

# “Dementia-Friendly design for Aging Couples: An Architectural Perspective”

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Research Booklet

## Research booklet

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Designing for Care in an Inclusive Environment

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## Abstract

With a growing elderly population in the Netherlands, this also brings challenges for our existing housing options, as well as the care system. In particular, the risk of dementia significantly increases with age. About 68 percent of people with dementia in the Netherlands lives at home and gets care from their family or close social network; often their partner. When an informal caregiver can no longer manage the care for someone with dementia, it becomes a significant reason for considering admission to a nursing home or an assisted living facility. There are currently few options for both partners to continue living together when they wish to do so.

In order to explore the collective requirements of both partners, the following research question was answered; *'What living environmental features can support elderly couples who wish to live together while one of them experiences dementia, to maintain their shared living arrangements?'*.

Literature research, fieldwork, interviews and case studies show a number of design guidelines that can be considered when designing for people with dementia, as well as their unaffected partner. For the partner with dementia, 'wayfinding', 'accessibility', and creating a 'home-like small-scale environment' were found to be important to consider while designing for them. For the 'healthy' partner, it was found that is important for them to be able to 'live a normal life', to 'take some pressure off' of them, to 'ensure safety of their partner with dementia', and to 'be able to do things together with their partner and separately'.

As the elderly population continues to expand, it is crucial to explore innovative living alternatives to ease the strain on informal caregivers and the healthcare system.

**Key words:** Dementia, living together, architecture, informal caregiving, housing options, healthcare.



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Introduction

# Dementia-friendly design for aging couples

## Introducing the topic

With the growing elderly population in the Netherlands (in Dutch called 'vergrijzing') this also brings challenges for our existing housing options. Because there are more and more elderly, there is also an increasing amount of people that need care. In particular, the risk of dementia significantly increases with age. In 2015, the government implemented reforms for long-term care to ensure the future affordability of healthcare. To do this, recent policies have been focused on enabling people to live at home for longer. As a result, seniors often rely on services such as home care and informal caregiving (mantelzorg) (SCP, 2017).

Just to sketch an image of the current situation; 1 in 5 people in the Netherlands develops dementia (Alzheimer Nederland). About 68 percent of people with dementia lives at home and gets care from their family or close social network (Cijfers rond Dementie, 2023). There is a total of about 350.000 of these informal caregivers that take care of someone with dementia, with 31 percent dedicating more than 40 hours per week to this responsibility. Half of these informal caregivers live together with the person with dementia. When an informal caregiver can no longer manage the care for someone with dementia, it becomes a significant reason for considering admission to a nursing home or an assisted living facility.

This raises question for the partners of the person with dementia whether they want to move with their partner to a care facility. It is important for the spouse to consider if they can handle to live in an environment with other individuals with care needs (Alzheimer Nederland). In the current healthcare system, there are few options for both partners to continue living together when they wish to do so. According to Zorgkaartnederland, there are 1,735 nursing and care homes in the Nether-

lands. Out of these, only 510 offer apartments for a couple to live together.

As the elderly population continues to expand, it is crucial to explore innovative living alternatives to ease the strain on informal caregivers and the healthcare system.

## Problem statement

Many elderly couples have been living together for multiple decades, and would like to keep on living together. However, when one spouse starts developing dementia, living together will become increasingly burdensome on their partner that has to care for them. As has been mentioned before, there aren't many housing options for this situation. How do you design a living environment where some inhabitants need care, and others don't? How do you deal with later stages of dementia, and how can couples still remain a sense of couplehood for as long as possible, instead of a patient-caregiver relationship?

The documentary "Uit elkaar" (separated (from each other)) also addresses these questions in a very touching way. It is a portrait of six couples who, as best as they can, try to find a place for dementia in their lives. Dementia changes their relationship; the healthy partner suddenly becomes not only a beloved but also a caregiver. The caregivers lovingly try to adapt to their partner's illness process. However, the care becomes increasingly burdensome. So burdensome that, at a certain point, it is no longer possible to continue living at home. Dementia forces them not only to say goodbye to a loved one but also to a shared life.

More than half of the caregivers for people with dementia in the Netherlands experience moderate to heavy levels of burden, and one in eight even admits to being severely overwhelmed (Dementiamonitor mantelzorg, 2022). New living solutions could make it possible for couples where one faces dementia to maintain their shared living arrangements and relieve the burden on the informal caregiver.

## Positioning of the research

An overview of the found literature on the topics concerning dementia, architecture, informal caregiving, and living together with dementia are structured in the presented diagram. There has already been extensive research on the ways in which the living environment impacts the well-being of people with dementia. In general, they can be categorized in the themes of 'orientation and way-finding', 'environmental attributes', 'Home-like environment', and 'outside environment'. Research can also be found on the living environmental needs of the 'healthy' partner. These highlight the themes of 'changes within the relationship', 'the caregiver burden', and 'doing things together and apart'. Although a lot of information can be derived from existing research, it is very valuable to include information from self-conducted interviews in the context of the Netherlands. An overview of these findings are shown in the following image. The primary and subsidiary research questions will be derived from this diagram.

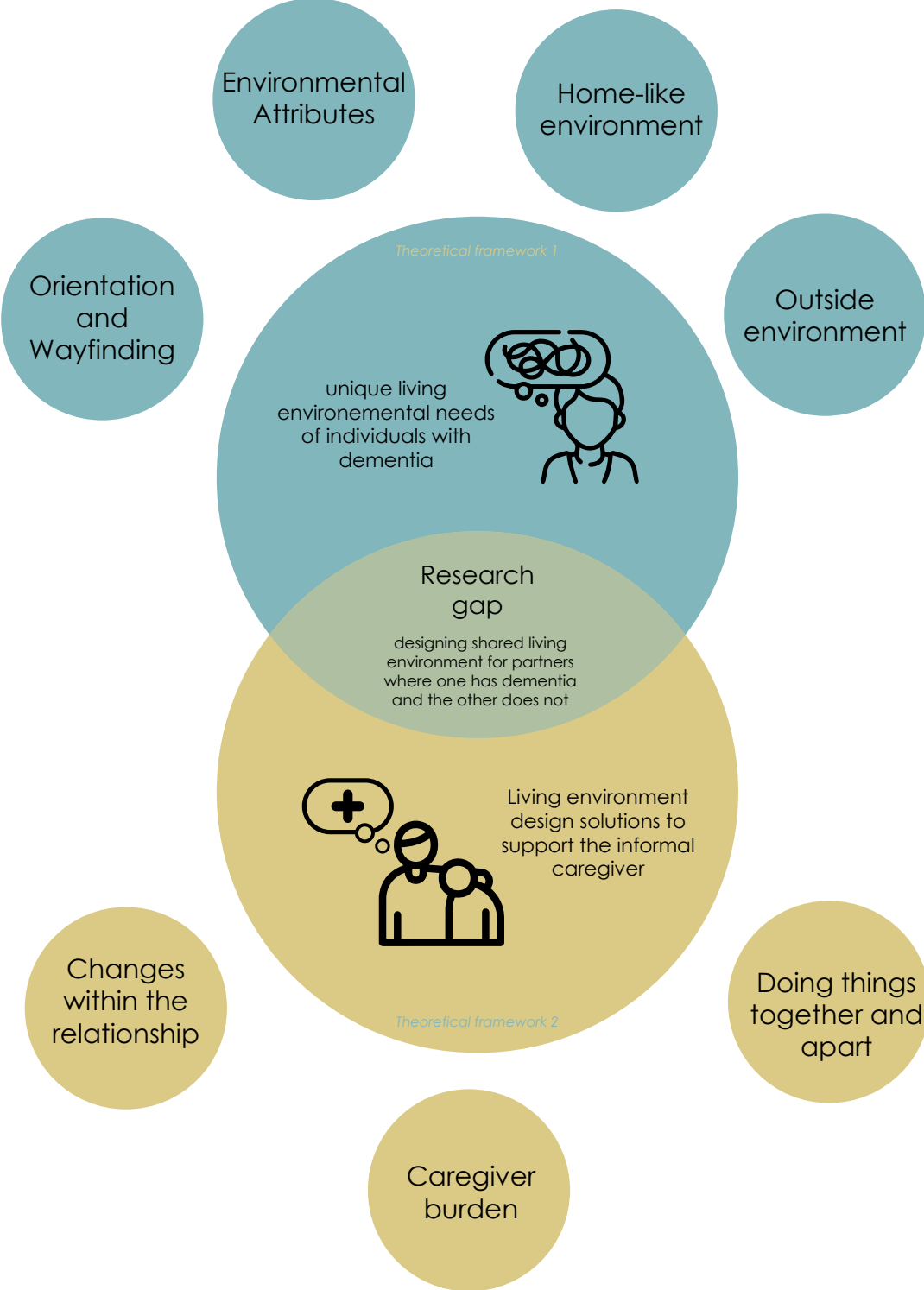
## Goal

Although there is separate research on the unique living environmental needs of individuals with dementia, and the themes for maintaining a fulfilling life for both partners in the context of dementia, there is a research gap where these two are combined. The goal of this research is therefore to identify and propose design solutions that cater the collective requirements of both individuals. This involves recognizing the needs of the person with dementia while also acknowledging the partner's role as an informal caretaker and cohabitant. This research aims to concentrate more on the living environmental scale, to present a toolbox for designers.



Fieldwork interviews

Kuliga, Berwig & Roes, 2021  
 Van Buuren & Mohammadi, 2022  
 Marquardt, 2011  
 Bielsten et. al., 2018  
 Marquardt, Bueter & Motzek, 2014  
 Ganoo-Fletcher & Saulue, 2023



Fieldwork interviews

Bielsten et. al., 2018  
 Chiao et. al., 2015  
 Gopinath, Peace & Holland, 2018  
 Hellström, Nolan & Lundh, 2005

Image 0.1: categorisation and interconnectedness of the literature.

## Theoretical framework

Diagram 0.1 shows the two overarching themes that are found in the literature. The first of design interventions for people with dementia, and that of how the living environment can support the 'healthy' partner and relieve the burden associated with caregiving.

The first framework is supported by for example the article by Marquardt, Bueter, and Motzek (2014), which summarizes the broad spectrum of research in the field of design for people with dementia. In this article, a total of 169 studies were identified and categorized thematically into four main groups: basic design decisions, environmental attributes, ambience, and environmental information. Additionally, matrices were used to demonstrate the impact of interventions on the behaviour, cognition, functionality, well-being, social abilities, orientation, and care outcomes among individuals with dementia. The outcomes within these categories is also confirmed by the other reviewed literature (see diagram 0.1). The conclusions that have been established in this literature can be easily be translated into design guidelines later on in the research.

The same applies to the second theoretical framework. This focusses on living environment needs of the 'healthy' partner as an informal caregiver. One of literatures that was found is that of Bielsten, Lasrado, Keady, Kullberg, and Hellström (2018). This research focusses on the need for the partner to maintain a fulfilling life. It indicates four main themes with related subthemes that could serve as suitable focal points for maintaining a fulfilling life for both partners in the context of dementia. Some highlights of this research are that couples confirmed the importance of meeting peers but none of the interviewed couples has had the opportunity to do so. This framework provides guidelines for the activities that are impor-

tant for the well-being of both spouses, such as taking a walk, having a connection with the neighbourhood and meeting friends and family. Also the importance of doing things separate from each other is important for the well-being of the healthy partner, as well as the partner with dementia.

These frameworks offer a start for structuring the first two chapters. The first chapter will focus on the needs of the partner with dementia, and the second on those of the 'healthy' partner. The third chapter will test the found design guidelines on case studies.

## Hypothesis

My hypothesis is that an innovative design for a shared living environment for people with dementia and their partners can effectively support couples in maintaining shared living arrangements and consequently relieve the caregiver burden. By developing a series of design guidelines for both individuals, the living environment can be designed to cater the collective requirements of both partners. A shared living environment does not necessarily have to mean that partners live in the same home, they could also live separately and still engage in shared activities outside of their living spaces.

## Research questions

The main research question for this thesis will be:

**What living environmental features can support elderly couples who wish to live together while one of them experiences dementia, to maintain their shared living arrangements?**

To answer this question, I will answer the following sub-questions:

1. What are the different stages of dementia and what are their needs in their living environment?
2. What living environmental features are important for the partner of someone with dementia?
3. What kind of living environments do already exist for elderly couples where one experiences dementia?

## Research scope and limitations

There are certain limitations on the scope and quality of this study because it must be completed within a specific time period and with a finite amount of resources.

As this research takes place in the Netherlands, the findings may not be applicable to a wider range of contexts. The problem statement is specific to the Netherlands, addressing the shortage of housing options in the current healthcare system for both partners, one healthy and one with dementia. This issue may not be relevant in different cultural and social contexts of other countries. Additionally, the research focuses solely on couples where only one partner has dementia, which may limit the relevance of the outcomes to scenarios involving both partners with dementia.

## Methods

To answer the research questions, different types of research will be conducted. This segment will elaborate how to implement and execute these distinct research techniques. How each research method is applied to the different research questions, and how they subsequently answer the main question of the research, can be found in the research scheme. The two theoretical frameworks that have been established, will form the base for the fieldwork observations and interviews.

### Literature study

An important criterion for the literature study is that it needed to revolve around dementia, caregivers, and living environmental features. The foundation of the research will consist of a literature review of books and articles as well as an analysis of existing research, concerning the topic of dementia design and couples living together with dementia. Exact information can be found in the 'Theoretical framework' section and bibliography. The literature review will provide answers to all three of the sub-questions. To find relevant literature, there will we searched using key-words such as 'dementia', 'informal caretaker', 'living together', 'couplehood', and 'architecture'. Additionally, an examination was conducted on the articles cited within the research that was found.

### Fieldwork/observations

During the fieldwork week I will visit two care facilities for people with dementia. I will also spend the night there to get a complete view of what happens there. Here I will make observations of people's daily lives and routines. I will make pictures of the elements I want to highlight in my research. For the observations, I will specifically look if I can recognize the living environmental attributes that have been established in the studies literature.

### Interviews

To answer the research questions, interviews will be conducted with healthcare providers during the fieldwork week and partners/family members of individuals with dementia residing there. The responses will likely overlap at times, providing complementary information together with the literature. A list of all the interview questions can be found in the appendix.

