, e.g., patient may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.</td>
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<td>(Moderately Severe Dementia)</td>
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<td>7</td>
<td>Very severe cognitive decline All verbal abilities are lost over the course of this stage. Frequently there is no speech at all - only unintelligible utterances and rare emergence of seemingly forgotten words and phrases. Incontinence of urine, requires assistance toileting and feeding. Basic psychomotor skills, e.g., ability to walk, are lost with the progression of this stage. The brain appears to no longer be able to tell the body what to do. Generalized rigidity and developmental neurologic reflexes are frequently present.</td>
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<td>People are dress up and assisted with small hygiene in shared rooms (no privacy)</td>
<td>Bathroom across the corridor</td>
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<td>People are assisted in private rooms</td>
<td>Shared toilet</td>
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<td>People are assisted in private rooms</td>
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<td>Shared rooms: no semi-private spaces allowed in the homes</td>
<td>Private rooms</td>
<td>Private shower and toilet</td>
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<td>Private rooms</td>
<td>Shower windows in a public space</td>
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<td>Private rooms</td>
<td>No windows in corridors</td>
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<td>Room is well lit</td>
<td>Ceilings have one window</td>
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<td>Rooms toned into warm colours</td>
<td>Rooms painted green</td>
<td>Reducened contrast</td>
<td>Reflective floors in the corridors</td>
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<td>Colour used throughout the corridors (not visible throughout the whole corridor)</td>
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<td>Change of patterns on the floors</td>
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