#### *Caregivers of people with dementia*

I want to learn from the experience of caregivers what the needs are of people with dementia, specifically in their living environment. This will help answer the first research question. I would also like to know from the caregivers if they have experience where the informal caregiver of a person with dementia still cares for them, and what kind of arrangements are made where they as a formal caregiver jump in. I would like to know from them how they think the living environment influences people with dementia.

#### *Partners of someone with dementia*

With the interviews of a partner of someone with dementia, I want to get to know what activities couples still do together, where they need specialized care and how dementia has impacted the life of both partners. This question will help to answer the second sub-question. Examples of questions are: What is it like to live with someone with dementia? What impact did this have on your life?

#### *family members*

Depending on whether the person with dementia still lives in an independent home or care institution, I want to have a conversation with family members of individuals with dementia. Asking questions like; What was the selection process for considering future housing options? Why did you choose this location?

## **Case studies**

Case studies do not permit generalization per se but may provide insights that can be 'transferred' or 'recontextualised' to other like situations. By testing them on the design guidelines that have been conducted while answering the first and second sub-question, a review can be made about the projects. The selection of these case studies is based on several criteria: the facility must cater to individuals with dementia and include apartments designed for couples.

## **Establishing design guidelines**

Combining the information from the fieldwork and literature, a number of design guidelines will be established. These will apply to the themes that can be found in figure 0.1. The guidelines are ranked by importance on a scale from one to three stars, based on how many times they were mentioned in interviews and literature. The conclusion will combine all the guidelines, looking where they overlap between those of the healthy partner and the partner with dementia.

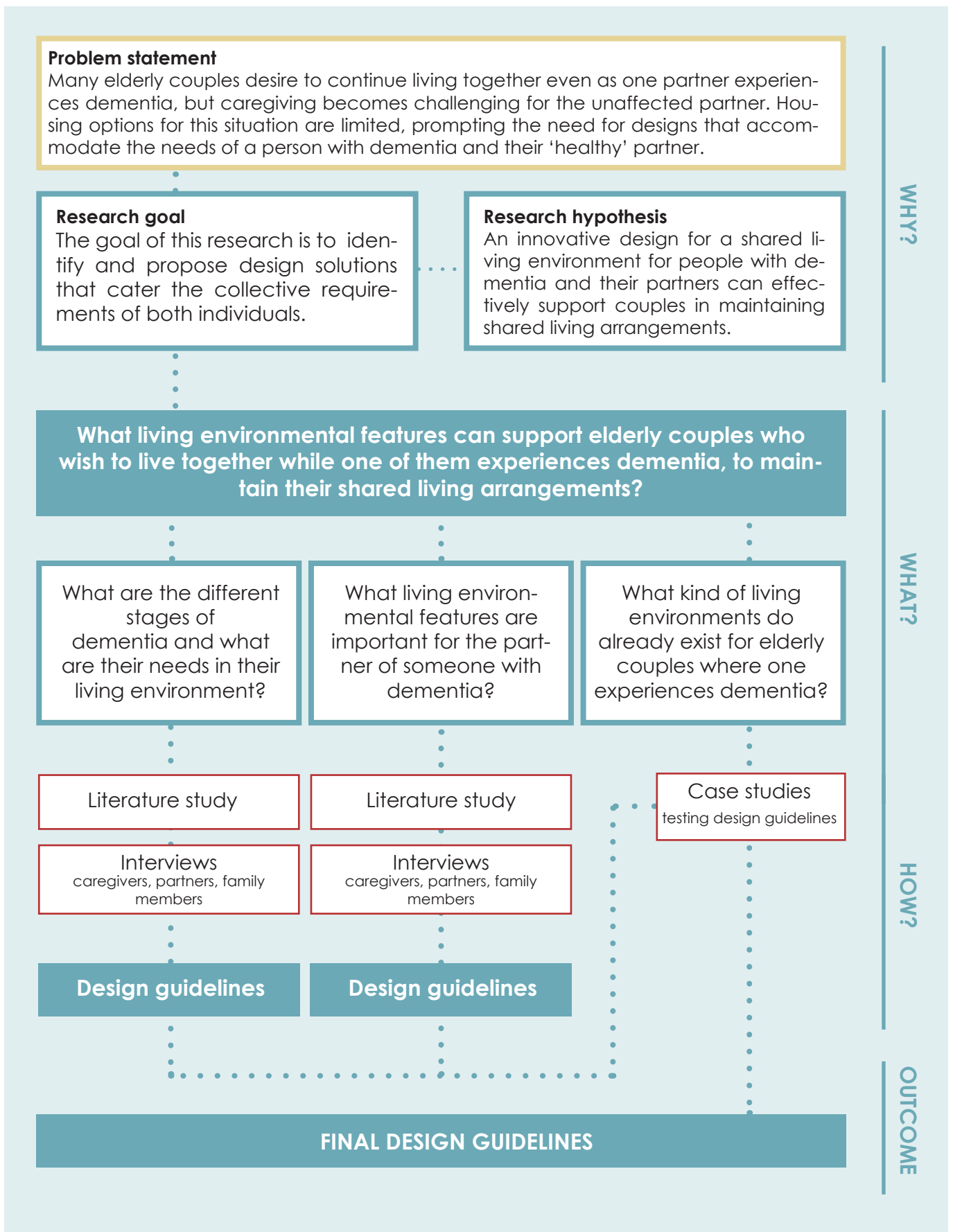


Image 0.2: Research scheme.

## Definitions

### **Living environment**

The living environment refers to the immediate surroundings, spaces, and conditions in which individuals or communities reside and interact on a daily basis.

### **Dementia**

Dementia is an umbrella term of multiple forms of this illness. Alzheimer's is the most common form of dementia, and therefore I will focus on this type. Alzheimer's can range from mild symptoms to someone being very forgetful and not being able to self-suffice. Dementia is not a fixed illness, but instead, it progresses.

### **Elderly couples**

Elderly is a subjective term and often used for people who are 65 years or older. Its main traits include unemployment and age-related impairments. (NHS England, n.d.)

### **Caregiver burden**

Zarit et al. (1986) defined the caregiver burden as 'the degree to which a carer's emotional or physical health, social life or financial status had suffered as a result of caring for their relative' (p. 261).

## Chapter 1

# Exploring dementia stages and living needs

*What are the different stages of dementia and what are their needs in their living environment?*

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## 1.1. Introduction

Dementia is not a linear illness that influences everybody in the same way. As the dementia progresses, the characteristics can change or worsen (Alzheimer Nederland, 2023). Because this research has an architectural and built environment focus, this chapter aims to provide design guidelines that are specific for people with dementia.

First, this chapter will explore how dementia develops over time, and give a brief explanation of the different types of dementia. Subsequently, the influence of the living environment on the well-being of people with dementia will be explored. Altogether this will result in a number of design guidelines that cater to the needs and well-being of a person with dementia.

## 1.2. Stages of dementia

Dementia is an umbrella term used to describe different forms such as Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy Body dementia. These are all illnesses that affect a person's memory, thinking, and the ability to perform daily activities (World Health Organisation, 2023). As a result, individuals affected by dementia require support for various everyday activities, and their need for care intensifies as the disease progresses.

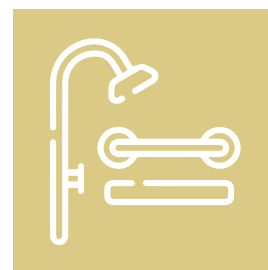
While the progression of the disease varies for each individual, dementia is often categorized into stages. These stages can assist doctors in making decisions about treatment or medications and provide healthcare professionals with insights into what to observe. The stages represent an 'average' course of the disease, and they are not sharply defined, overlapping with each other. The exact progression of dementia depends on the type of dementia and the individual affected (Alzheimer Nederland, n.d.).

One commonly used way to divide dementia in stages, is in 7 stages, ranging from no symptoms to very severe cognitive decline. Although staging can be a valuable tool for healthcare professionals to communicate about the general course of the disease, make treatment decisions and provide support, it should be used with caution. Individualized, person-centered care remains crucial for addressing the complexities of dementia. Rather than solely emphasizing cognitive decline in individuals with dementia, it is essential to shift the focus towards recognizing what they are still able to do. The living environment plays a crucial role in this perspective, as it should be designed to support the capabilities of individuals living with dementia.

Starting at stage 3, the symptoms become evident and recognizable as those of demen-

tia (Halstrom, 2023). By stage 5, individuals with dementia require consistent care to assist with Activities of Daily Living (ADLs). This transition also impacts the necessary adjustments in the living environment. For instance, caregivers might require additional space in the bathroom to aid someone in using the toilet or during bathing. As early as stage 3, there is a decline in someone's wayfinding abilities, making it beneficial if the environment is designed to support individuals dealing with this challenge.

People with dementia usually move to a care facility around the later stages, since they are encouraged by the Dutch government to live at home for as long as possible. By then, taking care of someone can become too hard for the partner that lives with them. This is when they might decide to get help from a care facility that can provide more specialized and thorough assistance.



### **Additional space in bathroom**

*Halstrom, 2023*

To make it easier for caregivers to help a person with ADL's such as showering, changing clothes or going to the toilet.

Stage	Diagnosis	Level of cognitive decline	Signs and symptoms	Level of care
<b>1</b>	No dementia	Normal behaviour	<ul style="list-style-type: none"> <li>- Normal function</li> <li>- No memory loss</li> </ul>	<ul style="list-style-type: none"> <li>- No care needed</li> </ul>
<b>2</b>	No dementia	Very mild	<ul style="list-style-type: none"> <li>- Losing track of familiar objects</li> <li>- Inability to recall names of friends, family members and former acquaintances</li> <li>- Age-associated memory impairment.</li> </ul>	<ul style="list-style-type: none"> <li>- No care needed</li> </ul>
<b>3</b>	No dementia	Mild decline	<ul style="list-style-type: none"> <li>- Increased forgetfulness</li> <li>- Getting lost while traveling</li> <li>- Difficulty with wayfinding and poor orientation</li> <li>- Decreased work performance</li> <li>- Difficulty finding the right words</li> <li>- Challenges with organization and concentration</li> </ul>	<ul style="list-style-type: none"> <li>- Does not have a major impact on day-to-day functioning.</li> <li>- Seek medical advice</li> </ul>
<b>4</b>	Early-stage	Moderate decline	<ul style="list-style-type: none"> <li>- Social withdrawal</li> <li>- Emotional moodiness</li> <li>- Lack of responsiveness</li> <li>- Reduced intellectual sharpness</li> <li>- Trouble with routine tasks</li> <li>- Forgetting recent events</li> <li>- Denial of symptoms</li> </ul>	<ul style="list-style-type: none"> <li>- Need for doctors and caregivers to observe hallmark signs that dementia is getting worse.</li> </ul>
<b>5</b>	Mid-stage	Moderately severe	<ul style="list-style-type: none"> <li>- Pronounced memory loss, including personal details and current events</li> <li>- Wandering</li> <li>- Confusion and forgetfulness</li> <li>- Disorientation and sundown syndrome</li> <li>- Further reduced mental acuity and problem-solving ability</li> </ul>	<ul style="list-style-type: none"> <li>- Need for caregiver to help perform ADLs * such as dressing or bathing.</li> <li>- More intense support and supervision needed</li> </ul>
<b>6</b>	Mid-stage	Severe	<ul style="list-style-type: none"> <li>- Sleep difficulties</li> <li>- Urinary or fecal incontinence</li> <li>- Aggression and anxiety</li> <li>- Personality changes including paranoia or delusions</li> <li>- Inability to perform ADLs</li> <li>- Pronounced memory loss</li> <li>- Inability to recognize loved ones and caregivers</li> </ul>	<ul style="list-style-type: none"> <li>- Need for caregiver to help perform ADLs such as eating, using the toilet and other self-care</li> </ul>
<b>7</b>	Late-stage	Very severe	<ul style="list-style-type: none"> <li>- Inability to speak</li> <li>- Lack of physical coordination and the inability to move without help</li> <li>- Impaired bodily functions</li> </ul>	<ul style="list-style-type: none"> <li>- Person can no longer care for themselves.</li> <li>- Full time care necessary</li> </ul>

Image 1.1: 7 stages of dementia. With each stage the impact on the surroundings of the person with dementia increases, as well as their need for care (Halstrom, 2023).

\* ADLs: Activities of Daily Living

### 1.3. Influence of the living environment

Dementia is associated with a high individual burden both for people affected by the disease and their caregivers. A lot of research has been conducted on the influence of the living environment on the well-being of people with dementia. This is of importance because it means that designers can influence the well-being of a person by making certain design decisions to relieve the burden of dementia on the individual, but also their caregiver.

#### 1.3.1 Orientation and Wayfinding

One crucial element of individuals with dementia is the loss of memory-related sense of place, time, and identity. Dementia patients may notice a disruption or even loss in their sense of time. Sometimes they are unable to determine the day or season.

The **layout of a building** has a big impact on the wayfinding ability of people. For example, long corridors have a negative impact on residents' behaviour – they show higher restlessness and anxiety. The floorplans should also reduce decision making and allow visual access and overview (Marquardt, 2011).

The study by Van Buuren and Mohammadi (2022) evaluated the floorplans of 12 care facilities on 14 criteria that support wayfinding for seniors with dementia. This study shows how design criteria and design typologies are interrelated. The 14 criteria are included in the design guidelines at the end of this section. The study found for example that a floorplan layout system with one straight corridor is most suitable for supporting wayfinding skills for seniors with dementia.

Additionally, a **small-scale living environment** ensures that residents can easily navigate and maintain an overview, as well as making them less behaviourally disturbed (Marquardt, Bue-

ter & Motzek, 2014). Studies also observed that small-scale units improved residents' social abilities and communication skills.

The benefits of a small-scale living environment became evident during the fieldwork week. When comparing two cases—one with living groups consisting of 7 residents and the other with 25 inhabitants per department—it is observable that the residents in the latter exhibit more disruptive behaviour. According to a caregiver (fieldwork interview 3), the difference is primarily that the care is tailored to the individual. The small-scale care facility she works at pays careful attention to each resident's preferences regarding waking up, meal times, indoor-outdoor activities, and going to bed.

**Environmental cues** (which comprise of signage, furnishing, lighting, colors, etc.) also promote wayfinding (Marquardt, 2011). Personal cues, such as written names, portrait-type photographs of residents as young adults, and personal memorabilia, were positively correlated with the residents' ability to locate their room or identify belongings.

Wandering is quite common for people with dementia and may be due to a number of reasons including (but not limited to) disorientation in a changed environment, loss of memory, excess energy, search for the past, expressing boredom, confusing night with day, continuing a habit such as long walks, agitation, discomfort or pain, belief they have a job to do and an inability to differentiate between dreams and reality (Hayne & Fleming, 2014). It is common to incorporate a wandering path into the design of a dementia care facility to **enable wandering to take place safely**. Examples of these wandering areas include gardens and areas from which they can safely observe various activities, such as children playing, without being over-stimulated.



Image 1.2-1.3: Examples of personalized front doors



### Visual accessibility between locations

*Kuliga, Berwig & Roes, 2021 + Van Buuren & Mohammadi, 2022*

To stimulate better wayfinding for people with dementia.



### Safe wandering areas

*Hayne & Fleming, 2014 + interviews*

Provide safe wandering areas inside as well as outside. People should be able to wander and return easily back home. For example, a park environment.



### Small scale building/living

*Marquardt, 2011 + Marquardt, Bueter & Motzek, 2014 + fieldwork interviews*

for overview and easy navigation. Maximum of 8 residents living together.



### Personal furniture and elements

*Interviews + Bielsten et. al., 2018*

Being able to furnish your room as you like, to foster independence. For example a personalized front door for recognizability.



### Utilize kitchen or living room as reference points

*Marquardt, 2011 + Van Buuren & Mohammadi, 2022*

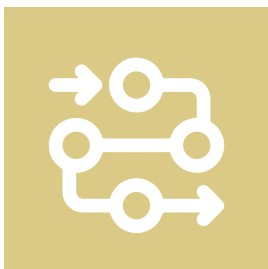
Spatial proximity of kitchen, dining, and activity rooms as meaningful reference points. Best located at the end of the corridor.



### Circulation system of straight corridors

*Van Buuren & Mohammadi, 2022*

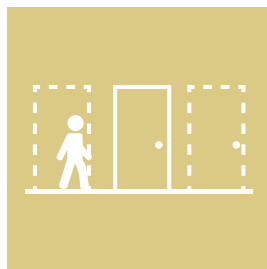
Corridor should be short in length and have a spacious width that has enough room for two passersby. Entrance doors alongside corridor.



### Sequence of spaces

*Van Buuren & Mohammadi, 2022*

Sequence of spaces in the house should be in the line of entrance, living room, and individual room of the resident.



### Decrease amount of repetitive doors

*Van Buuren & Mohammadi, 2022*

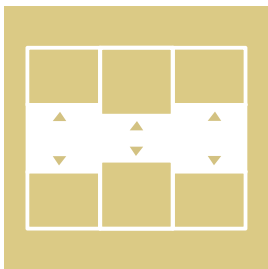
Decrease amount of doors in the corridor and living room.



### View outside from the corridor

*Van Buuren & Mohammadi, 2022*

Entrance of natural daylight. Make use of natural daylight and view outside in the corridor.



### Rhythmic niches in hallways

*Van Buuren & Mohammadi, 2022*

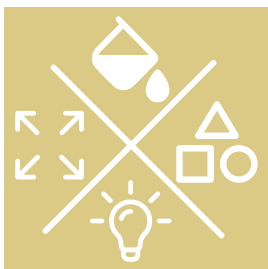
Rhythmic niches in corridors for differentiation and better wayfinding.



### Spaces for both retreat/privacy as well as social inclusion

*Kuliga, Berwig & Roes, 2021 + interviews*

To prevent over stimulation.



### Differentiations in size, form, color, and lighting

*Marquardt, 2011*

In order to distinguish and find rooms with a comparable meaning or function.



### No use of elevators

*Hayne & Fleming, 2014*

All rooms on the same level. The high stimulation of elevators can cause a dramatic change in behaviour.

### 1.3.2. Environmental attributes

This section will focus on the the senses of people with dementia. As cognitive function deteriorates, the world is experienced at a sensory level, with reduced ability to integrate the sensory experiences to understand the context (Behrman, Chouliaras & Ebmeier, 2014). Therefore, people with dementia are very sensitive to sensory experiences and their environment needs to be managed carefully to make it understandable, comfortable, and (if possible) therapeutic.

#### *Acoustics*

High levels of noise are associated with increased wandering and aggressive and disruptive behavior (Marquardt, 2014), which means that it is important to reduce unnecessary stimulation from sound. High stimulation (as measured by agitation levels) has been typically found to occur in elevators, corridors, nursing stations, bathing rooms other residents' rooms and common rooms (Hayne & Fleming, 2014). It is therefore important to apply acoustic insulation in these rooms, by means of using sound-absorbing materials. Noise in common rooms can be reduced by being able to close off a certain part of the room.

Besides reducing unwanted sounds, it is also important to highlight helpful sounds (Hayne & Fleming, 2014) such as bird song, wind rustling through the trees and water features in outdoor areas, familiar music, the clock chiming every hour, or the kettle whistling. In other words, creating a home-like environment for familiar acoustics. However, these sounds should not be too loud.

#### *Lighting*

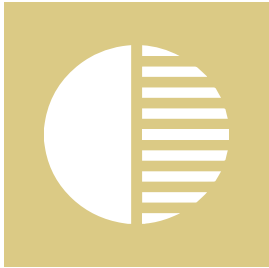
Many elderly people are not exposed to high enough luminance levels to maintain their internal clock (Behrman, Chouliaras & Ebmeier, 2014). This is due to a combination of lack of

time spent outdoors, and a poorly lit indoor environments. Adequate lighting should therefore be prioritized, as it also may lead to decreased disruptive behaviour (Marquardt, Bueter & Motzek, 2014).

#### *Colors, contrast and patterns*

Considering that visual impairments are frequently found with elderly, and therefore also in people with dementia, this needs to be considered in design. Contrast and especially light–dark contrast allow us to effectively differentiate contours, depth, shape, and objects in the environment. As a result, low contrast makes it harder for us to read our environment (O'Connor, 2020). However, caution is necessary when using patterns and dark lines on flooring, which may be found confusing and even cause falls (Marquardt, Bueter & Motzek, 2014).





### Colour or textural contrast

Ganoo-Fletcher & Saulue, 2023 +  
O'Connor, 2020 + Marquardt, Bueter &  
Motzek, 2014

To define borders, establish special zones, and aid in orientation and wayfinding for the visually impaired.



### Personal furniture and elements

Hayne & Fleming, 2014 + interviews

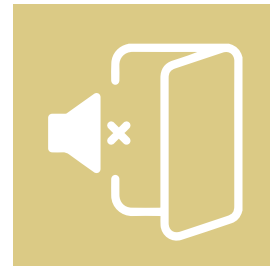
For a homelike environment with materials that



### Sufficient lighting indoors

Marquardt, Bueter & Motzek, 2014;  
Behrman, Chouliaras & Ebmeier, 2014

To maintain a person's internal clock and to decrease disruptive behaviour.



### Reduce noise by closing off rooms

Marquardt, 2011 + Van Buuren & Mohammadi, 2022

Reduce unnecessary stimulation from sounds.



### Differentiations in size, form, color, and lighting

Marquardt, 2011; O'Connor, 2020 +  
Marquardt, Bueter & Motzek, 2014

In order to distinguish and find rooms with a comparable meaning or function.



### Windows open to nature for positive sounds

Hayne & Fleming, 2014

Stimulate positive sounds from nature.



### Acoustic insulation

Hayne & Fleming, 2014

Reduce unnecessary stimulation from sounds.

### 1.3.3. Home-like environment

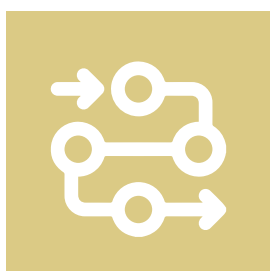
The importance of a non-institutional character of long-term care facilities is not only stressed in literature (Marquardt, Bueter & Motzek, 2014; Hayne & Fleming, 2014), but also in interviews with people with dementia, their close family and caregivers (fieldwork interviews 2 and 5). Being able to bring your own furniture and personal elements makes a room feel more familiar and safe. A homelike, personalized environment also has positive effects on residents, such as fewer behavioural problems and improved eating behaviour. It also supports residents' engagement in daily activities and informal social interactions.

Facilities with a homelike environment often-times provide a frame for less institutional care routines. For example, at a small-scale facility that was visited, the inhabitants helped with cooking, and other chores like folding laundry. These activities also contribute to the feeling of a real home, and not like that of a care facility. At this care facility, the residents could also wake up whenever they wanted.

In contrast, at another care facility for people with dementia that was visited, the residents had to wake up at a certain time everyday to be on time for breakfast. The rooms of residents

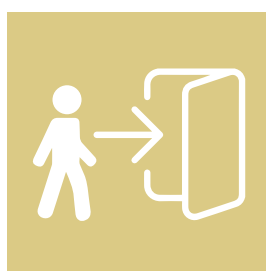
were not really seen as their private space, as the caregivers would come in without knocking. The daughter of a couple that lived their described that they had to put a sign on the door to ask them to knock. This is also a question of respecting people's privacy.

A homelike environment also means freedom of choice. In your own home, you are able to go outside whenever you want to, and you can sleep in if you want. Being forced to do, or not do, something, can cause a lot of stress to people with dementia (fieldwork interview). Certainly, having the freedom to go outdoors and having more items in a room can introduce additional risks. A caretaker notes that even the everyday environment poses its own set of hazards, such as uneven paths both indoors and outdoors. However, she believes that these challenges are beneficial for the residents, as they encourage greater physical activity.



**Sequence of spaces**  
*Van Buuren & Mohammadi, 2022*

Sequence of spaces in the house should be in the line of entrance, living room, and individual room of the resident, just like in a regular home.



**Garden directly accessible**  
*Ganoo-Fletcher & Saulue, 2023*

The garden should be levelled and accessible from the inside for people with or without wheelchairs.



**Personal furniture and elements**  
*Hayne & Fleming, 2014 + interviews*

For a homelike environment with materials that



*Image 1.4-1.5: Living room and personal room of a small-scale dementia living group. Inhabitants are allowed to bring their own furniture and also put it in the living room. They can also decorate and paint their room however they want, Enhancing the feeling of a home-like environment.*

### 1.3.4. Outside environment

The previous sections already touched upon the importance of the outside space, for example that it can provide positive stimuli such as sounds of birds and wind through trees, and natural light. Although the previous guidelines so far mostly touch upon the design of the inside environment, the design of the outside landscape should also be designed to support the physical and emotional well-being of people with dementia (Ganoo-Fletcher & Saulue, 2023).

A couple that lived in a closed department for people with dementia (fieldwork interview 5), told that some inhabitants wouldn't leave their floor for months, because they couldn't leave due to the elevator. Because of a shortage of staff, they also could not take them outside. In contrast, at another care facility that was visited, the inhabitants could walk outside whenever they wanted (fieldwork interview 2). They also stayed active by working in the garden, taking care of the farm animals and going to the swimming pool. Not only does this keep people active, they also have a goal for the day. The living environment of people can therefore stimulate people to stay active. It should also be noted that most people at the first facility were in a wheelchair, whereas there were almost no people with a wheelchair or walker at the second facility (fieldwork interviews 2 and 5).

To keep people with dementia physically active, it is important for them to be able to do this in an outside environment, as this gives them more freedom of movement than an inside environment. Architecture office PRP has made a factsheet that outlines the fundamental principles to consider to cater the landscape design to the needs of individuals with dementia, their families, and care provi-

ders (Ganoo-Fletcher & Saulue, 2023). These design principles are based on their experience in creating external spaces for older people and vulnerable adults. The report distinguishes 4 main themes in landscape design for people with dementia.

The first theme of creating a well-designed landscape is that of **access, movement and orientation**. The garden should be levelled and accessible from communal rooms or private patios. Not all elderly people are equally physically mobile, which is why the garden should be accessible to wheelchairs. The routes should be laid out in a legible manner, and by removing barriers, confidence and independence will be promoted. Navigation markers such as strongly scented plants, garden features, sculptures or memorable features will improve wayfinding. In terms of wandering, circular walking routes can be implemented so residents will return to their starting point. Routes must never terminate at dead ends and exit gates should be concealed.

The next theme is that of **memory and mental mapping**. Particular images and smells can stimulate memories - giving a strong sense of normality, security and refuge. Engaging in gardening activities can also bring back memories. Examples of activities are hanging the laundry, picking flowers and growing herbs and vegetables for the kitchen.

A landscape can offer a lot in terms of **sensory stimulation**. Foremost, the surrounding environment should offer a peaceful setting. To enhance a sense of security, the pathways, trees and features can be illuminated, this also enables residents to enjoy the gardens at night. Through colour or textural contrast, the landscape will be better readable for the visually impaired. With raised beds, the plants will

be more accessible to wheelchair users and those who have difficulty bending.

Lastly, in terms of **shelter and shade**, a pergola or climbing plants can be used to create shade. Plants can also be used to reflect 'seasonal change', stimulating a resident's connection to natural timelines and chronology. During winter, a winter garden or a heated summer house enable access to a garden environment at all times of the year.



*Image 1.6-1.7: garden at dementia care facility. On the left; raised beds and vegetable garden, on the right; connection to garden from apartment. There is a birdhouse that people can watch from the inside*

**A DAY IN A ...**

# Dementia Friendly Garden

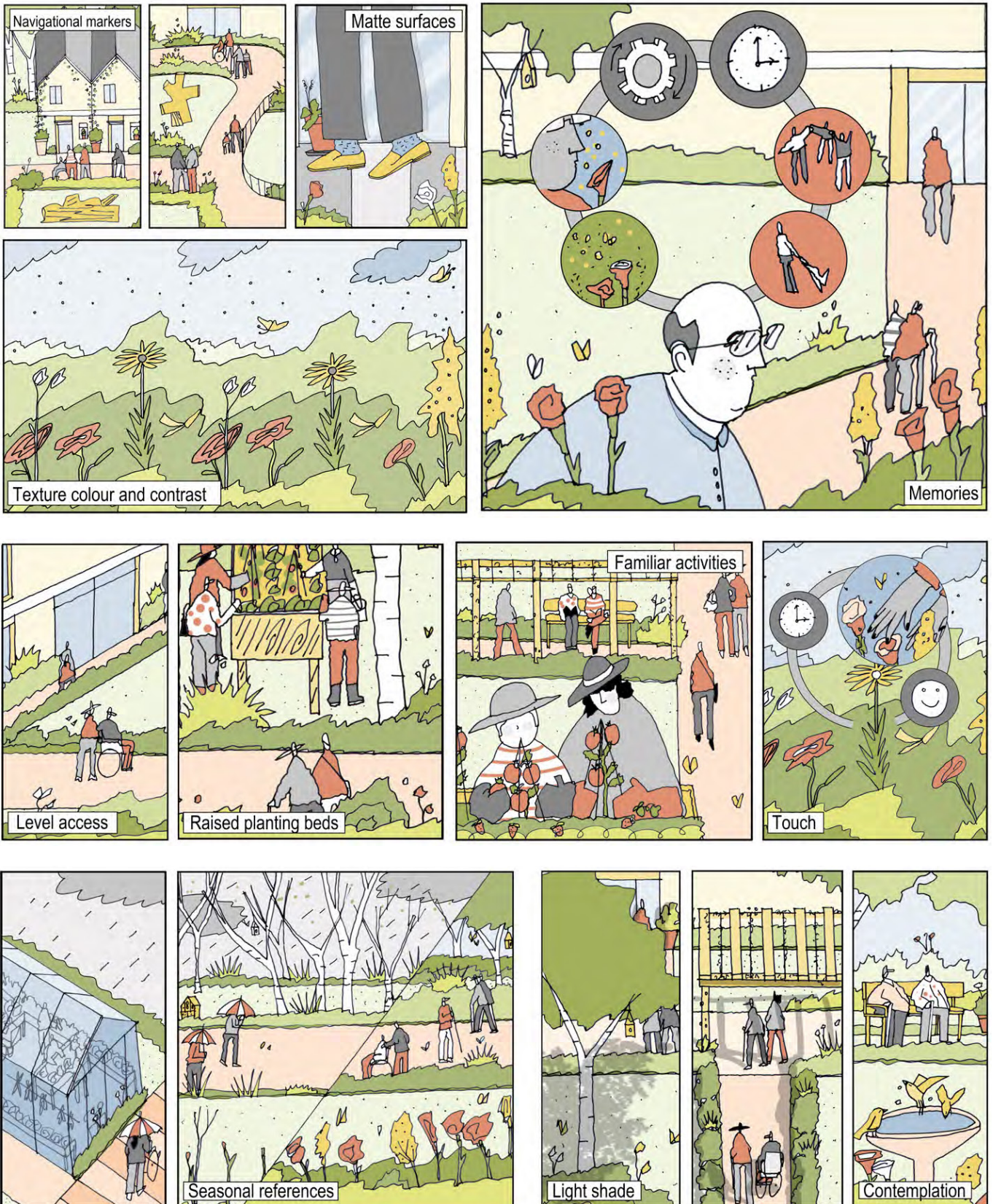


Image 1.8: dementia friendly garden.



### Colour or textural contrast

*Ganoo-Fletcher & Saulue, 2023 + O'Connor, 2020 + Marquardt, Bueter & Motzek, 2014*

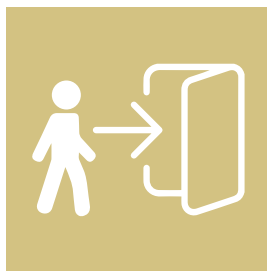
To make the landscape better readable for the visually impaired.



### Implement circular walking routes in landscape

*Ganoo-Fletcher & Saulue, 2023*

Circular walking routes so that wandering people with dementia will return to their starting point. Routes must never terminate at dead ends and exit gates should be concealed.



### Garden directly accessible

*Ganoo-Fletcher & Saulue, 2023*

The garden should be levelled and accessible from the inside for people with or without wheelchairs.



### Include winter garden or a heated summer house

*Van Buuren & Mohammadi, 2022*

To enjoy nature even in winter.



### Navigation markers implemented in landscape

*Ganoo-Fletcher & Saulue, 2023*

Such as strongly scented plants, garden features, sculptures or memorable features.



### Vegetable garden

*Ganoo-Fletcher & Saulue, 2023*

To give a positive experience that can bring back memories. When the beds are raised they are more accessible.



### Illuminate garden

*Ganoo-Fletcher & Saulue, 2023*

To enhance a sense of security, and being able to enjoy the gardens at night.



### Swimming pool nearby

*Interviews*

Swimming is an activity that many elderly enjoy.



### Provide shade in garden

*Ganoo-Fletcher & Saulue, 2023*

Provide shade with for example a pergola.



### Plants to reflect 'seasonal change'

*Ganoo-Fletcher & Saulue, 2023*

To stimulating a resident's connection to natural timelines and chronology.

## 1.4. Conclusion

*What are the different stages of dementia and what are their needs in their living environment?*

The amount of assistance with daily tasks that a person with dementia needs, depends on which stage of dementia a person is at. As the disease progresses, its characteristics can change, and this variability underscores the importance of individualized care. This chapter has delved into the multifaceted aspects of dementia, emphasizing the significance of the living environment and its impact on the well-being of individuals affected by dementia.

There were many guidelines found for the design of the living environment of people with dementia. Some that are very specific to for example one room, and others that can apply to different scales. The guidelines were ranked by importance, based on the frequency they were mentioned in literature and interviews. The main themes that were found, not only coexist, but are also interconnected and share common elements. The most important guidelines that were found apply to different scales and have the biggest overall impact when applied.

For example, having personal furniture and elements, not only creates a home-like environment, it also helps with people's wayfinding, and creating a pleasant acoustic environment, which as a result also improves the behaviour of people with dementia.

A small-scale living environment also contributes to creating a home-like environment, that does not have an institutional character. Studies also observed that small-scale units improved residents' social abilities and communication skills. A small-scale environment also allows for a more individualized, person-centered care, which remains

crucial for addressing the complexities of dementia.

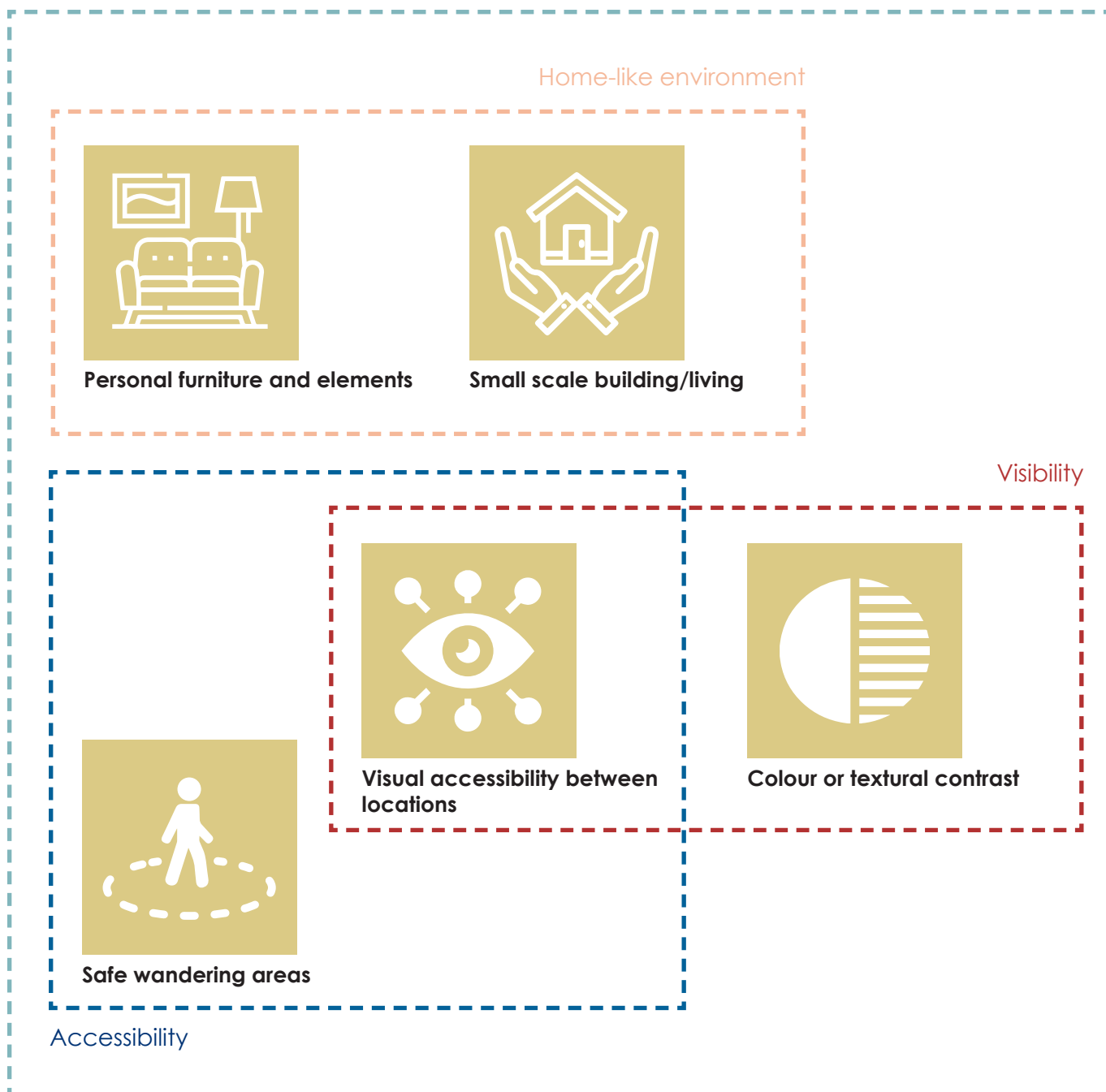
Visibility inside and outside is also an important factor to consider when designing the living environment for people with dementia. First of all, there should be visual accessibility between locations. This can be achieved by using rooms like the kitchen or living room as reference points, making spaces directly accessible, or using a straight corridors. Another way to promote visibility is to apply contrast in color or texture to the inside and outside space. Elderly with dementia are also often visually impaired, which is why a well lit room or a differentiation of rooms by color, lighting, size or form can help with the visibility of their surroundings and consequently help with their wayfinding. Consequently, good visibility also helps with people's wayfinding.

Lastly, wandering is quite common for people with dementia, which is why this should be considered when designing. Therefore a safe wandering area where people won't be over-stimulated should be included in the environment of people with dementia. Although people wander inside the home, the outside environment should also be directly accessible.

The following image shows the five main design guidelines and their overarching themes. Since all guidelines apply to the living environment, it is also unsurprising that wayfinding is an all encompassing theme.

While the other guidelines with only one or two stars in their ranking are important as well, they contribute or execute these main guidelines that apply to the design of the living environment of people with dementia.







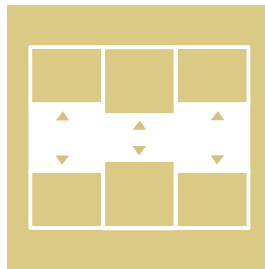
**Implement circular walking routes in landscape**



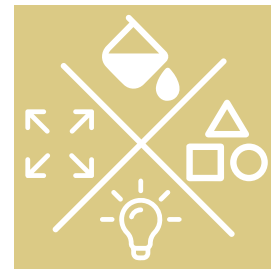
**Utilize kitchen or living room as reference points**



**Circulation system of straight corridors**



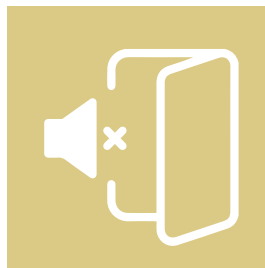
**Rhythmic niches in hallways**



**Differentiations in size, form, color, and lighting**



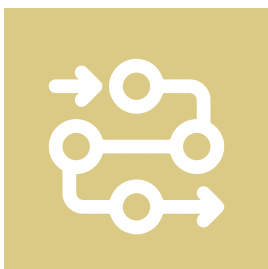
**Sufficient lighting indoors**



**Reduce noise by closing off rooms**



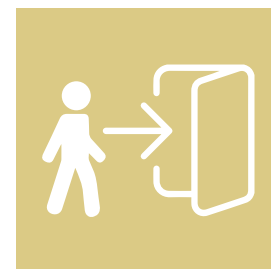
**Spaces for both retreat/privacy as well as social inclusion**



**Sequence of spaces**



**Windows open to nature for positive sounds**



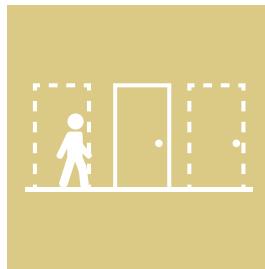
**Garden directly accessible**



*Important guidelines*



**No use of elevators**



**Decrease amount of repetitive doors**



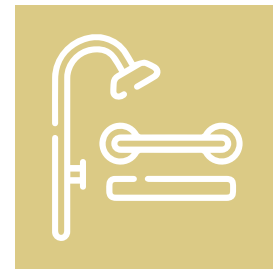
**View outside from the corridor**



**Include winter garden or a heated summer house**



**Acoustic insulation**



**Additional space in bathroom**



**Navigation markers implemented in landscape**



**Vegetable garden**



**Illuminate garden**



**Swimming pool nearby**



**Provide shade in garden**



**Plants to reflect 'seasonal change'**



*Guidelines that would nice if they were implemented, but are not necessary.*

## Chapter 2

# The caregiver experience

*What living environmental features are important for the partner of someone with dementia?*

---



## 2.1. Introduction

In the Netherlands, there are about 320.000 informal caregivers of people with dementia, many of whom provide care every single day. These caregivers encompass the partner, children, friends, or other people close to the person with dementia (Zorg voor Beter, 2023). Unfortunately, a significant amount of these informal caregivers find themselves overwhelmed by the burden of their roles.

Often, these informal caregivers see taking care of their loved ones with dementia as a natural part of their commitment, supporting each other in good and tough times. As one partner of a person with dementia put it: "I said yes to good times and bad times, so it goes without saying that I take care of my partner now that she needs me" (Fieldwork interview 1).

However, the burden this task brings with it, is often overlooked. This chapter will focus on the perspective of the 'healthy' partner within the context of dementia caregiving. Specifically, this chapter will explore the impact of living with, and caring for a partner with dementia has on their overall life and well-being. Given the architectural focus of this research, this chapter will examine how the living environment can support the 'healthy' partner and relieve the burden associated with caregiving.

## 2.2. Impact of having a partner with dementia

Dementia can have a significant impact on a couple's relationship, as it affects not only the individual with dementia but also their partner (fieldwork interviews).

Taking care of a person with dementia is most challenging for informal caregivers when it comes to their partners' ability to perform daily tasks, the frequency of behavioural issues, and the occurrence of mental symptoms like wandering and delusions (Chiao et. al., 2015). For example, one partner of a person with dementia mentions that his wife doesn't think of him anymore as her husband, but her boyfriend, as he reminds her only of that time (fieldwork interview 6). These delusions can be hard to take in every day, and can eventually take their toll. However, there can also still be very fun and loving moments between two partners, even with dementia.

### 2.2.1. Changes within the relationship

The quality of the relationship may deteriorate, as a result of the transition from a mutually interdependent relationship, toward a caregiver-care-receiver relationship (Bielsten et. al., 2018). As a result of these role changes, the healthy partner often finds themselves taking care of their significant other around the clock (fieldwork interview 7). Social activities a couple once enjoyed together, might now be overwhelming to the person with dementia. This means that the social life of the healthy partner also changes significantly. The person with dementia may wander through the neighbourhood or leave the stove on (fieldwork interview 6), meaning that they can't be left alone. Engaging in a club or pursuing hobbies, which the healthy partner initially enjoyed, may become impractical or unfeasible over time. It's important to acknowledge and adapt to the changes dementia brings into couple's lives in order to find new ways to maintain a fulfilling and shared lifestyle despite

the evolving circumstances.

### 2.2.2. Relieving the caregiver burden

Because of the changes within the relationship, but also the increasing care the healthy partner needs to give, continuing to live together becomes challenging (fieldwork interview 6, 7). To take some pressure off the healthy partner, a **daycare** can be very helpful. Bringing the partner with dementia to a daycare centre allows the healthy partner to do something for themselves, without worrying about their partner (fieldwork interview 6). Although the partner with dementia might be reluctant to go at first, a daycare can often be of great joy for them too, by providing meaningful activities for the day.

In some cases, the decision for the partner with dementia to move out stems from the home no longer being suitable for their needs. The stairs may become an obstacle, or the bathroom is too small to help them properly. This also causes stress to the healthy partner, worrying about their partners **safety** (fieldwork interview 6, 7). Therefore care features such as a zero-step home, a bigger bathroom with care features, and an electrical stove can create a safe indoor environment. Also outdoor safety was mentioned by a partner as being important since his partner start to wander sometimes (fieldwork interview 6). He didn't want his partner to walk through the neighbourhood with no limit. Other interviewees also stressed the importance of **being able to go outside** whenever they want to, and not with the approval of a formal caregiver (fieldwork interview 5).

The interviewed caregivers at a residential care farm for people with dementia mentioned that at their facility, inhabitants are allowed to move on the area of the facility freely. The terrain is not without risk; there are little

steps, and the pavement is not even. According to the caregivers, this environment fosters the well-being and vitality of its residents (fieldwork interviews 1, 2, 3).

Safety extends beyond physical aspects to psychological well-being. Interviewed couples of the research by Bielsten et. al. (2018) referred to the psychological meaning of home as a place representing peace, well-being, and familiarity. A home-like environment with personal items (see section 1.3.4), is therefore advisable.

*"I feel peace and harmony in my home. We like to go out as well, but there's nothing better than coming home when you've been out, closing the door behind us and just relax".*

This connects to the importance of being able to **live a normal life**. Also pursuing hobbies, and **fostering independence** are important for both partners (Bielsten et. al., 2018). This includes being able to decorate your room with your own furniture and personal belongings (interview 5), to go for a walk together, doing groceries, and being able to close your front door at the end of the day.

Another challenge when living with a partner with dementia can be the occurrence of wandering (Chiao et. al., 2015). In such cases, having a **spare bedroom** for separate sleeping arrangements can be beneficial, allowing the healthy partner to get some good rest (Gopinath, Peace & Holland, 2018) fieldwork interviews 4, 6). This room can also be used by the healthy partner to retreat during the day.

### 2.2.3. Doing things together and apart

Another theme that was found through the conducted interviews, regarding the well-being of the healthy partner, revolves around the importance of doing things together and

apart (fieldwork interviews 1, 2, 4-7; Bielsten et. al., 2018).

Many couples like to do **physical activities** together, mostly walking. Also meeting with friends or other couples is something couples really like to do, or doing chores. However, preserving **space for personal time** is important for both partners.

The article of Bielsten, Lasrado, Keady, Kullberg, and Hellström (2018) focuses on how couples navigate their lives together and emphasizes the importance of shared experiences and activities. It explores the challenges and opportunities in maintaining a fulfilling life for both partners in the context of dementia. For example, **meeting with peers**; but also deciding who to socialize with, by adapting the activity to the capability of the partner with dementia. Being in large groups might be too intense for some people with dementia. Several interviewees expressed that they like to connect other couples where also one partner has dementia (fieldwork interviews 1 and 6). For example, one care facility organized a valentines dinner for various couples. One couple (interview 5) pointed out that it is nice to meet with other couples where a partner has dementia, because you are in the same situation and can share about it.

According to Bielsten et. al. (2018), relationships with neighbours in the **neighbourhood** and the sense of having support of each other in everyday life play an important role and contributed to a sense of security. For example with local organisations for all ages.

Another finding from the interviews is that healthy partners that don't live with their significant other anymore, like to visit them regularly (fieldwork interviews 1, 4, 7). All of the interviewee visit their partner almost every day. Being able to **visit your partner easily** is therefore very important.

## 2.3. Conclusion

*What living environmental features are important for the partner of someone with dementia?*

Based on the findings of this chapter, some guidelines can be established for the living environment. These guidelines are specifically important for the healthy partner of a person with dementia. The guidelines can apply to their partner with dementia, to themselves, or both.

These guidelines can be divided into four themes; safety inside and outside the home, ways of taking pressure off the healthy partner, fostering independence and doing things together and apart from each other.

Resulting from the interviews, not all partners of someone with dementia think it is the best option for them to continue to live together with their partner, since it can be exhausting at times. Partners that were interviewed that lived separately were content with this situation, and visited their partner regularly. It is therefore important to be able to visit your partner easily. On the other hand, partners

that would like to continue living together, also have specific requirements. These are focussed on taking pressure off the caregiver burden. By being able to bring their partner to a daycare and having a spare room to retreat to during the night to sleep, since their partner may wander. Apart from these three guidelines that are specific to the living arrangements of a couple, the established guidelines are applicable to both situations of living together and apart.

The guidelines are ranked by importance on a scale from one to three stars, based on how many times they were mentioned in interviews and literature.



### Visit partner easily

*Interviews*

In the case that the healthy partner doesn't live with their partner with dementia, it is important to have a good connection to the place where they live



### Daycare

*Interviews*

When partners live together, it is important to bring the person with dementia to a daycare so the healthy partner is able to do something for themselves.



### Spare room to retreat

*Interviews + Chiao et. al., 2015 + Gopinath, Peace & Holland, 2018*

When partners live together, the healthy partner may need a room to retreat to during the night to sleep, or to have personal time during the day.

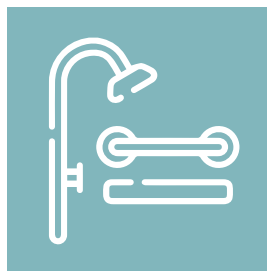




### Safe wandering areas

Hayne & Fleming, 2014 + Interviews

This can be an enclosed outside space of which the border doesn't have to be harsh, it can also be a soft, green barrier.



### Safety measures within home

Interviews + Bielsten et. al., 2018

A safe living environment such as a zero-step home and care features like a larger bathroom and electrical stove.



### Flexible community spaces

Interviews + Bielsten et. al., 2018

To receive family, friends, and to meet with other couples. Activities such as cooking together, having a coffee, or playing games. Besides having a space for social inclusion, it is also essential to have a contrasting area dedicated to retreat.



### Personal furniture and elements

Interviews + Bielsten et. al., 2018

Being able to furnish your room as you like, to foster independence.



### Direct connection to outside and communal spaces

Interviews

To have the freedom of choice to go outside and join activities.



### Basic amenities nearby

Interviews

To be able to live a normal life. Do groceries, and have a connection to the neighbourhood.



### Connection to neighbourhood

Interviews + Bielsten et. al., 2018

Offering facilities that are good for people living in the close neighbourhood, to foster connection and a support system. For example a child day care, library or cafe.



### Outside walking paths

Interviews

For couples to enjoy a walk together. This can also be in the neighbourhood

## Chapter 3

# Case studies

*What kind of living environments do already exist for elderly couples where one experiences dementia?*

---



### 3.1 Introduction

This chapter explores three case studies that all offer housing for couples with dementia. The design guidelines that have been established in the previous chapters will be tested in the context of these case studies. The chapter's conclusion will highlight the extent to which these case studies meet the collective needs of the healthy partner and the partner with dementia, offering insights into the practical application of the design guidelines in real-world scenarios.

#### *Selecting the case studies*

The selection of these case studies was guided by specific criteria. To ensure relevance and applicability, the chosen cases are care facilities with centralized care services, and they feature apartments specifically designed to accommodate couples. This selection of cases provides a basis for evaluating the practical implementation of the established design guidelines from chapter 1 and 2.

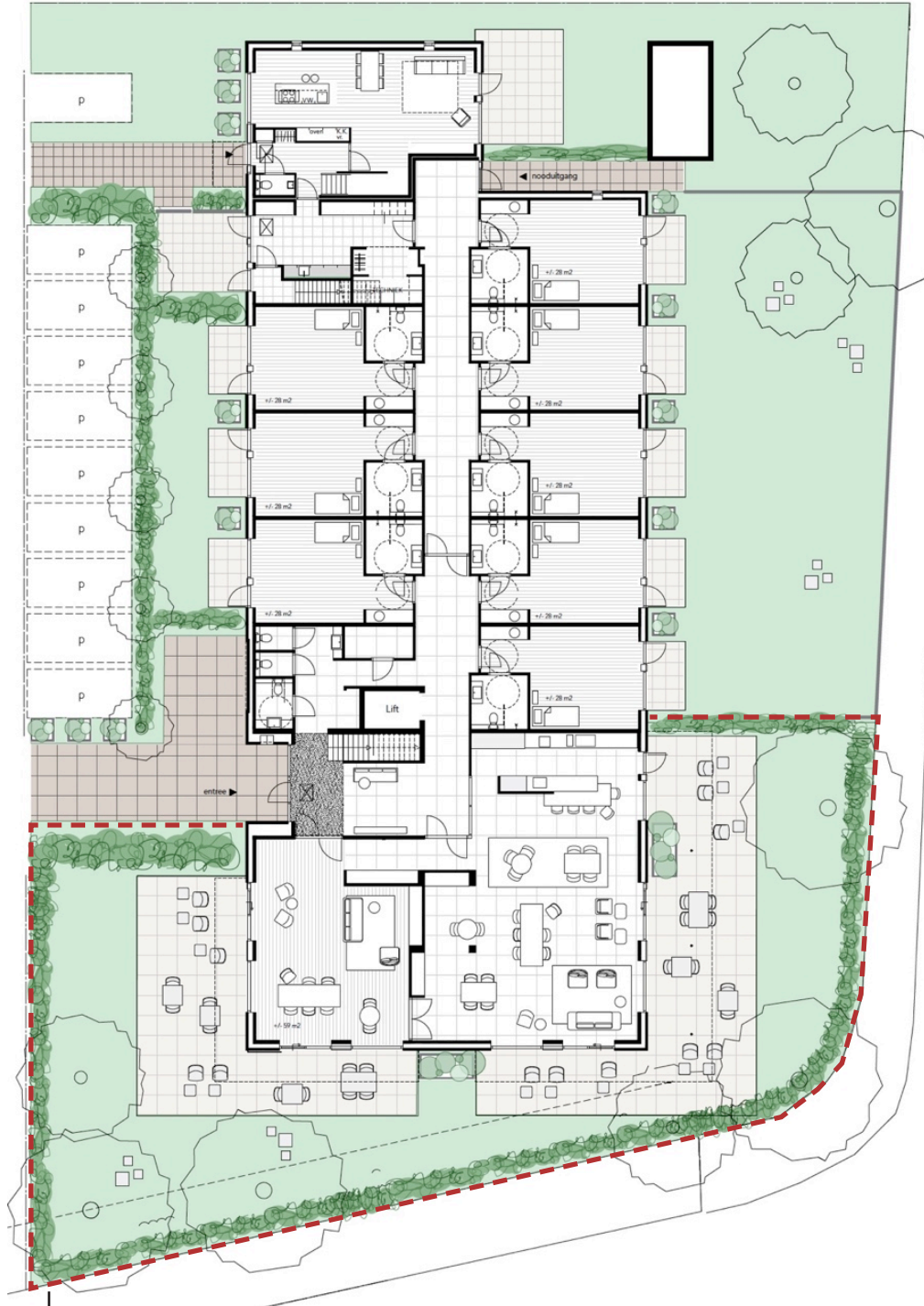
### 3.2. Case study 1: Gastenhuis, Vleuten - The Netherlands

'Het Gastenhuis' has several locations in the Netherlands, offering small-scale care to people with dementia in a homely environment (het Gastenhuis, 2024). Their location in Vleuten consists of a two-story building with twenty residential units for people with dementia (B en O architects, 2024). Each resident has their own apartment with a bathroom. Two apartments are suitable for couples who wish to live together. In addition, there is a common living room, a large kitchen, and a social space. The 'Guest House' is managed by a caregiving couple, and a dwelling has been built for them next to the building.

The building has the appearance of a residential house. On the ground floor, the communal terrace, social space, kitchen and living room are situated. A canopy runs along the entire length of the facade of the social space and living room, providing shade for residents during warm days.



Image 3.1: Gastenhuis Vleuten, exterior.



Green barrier

Image 3.2: Gastenhuis Vleuten, ground floor plan.

What makes the Gastenhuis unique, is its small scale living environment. Because of this, it operates more as a home and less as a traditional care institution. The common areas, including the entrance, living room and kitchen provide a homely atmosphere. These spaces cater to different activities, such as playing games, having movie nights, getting a manicure and crafting projects. There is also a child daycare that visits once in a while; both the children and elderly really enjoy doing things together.

The inhabitants also help with preparing the food and setting the table. Every day there is a menu for the lunch and dinner, and there is a cook that coordinates the preparation of these. If it is someone's birthday, they even prepare something special.

Inhabitants are able to take a walk every day, together with a volunteer or caregiver. There is also an outdoor terrace where they can enjoy the sun during summer. Perhaps a conservatory could also be nice to also enjoy the sun during winter. Residents can go outside whenever they want. The front door is always open, although the terrain is surrounded by a soft

green boundary. This reduces the frequency of having to bring someone back and it also allows for a safe wandering space.

The apartments are very spacious, allowing the residents to furnish it however they want to. There are three apartments that are big enough for a couple to live there. They both have to have an indication of dementia. These apartments have a separate bedroom. Privacy is also highly respected, with staff members always knocking before entering. Family members and partners of the inhabitants are also always able to visit.

Despite my brief visit, the residents seemed happy and satisfied, enjoying the freedom to do activities they like. The Gastenhuis focuses on creating a comfortable home-like atmosphere and giving residents with dementia the independence to make their own choices.



Image 3.3-3.4: Gastenhuis Vleuten. Left: apartment of a resident, Right: common room.



Image 3.5: Gastenhuis Vleuten, exterior.



Image 3.6: Gastenhuis Vleuten, interior (shared kitchen).

### 3.3. Case study 2: de Korenbloem, Kortrijk - Belgium

De Korenbloem is a care campus in Kortrijk, Belgium. It is one of the 'Invisible Care' pilot projects of Team Flemish Government Architect. It was set up after a research into how care can be better embedded in society (the great transformation, 2021). The project wants to break down the existing barriers between 'care' and society, by opening up the care campus to neighbourhood activities and associations. The design is by Sergison Bates Architects, Studio Jan Vermeulen and Tom Thys Architecten. The campus consist of multiple buildings that are connected by a large garden. Two historic buildings house the day care centres and neighbourhood services. Two new buildings (the 'Landhuis' and 'Portiekwoning') house permanent inhabitants. These create a connection between the street and inner area.

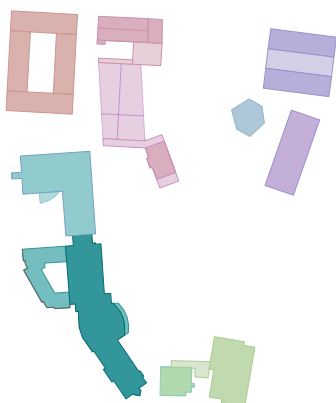
The 'Korenbloem' is in essence a protective living environment for young people with dementia and people that had a stroke. Young people with dementia often have children who are still studying or a young partner who is going to work. The Korenbloem offers flats where the person with early-onset dementia can continue to live with their partner. The partner can continue to carry out his or her

activities, while the person with dementia can live in a protected environment. This is unique in Flanders.

An important base for the Korenbloem is the integration into the neighbourhood. Kids from a school nearby come by and read to the inhabitants, there are activities organized with organisations in the large garden and they work together with a petting farm. This way, the care campus is not a 'golden cage' for the inhabitants, but they remain part of society. They do every-day things, not just to stay busy, but to have meaningful daily activities. This consists of for example helping with doing groceries, baking a cake, or helping out in the kitchen.

The other base for the design of the Korenbloem is that of 'small worlds'. For people with dementia, their experienced surroundings get smaller. Therefore small-scale living suits their perception (de Korenbloem, 2024).

The Korenbloem consists of multiple buildings, that all in their own way contribute to the diversity of the Care Campus. Two buildings include apartments for couples; the 'Portiekwoning' and the 'Landhuis'. This analysis will focus on these two.



Building: diversity and identity



Campus: small-scale living, big scale care



Neighbourhood: garden as connecting element

Image 3.7: Dissecting the care campus

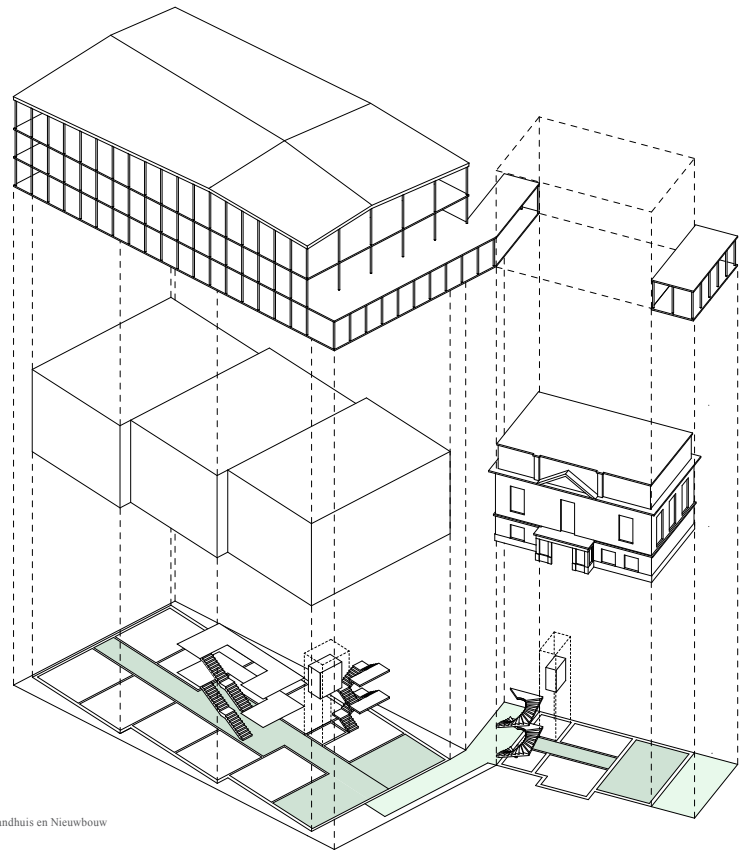




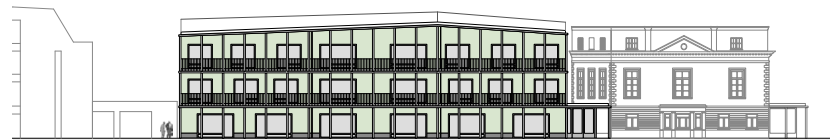
Image 3.8: care campus 'de Korenbloem'.

## 1. 'Landhuis'

The 'Landhuis' project is connected to an existing building. Both have their own circulation system, but are connected at ground floor level. The ground floor of the day-care is used as a daycare. In the new building, care dwellings are situated of 35 m<sup>2</sup>. The first floor of the new building has 7 bigger care dwellings of 60 m<sup>2</sup>. The 'healthy' partner can also move into this flat. The inhabitants of these flats can make use of the common room on the ground floor. The second floor has another living group of 10 rooms of 30 m<sup>2</sup>, that are subdivided into groups of 5. There are central common rooms for various uses, that allow for 'small-worlds'.



Axonometrie Landhuis en Nieuwbouw



Gevel West  
18

Image 3.9: axonometric view and facade of Landhuis Korenbloem



Image 3.10: exterior Landhuis Korenbloem





Image 3.11: floorplans Landhuis Korenbloem

## 2. 'Portiekwoning'

Het portiek consists of four living groups, consisting of ten people per story. It is connected on the ground floor and first floor to an existing villa, that is now used as common spaces for the living groups. Every story consists of one living group of about 9 apartments. The top level has apartments for couples, where one has dementia.

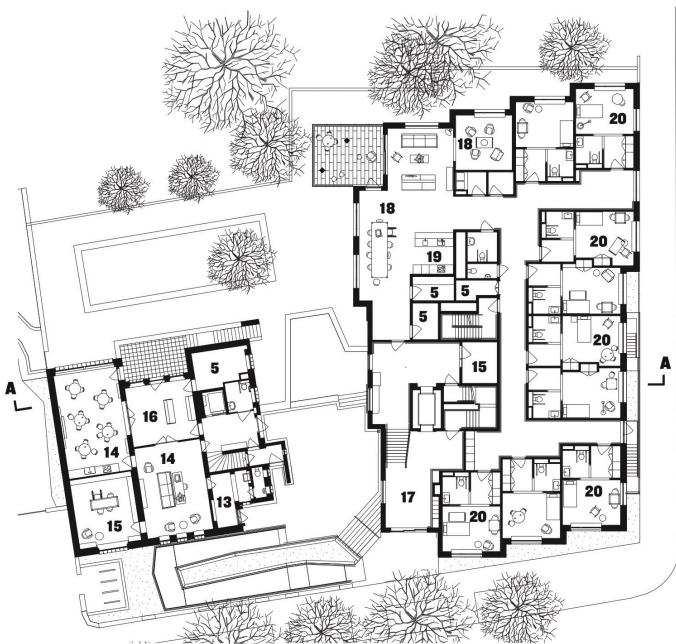
The existing villa is used as an entry to welcome visitors. A concierge who can assist in looking up the home address of a resident or can provide information about an activity in the day care centre. Although this is helpful, it diminishes the idea of this project to have a non-institutional character.

Of the apartments for couples, one is a two-bedroom apartment that even has two bathrooms. This apartment could be split into two apartments in the future. There are two other one-bedroom apartments. They all have access to a personal terrace and communal space. Although the access system is straight forward for healthy people, it can get confusing for people with dementia because you have to go through a lot of doors and hallways before you reach your apartment. The hallway on the fourth floor also doesn't have access to natural daylight.

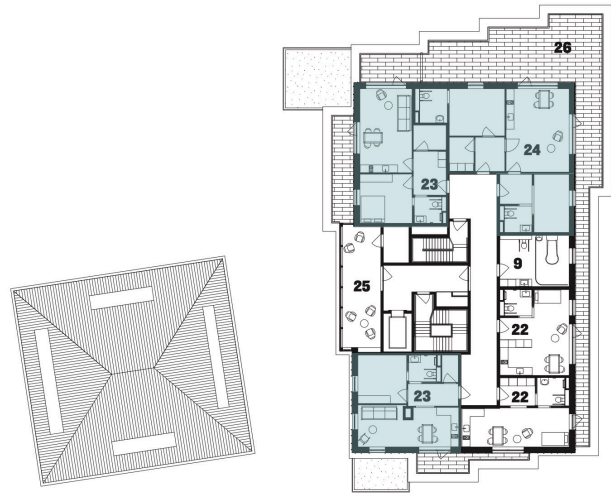


Image 3.12: exterior Portiek

## 2-person Apartments



upper ground floor



fourth floor



lower ground floor plan



first floor

- |                                    |                            |
|------------------------------------|----------------------------|
| 1 wellness room                    | 14 café                    |
| 2 gym                              | 15 office                  |
| 3 hairdresser                      | 16 bar                     |
| 4 workshop                         | 17 entrance (new building) |
| 5 storage                          | 18 living room             |
| 6 multifunctional room             | 19 kitchen                 |
| 7 plant room                       | 20 bedroom                 |
| 8 staff changing room              | 21 balcony                 |
| 9 communal bathroom                | 22 studio flat             |
| 10 daycare kitchen                 | 23 one-bedroom flat        |
| 11 daycare living room             | 24 two-bedroom flat        |
| 12 daycare rest space              | 25 communal space          |
| 13 entrance (former Villa Portiek) | 26 terrace                 |



Image 3.13: floorplans Portiek

**Story about inhabitants living in the  
'Portiekwoning' (Tribillon, 2023)**

"...We conclude our tour with one of the flats, where Annie lives with her husband André, who has dementia. She invites us into one of the **two-bedroom** flats nested in the champagne-coloured metallic structure that tops the building. When taking care of a loved one's declining health becomes overwhelming, these flats offer a solution where **a couple can continue living together while benefiting from the support of the care home**. The flat is made up of a large living room including a kitchen, a massive terrace and two en-suite bedrooms including one designed specifically for the residents with dementia. The fully accessible bathroom is cleverly hidden in plain sight, thanks to two sliding doors forming a corner when closed. In the living room, there are plants, furniture from the couple's former home, and books on the table. Pictures of Annie and André kissing and goofing around are hung on the wall. Annie, a bubbly woman in her late sixties, explains how both have found solace here. Switching from Flemish to English, before we settle on French, she explains they moved here four years ago from Brussels. Her husband was so poorly that she did not expect him to survive more than a few weeks. Years have passed and they are still here: **André's physical condition has improved tremendously, and his dementia has stopped progressing**. This type of accommodation is rare in Belgium, she adds, and she feels lucky they have it. "



Image 3.14-3.15: interior Portiek



Image 3.16 : exterior from park of Portiek

### 3.5. Conclusion

*What kind of living environments do already exist for elderly couples where one experiences dementia?*

To get more insight into existing living environments for elderly couples with dementia, two case studies and three buildings have been analyzed based on the findings of the first two chapters. Both of these care facilities offer apartments for couples.

Overall, the Portiekwoning of the Korenbloem care campus scores the worst on wayfinding. Especially the floorplans and circulation system are problematic. There are a lot of doors that people have to get through before they reach their apartments, which makes wayfinding difficult. The visual accessibility between locations within the building can also be improved. There is also no view outside from the hallway. This is solved at the Landhuis by adding a skylight above the staircases. Although an outside view would be desirable.

The set up of the Korenbloem allows for visibility between locations, since the buildings are placed at the edges of the plot, with the park in the middle allowing for visual accessibility.

Furthermore, all cases have multiple levels and have besides staircases also an elevator. If we take the guideline of having a homelike sequence of spaces and circulation system, we can say that a complex shouldn't have more than 2 or 3 stories. Apartments further up make it less attractive to take the stairs. It can also get confusing for inhabitants which story they live.

What all three cases do very well, is the addition of personal furniture and elements in the apartments, but also in the common spaces to create a homelike environment. The gardens of both cases are also great for people

to explore in a safe way on their own or together, since they are surrounded by a soft green border.

The first case in Vleuten is unfortunately not open to live in for the healthy partner. Because of this, some of the guidelines from chapter 2 are not applicable to this case. However, couples where both partners have dementia are able to live here. If there are multiple couples living here, they can seek contact with each other.

Both locations form a connection to the neighbourhood, by connecting with children. The case in Kortrijk also has a child daycare on the care campus, and in Vleuten, children from a nearby daycare also visit the elderly. Both the elderly and children really enjoy this.



Design guideline	Case study 1: Gastenhuis Vleuten	Case study 2: Korenbloem - Portiekwoning	Case study 2: Korenbloem - Landhuis
Visual accessibility between locations	✓	✗	✓
Spaces for retreat/privacy and social inclusion	✓	✓	✓
Small scale building/living	✓	✓	✓
Differentiation in size, form, color, and lighting	✓	✓	✓
Utilize kitchen or living room as reference points	✓	✓	✓
Personal furniture and elements	✓	✓	✓
Decrease amount of repetitive doors	✗	✗	✓
No use of elevators, everything on the same level	✗	✗	✗
Circulation system of straight corridors	✓	✗	✓
Rhythmic niches in corridors	✓	✗	✓
Sequence of spaces (entrance, living room, individual room)	✓	✗	✗
View outside from the corridor	✗	✗	✓
Safe wandering areas	✓	✓	✓
Colour or textural contrast	✓	✓	✓
Sufficient lighting indoors	✗	✗	✓
Reduce noise by closing off rooms	✓	✓	✓
Windows open to nature for positive sounds	✗	✓	✓
Acoustic insulation	✓	✓	✓
Garden directly accessible	✓	✓	✓
Implement circular walking routes in landscape	✗	✓	✓
Include winter garden or a heated summer house	✗	✗	✗
Navigation markers implemented in landscape	✗	✗	✗
Vegetable garden	✗	✗	✗
Illuminate garden			
Swimming pool nearby	✓	✓	✓
Provide shade in garden	✓	✓	✓
Plants to reflect 'seasonal change'	✓	✓	✓
Safety measures within home	✓	✓	✓
Flexible community spaces	✓	✓	✓
Basic amenities nearby	✓	✓	✓
Connection to neighbourhood	✓	✓	✓
Outside walking paths	✗	✓	✓
Visit partner easily	✗	✗	✗
Daycare	n.a.	✓	✓
Spare room to retreat	n.a.	✗	✗

Image 3.17: testing the design guidelines across the three case studies. In white are the design guidelines of the person with dementia (chapter 1), in grey the design guidelines of the healthy partner (chapter 2).

# Conclusion

*What living environmental features can support elderly couples who wish to live together while one of them experiences dementia, to maintain their shared living arrangements?*

---

The main research question for this thesis was;

*What living environmental features can support elderly couples who wish to live together while one of them experiences dementia, to maintain their shared living arrangements?*

To answer this question, I will first answer the three subquestions.

### **1. What are the different stages of dementia and what are their needs in their living environment?**

The amount of assistance with daily tasks that a person with dementia needs, depends on which stage of dementia a person is at. As the disease progresses, its characteristics can change, and this variability underscores the importance of individualized care.

When designing an environment for people with dementia that supports their well-being and needs as the illness progresses, there are a number of design guidelines that should be included. These can be found at the end of this chapter.

First of all, a **small-scale environment** with a home-like character is important, as it is a suitable setting for a more individualized, person-centered care, which remains crucial for addressing the complexities of dementia.

**Visibility** inside and outside the home is crucial, as many elderly with dementia are also often visually impaired. Visibility can be achieved with contrast in colour or texture, with visibility between locations, and using reference points.

The living environment should also allow for wandering, as this is quite common among people with dementia. The **accessibility** of safe wandering areas where people won't be over-stimulated should therefore be included. Consequently, the outside environment must

be directly accessible.

These three themes of a small-scale environment, visibility and accessibility all influence the **wayfinding** of people with dementia in their own way. Wayfinding is therefore an overarching theme when designing. Because of the deterioration of cognitive function, the world is experienced at a sensory level. Therefore, people with dementia are very sensitive to sensory experiences and their environment needs to be managed carefully to make it understandable and comfortable, to support their well-being.

### **2. What living environmental features are important for the partner of someone with dementia?**

When designing an environment that supports the partner of someone with dementia, there are a number of design guidelines that should be included. These can be found at the end of this chapter.

These guidelines can be divided into four themes. First of all, the environment should ensure that there is less pressure on the healthy partner, to consequently **relieve the caregiver burden**. Unfortunately, a significant amount of these informal caregivers find themselves overwhelmed by the burden of their roles. This is because of the changes within their relationship with their partner - moving from a mutually interdependent relationship, toward a caregiver-care-receiver relationship - and the increasing amount of care that their partner needs with daily tasks.

An environment that supports the partner, can for some partners mean that they don't live together anymore with their partner with dementia. In that case, it is important for them to visit their partner easily. In the case of them still

living together with their partner, there should be a daycare available and the home should include a room for the healthy partner to retreat.

Something that should always be included, is to ensure **safety** inside and outside the home. This way, the partner doesn't have to worry about their partners safety and well-being. Secondly, it should be prioritized that the healthy partner is able to **live a normal life**. This includes doing things together with their partner, such as taking a walk, or meeting friends or other couples. But also doing things apart from each other, like having hobbies, and space for personal time.

### **3. What kind of living environments do already exist for elderly couples where one experiences dementia?**

Three cases were analyzed and reviewed based on the findings of the first two subquestions. What we can learn from these case studies, is designing for couples with dementia involves creating environments that prioritize ease of navigation, visual accessibility, home-like atmospheres, and opportunities for community engagement. Additionally, fostering connections with the neighborhood, particularly through intergenerational interactions, can contribute to a more enriching living experience.

### **What living environmental features can support elderly couples who wish to live together while one of them experiences dementia, to maintain their shared living arrangements?**

Dementia is associated with a high individual burden both for people affected by the disease and their partner as an informal caregiver. To facilitate the well-being of elderly couples wishing to live together while one partner experiences dementia, it is crucial to consider specific living environmental features that support the collective needs of both partners. The living environment should be carefully designed as a small-scale, dementia-friendly space that not only alleviates the caregiver burden on the healthy partner but also addresses the unique challenges presented by cognitive decline of the partner with dementia.

This involves incorporating features that make it understandable and comfortable on a sensory level for the partner with dementia as their cognitive function deteriorates. Additionally, it is crucial to enable the healthy partner to lead a normal life despite the changes brought about by the various stages of dementia. Given the variable nature of dementia among individuals, each couple's needs may differ. This makes it necessary for the environment to be catered to these varying requirements.

All design guidelines are compiled and ranked based on their importance, using a three-star system.

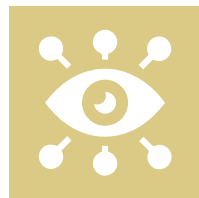




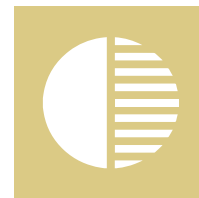
Personal furniture and elements



Small scale building/living



Visual accessibility between locations



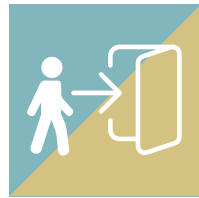
Colour or textural contrast



Safe wandering areas



Personal furniture and elements



Direct connection to outside and communal spaces



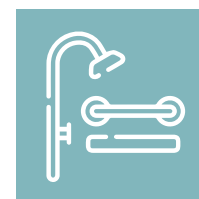
Visit partner easily



Daycare



Flexible community spaces



Safety measures within home



Windows open to nature for positive sounds



Differentiations in size, form, color, and lighting



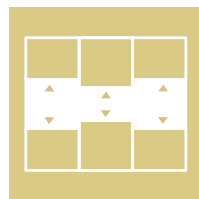
Implement circular walking routes in landscape



Utilize kitchen or living room as reference points



Circulation system of straight corridors



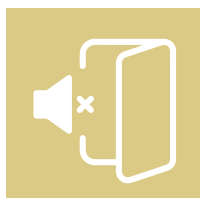
Rhythmic niches in hallways



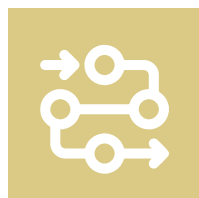
Spaces for both retreat/privacy as well as social inclusion



Sufficient lighting indoors



Reduce noise by closing off rooms



Sequence of spaces



Basic amenities nearby



Spare room to retreat



Connection to neighbourhood

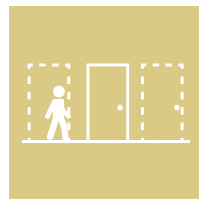


■ guidelines that are important for a person with dementia

■ guidelines that are important for the partner of a person with dementia



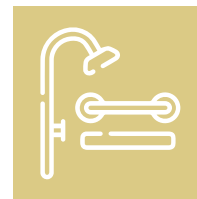
No use of elevators



Decrease amount of repetitive doors



Navigation markers implemented in landscape



Additional space in bathroom



Include winter garden or a heated summer house



Acoustic insulation



Swimming pool nearby



Illuminate garden



Vegetable garden



Provide shade in garden



Plants to reflect 'seasonal change'



Outside walking paths



View outside from the corridor



## Discussion

This study discusses how a shared living environment for partners where one has dementia and the other does not can be designed. This encompasses the unique living environmental needs of individuals with dementia, as well as living environmental design solutions to support the unaffected partner as an informal caregiver.

A noteworthy finding from the research is the limited options available within the current healthcare system for elderly couples who wish to continue living together when one partner has dementia. This underscores the importance of exploring alternative living arrangements that cater to the specific needs of both partners.

Designing living environments that promote autonomy, safety, and comfort for the partner with dementia, while also alleviating the burden on the healthy partner, was found to be a crucial focal point.

Although this research provides insights based on different research methods, future research could dive more into the needs of the healthy partner, who may experience stress, social isolation, and disruption to their own routines and activities due to caregiving responsibilities. Future research could also make more specific observations in couple's homes and their routines and how their living environment can be improved.

There is often a focus on the 'sick' partner, but transmitting them into a care facility also has significant implications for their partner. Shifting this focus is something to consider in future research.

## Reflection

1. What is the relation between your graduation (project) topic, the studio topic (if applicable), your master track (A,U,BT,LA,MBE), and your master programme (MSc AUBS)?

In relation to the Dwelling Graduation Studio: Designing for Health and Care in an inclusive environment, the conducted research is aiming to identify and propose design solutions that cater the collective requirements of both the partner with dementia, and the 'healthy' partner as an informal caregiver. These guidelines can improve the well-being of both partners. The proposed design solution for healthy elderly and their partner with dementia implements these guidelines.

2. What is the relevance of your graduation work in the larger social, professional and scientific framework.

More than half of the caregivers for people with dementia in the Netherlands experience moderate to heavy levels of burden, and one in eight even admits to being severely overwhelmed (Dementiamonitor mantelzorg, 2022). New living solutions could make it possible for couples where one faces dementia to maintain their shared living arrangements and relieve the burden on the informal caregiver.

In terms of the scientific framework; although there is separate research on the unique living environmental needs of individuals with dementia, and the themes for maintaining a fulfilling life for both partners in the context of dementia, there is a research gap where these two are combined and overlapping themes are explored. There is also a lack of the perspective of the partner as an informal caregiver and the living environmental needs that are important for them. This research aims to add to this perspective and combine the



collective needs of both partners.

The proposed architectural design proposes a new way of living with dementia, focussing on making it possible for couples to keep on living together while one of them experiences dementia. This environment should both cater the needs of the person with dementia, as well as the 'healthy' partner.

So far, I am satisfied with how the design has progressed; I have gained more and more control over the design, and I notice that it is becoming increasingly refined as a result. Some guidelines were easy to incorporate (safety measures within home; including communal spaces; using straight corridors) and were a starting point for the concept of my building. For example that the garden or outside space must be directly accessible for people with dementia. This is why the dementia living groups are on the ground floor.

One aspect of the design that I found difficult was the theme of wayfinding for people with dementia. I made some guidelines but sometimes it was still hard to place yourself into another person's shoes and to judge whether what you designed actually works and is understandable for them. Are people able to find their own front door? Are they able to move through the building independently? I wished for more specific guidelines, especially regarding wayfinding. Something else that I found difficult was to decide on the scale of the building. According to the guidelines, it should not have an institutional character (how can people personalize space?), and the living environment must be small scale (when is it too big?). I successfully achieved this goal by making a distinction between large collective spaces (for example the atrium) and small scale areas (such as the collective living rooms) and by dedicating areas for people to personalize. One guideline that ended up being crucial for my design was to have

safe wandering areas. I focussed on this both inside and outside the building, thinking about different levels of wandering areas someone encounters when they leave their apartment

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# Illustrations

## Introduction

**0.1** : made by author

**0.2** : made by author

## Chapter 1

**1.1** : made by author

**1.2, 1.7** : pictures taken by author.

**1.8** : Ganoo-Fletcher, A., Saulue, H. (2023)

## Chapter 3

**3.1, 3.5** : B en O architects, 2024.

**3.2**

**3.3, 3.4** : pictures taken by author.

**3.6** : Het Gastenhuis, 2024.

**3.7, 3.8, 3.9, 3.11, 3.12** : Desmet, M. (2024). document 'ontwerpend onderzoek'.

**3.10** : picture by Stijn Bollaert. retrieved from Pintos (2023).

**3.13** : Tribillon, 2023.

**3.14, 3.15, 3.16** : Sergison Bates Architects, n.d.

**3.17** : made by author.

## Fieldwork preparations

### Weekplan

I am planning on visiting two different care facilities that are solely for people suffering from dementia, together with to other students. On both locations we will be conducting the same interviews and workshops in order to distinguish differences and / or similarities between the two locations after visiting them (concept, size, type of care, daily routines etc.). In this diagram is displayed what we are planning to do during this fieldwork week on both locations. The first location is a small-scale living environment for people with dementia. They live in smaller living groups of 8 people. The second care facility is more large-scale, with groups of about 23 people per floor.

	MONDAY 13th November	TUESDAY 14th November	WEDNESDAY 14th November	THURSDAY 15th November	FRIDAY 16th November
MORNING	<b>Introduction</b> Tour location 1 and meeting the residents  <b>Observing</b> Day in the life of a space	<b>Observing</b> Day in the life of a resident	<b>Interview</b> Founder Location 1	<b>Introduction</b> Tour Location 2 and meeting the residents  <b>Observing</b> Day in the life of a space	<b>Observing</b> Day in the life of a resident
AFTERNOON	<b>Interviews</b> Family-member(s) of residents	<b>Workshop daycare</b> Draw your room from memory	<b>Interview</b> Employee(s) Location 1	<b>Workshop Residents</b> Draw your room from memory	<b>Interview</b> Employee(s) Location 2  <b>Interviews</b> Familymember(s) of residents
EVENING		<b>Workshop Residents</b> Draw your room from memory			

←
FIELDWORK LOCATION 1
→
←
FIELDWORK LOCATION 2
→

## ■ Interview questions

These questions are a starting point for the interviews. However, the interview will also be guided by what the person in question has to say. Additional questions will be devised on the spot, which can later be read in the transcript.

We will interview various people, including the owners of the healthcare institution, healthcare workers, volunteers and relatives of residents.

### Algemeen

- Wie bent u?
- Wat is uw functie binnen deze locatie?
- Beschrijf locatie 1 / locatie 2 in 3 woorden?
- Hoe ziet u de balans voor zich tussen bescherming en vrijheid van de bewoners? (Hoe ver ga je voor hun veiligheid?)
- Is het een open of gesloten woning?

### Concept woning

- Hoelang blijven mensen daar wonen? Kunnen ze blijven wonen tot het einde van hun leven?
- Hoe wordt er beslist wie er wel of niet kan wonen (indicatie / sollicitatie / loting)?
- Welk stadium van dementie hebben mensen hier? Wonen mensen met verschillende stadia met elkaar?
- Kunnen mensen daar samenwonen met een partner?

### Zorg bewoners

- Vanaf welk punt zie je dat ouderen met dementie jouw intensievere zorg nodig hebben? Welke dingen kunnen ze nog wel zelfstandig?
- Wat zijn jouw taken? Hoe ziet je dag eruit?
- Zijn er situaties waarbij beide van het stel samen in dezelfde zorginstelling wonen? Gebeurt dit wel eens en wat zijn volgens jou de voor en nadelen?
- Kunnen ouderen met dementie het beste zo lang mogelijk thuis wonen, of beter vroeg naar een zorginstelling om daar te wennen?
- Hoe zou jij als officiële zorgverlener kunnen samenwerken met een mantelzorger?

## **Ontwerp leefomgeving**

- Hoe denkt u dat het verschilt ten opzichte van andere zorginstellingen?
  - Zijn er speciale ontwerpelementen toegevoegd aan deze locatie om bij te dragen aan het verlichten van de symptomen?
  - Waarom is er gekozen voor een woning in combinatie met een boerderij?
- Wat is het voordeel van kleinschalig wonen?
- Hoe denkt u dat de leefomgeving waarin de woning zich bevindt bijdraagt aan het welzijn van de bewoners?
  - Is de locatie gekozen om zijn leefomgeving of is de leefomgeving ingericht naar wens?
- Wat maakt een kamer voor iemand met dementie uniek (ontwerpelementen)?
- Zijn er specifieke momenten op de dag waarop problemen?
  - Speelt de leefomgeving daar een rol in?
- Zijn er ontwerpelementen die je mist op deze locatie die zouden kunnen bijdragen aan het dagelijkse ritme van de bewoners (makkelijkere routes, vorm van ruimtes etc.)?

## **Dagelijks leven bewoners**

- Op wat voor manier worden deze mensen gestimuleerd/actief gehouden?
- Hoeveel doen deze mensen zelf? Waar moeten ze bij geholpen worden?
- Kunnen de bezoekers altijd langskomen (specifieke bezoeken)?

## **Bezoekers (familieleden en overige bezoekers)**

- Voelt u zich hier op u gemak als u uw familieleden bezoekt?
  - Zo ja / nee, wat draagt bij aan dit gevoel?
- Wat was het keuzeproces om toekomstige woonmogelijkheden te overwegen?
- Waarom is er voor Locatie 1/Locatie 2 gekozen?
  - Zocht je naar opties die er niet (in de buurt) waren?
  - Komt de bewoner uit deze regio?



## Partner

- Wat is de impact op je leven om een partner te hebben met dementie? Waaraan merk je dit het meest?
- Wat zijn de uitdagingen die zich voordoen om met iemand dementie te wonen?
- Heb je weleens afstand nodig van je partner met dementie? Hoeveel afstand heb je nodig?
- Zou je ook in latere fases van de dementie nog met je partner samen kunnen/willen wonen?
  - Waarom zou dat wel/niet kunnen?
  - Hoe zou dat eruit zien?
- Denk je dat het bevorderlijk is voor het welzijn van je partner om samen te blijven wonen?

\*all names have been substituted by a pseudonym

# Interviews fieldwork

## 1. Partners - Jan en Linda

### Zorgboerderij

Tijdens de fieldwork hadden we een gesprek met twee partners van mensen die wonen op de zorgboerderij. Dit ging vooral over hoe het is als partner om te zien dat je partner dementie krijgt. Jan is de man van Eva en Linda is de vrouw van Rob.

Volgens hen is het hartverscheurend en mensonterend omdat ze hun eigen partners niet meer herkennen. De persoon die hier woont is niet dezelfde persoon aan wie je ooit het ja-woord hebt gegeven.

Beide partners gaven aan dat de dementie al jaren langer aan het ontwikkelen was voordat ze het hebben laten diagnosticeren. Bij Rob herkende Linda het omdat een vriend van hun 4 jaar ouder was en een jaar eerder met dementie was gediagnosticeerd. Op vakantie zei hij rare dingen en toen later kwam zij erachter dat hij op zijn werk ook dingen aan het vergeten was. Bij Jan was het dat hun kinderen zeiden dat Eva wel heel vaak dezelfde vragen opnieuw stelde.

Wim zei ook dat mensen het bij hem niet zien dat hij ziek is. Pas als je hem kent of langer met hem spreekt, kom je erachter dat hij dementie heeft.

Jan geeft aan dat je niet wilt dat je partner dementie krijgt, maar als dat dan zo is dan is deze plek wel echt de beste plek om te zitten. 'Van alle vreselijke plekken is dit de beste'.

Het is zwaar om de partner te zijn van iemand met dementie. Je krijgt als partner vaak de volle laag van de persoon met dementie en wordt beschuldigd van het feit dat ze hier moeten blijven en niet mee mogen naar huis. Maar uiteindelijk staan ze nooit bij het hek van het terrein om te 'ontsnappen'.

Wat zij mooi vinden aan deze plek is dat ze niet opgesloten zitten maar dat ze vrij rond kunnen lopen tussen de verschillende woningen maar niet het terrein af kunnen.

Linda zei ook nog dat het haar opviel dat veel mensen die hier wonen geen partner meer hebben doordat ze gescheiden zijn voor de diagnose: zij denkt dat dat door de ziekte komt en dat als ze de diagnose bij sommige gevallen eerder hadden geweten dat partners dan misschien niet gescheiden waren omdat er een verklaring was voor het gedrag. Als je weet dat je partner ziek is, ga je ervoor zorgen.

Er wordt een voorbeeld genoemd van een initiatief dat werd georganiseerd. Er was een valentijnsdiner, waarbij alle mensen die nog een partner hebben, er waren. Ze gaven rozen uit wat Jan een mooi detail vond, en wat liet zien hoe ze hier te werk gaan.

Jan komt iedere dag langs om Eva te bezoeken, dit vindt hij normaal, hij heeft het ja-woord gezegd tegen goede en slechte tijden. Hij herkent zijn vrouw niet meer, hij ziet een ander persoon nu in het huis dan waarmee hij ooit is getrouwd. Hij vindt het bijvoorbeeld pijnlijk om te zien dat zijn vrouw babyborns vasthoudt. 'Gore grapjes' werken wel. Dan kun je nog wel contact maken.

## 2. Caregiver - Cynthia

### Zorgboerderij

Cynthia werkt er al sinds het begin en ze zegt ook dat vooral de visie van het complex heel mooi is; 'we zijn hier bij de bewoners thuis en helpen hen, zij zijn niet bij ons thuis'. Monique tijdens de lunch van 5e zei dat ook al.

Verder zei Cynthia dat ze het ook mooi vindt dat de omgeving niet zonder gevaar is, omdat in hun visie dat in de normale wereld ook niet zo zou zijn. De paden binnen en buiten kunnen soms niet volledig glad of recht zijn, maar dat is juist goed voor de bewoners.

Cynthia vertelt ook dat er iets meer gevraagd wordt van de medewerkers van de zorgboerderij meer initiatief moet worden getoond. Dit is niet voor iedereen wat, maar deze be-trokkenheid zorgt wel voor de kwaliteit van de zorg die de Reigershoeve biedt.

Cynthia vertelt over een koppel dat samenwoonde in een van de appartementen, dit was wel krap. Ook was het wel lastig om met de gezonde man om te gaan omdat die geen zorg nodig had. Hij wilde zich ook een beetje bemoeien met het huishouden waardoor er van 2 kanten irritaties ontstonden. Hij was ook de enige in de groep die gezond was, wat zijn positie lastig maakte. Ze hadden ook een Duitse herder, dat werkte niet op de afdeling met huisgenoten. Maar als een volgende bewoner weer met een hond aan zou komen, zouden ze het gewoon opnieuw uitproberen.

Ze hebben nu plek voor 3 logees maar ze zouden graag willen dat er bijvoorbeeld nog wat wordt aangebouwd zodat ze 5 logees kunnen hebben omdat ze merken dat er veel vraag naar is. Hele mooie manier om partners van mensen met dementie die nog thuis wonen te ontlasten.

Het viel Cynthia op dat er bijna niemand hier met een rolstoel loopt en heel weinig mensen overlijden hier (afgelopen jaar maar 1); zij denkt dat dat zou kunnen komen door deze specifieke leefomgeving. Veel groen, normale omstandigheden (risico op vallen) en de mensen blijven actief en hebben ook een doel doordat er dagbesteding is en dat ze samen voor de dieren zorgen.

### 3. Caregiver - Merel

#### Zorgboerderij

Merel is een zorgmedewerkster op de zorgboerderij. Met haar hebben we het vooral veel gehad over het verschil tussen grootschalige zorginstellingen en kleinschalig wonen zoals bij deze zorgboerderij. Zij heeft 27 jaar gewerkt bij een grote zorginstelling in de buurt en sinds 6 jaar werkt ze hier en ze is heel blij dat ze deze stap heeft gemaakt.

Het grote verschil is volgens haar vooral dat de zorg is ingericht op de individu dus ze kijken hier heel erg wat elke bewoner zelf fijn vindt qua opstaan, eetmomenten, buiten-binnen en naar bed gaan. Ook hoeveel ze op hun eigen kamer zitten en wanneer ze in de gezamenlijke woonkamer zitten mogen ze zelf kiezen.

Soms proberen ze verschillende bewoners aan elkaar te koppelen. Er zijn verschillende huizen, maar dan proberen ze samen bijvoorbeeld Formule1 te kijken. Dat gaat niet altijd goed, soms wel.

De zorgboerderij voelt als een familie. Bij de grootschalige zorginstelling werd niet erkend dat er bijvoorbeeld iets heftigs gebeurde.

Qua indeling mist ze wel dat de ene kant van de eigen appartementen alleen een raam (geen openslaande deuren naar de tuin) heeft en de andere kant heeft wel deuren, wat fijner is en meer vrijheid geeft. De individuele kamers zouden misschien wel wat groter mogen, vooral als mensen in rolstoelen zitten is het vrij krap als je dan ook nog eigen meubels in deze ruimte hebt. Ook de gangen zijn vrij krap. Als iemand tegelijk met z'n rollator de gang op gaat ontstaat er nog wel eens ruzie. De woonkamer en eetkamer zijn één grote ruimte maar het zou misschien beter zijn voor de rust voor sommige bewoners om een soort af te sluiten deel te maken dmv te openen

schuifdeuren tussen de serre en de rest van de ruimte. Sommige bewoners triggeren elkaar ook heel erg, dus een beetje meer scheiding op sommige momenten zou fijn zijn. Een scheiding die de leiding zelf kan regelen, soms dicht als het nodig is soms open.

Er zijn ook allemaal beweegactiviteiten en er is 1 dienst die soms langskomt en dan allemaal activiteiten gaat doen. Waar ze eerst werkte moest je toestemming vragen om naar buiten te gaan, terwijl ze daar wonen. Dit komt wel door de onderbezetting van zorgpersoneel. Het gebeurt vaak dat mensen met dementie medicijnen krijgen om ze te kalmeren, dat gebeurt bij deze zorgboerderij bijna nooit vertelt ze.



Image x: Zorgboerderij - gemeenschappelijke ruimtes en buitenruimte



Image x: Zorgboerderij - woonkamer, keuken en kamer van een van de bewoners

## 4. Partner

### *Grootschalige zorginstelling*

We werden aangesproken door twee mannen; hun vrouwen woonden op een PG afdeling en een van de twee heren vertelde later dat hij zelf tegenover dit complex woonde. Eerst nog samen met zijn vrouw maar de mantelzorg voor zijn dementerende vrouw werd voor hem te veel en braken hem op. Toen hebben ze besloten dat zij in dit complex ging wonen en nu bezoekt hij haar elke middag maar kan hij 's ochtends zijn eigen ding doen en 's nachts goed door slapen.

## 5. Echtpaar

### *Grootschalige zorginstelling*

Meneer en mevrouw Driessen wonen samen op één kamer in een grootschalige zorginstelling voor mensen met dementie en mensen die lichamelijke zorg nodig hebben. Hier wonen mensen op afdelingen van 20 tot 25 mensen, waarbij iedereen zelfstandige kamers heeft en er twee gemeenschappelijke ruimtes zijn met een keuken en plek is om te eten. Alle verdiepingen zijn gesloten afdelingen, met een lift naar beneden. Op de begane grond zijn gemeenschappelijke voorzieningen zoals een café en knutselruimte. Ook worden er verschillende activiteiten georganiseerd zoals knutselen en muziek. Bewoners met dementie mogen echter niet zelfstandig naar beneden gaan, je hebt een code nodig om bij de lift te komen. Wanneer de zorgverleners vinden dat je niet 'goed genoeg' bent om te gaan, dan mag je niet naar beneden. Het kan daarom vaak voorkomen dat bewoners weken lang niet buiten komen.

Meneer en mevrouw Driessen is het enige echtpaar op hun afdeling. Beiden hebben dementie, meneer is in een later stadium dan mevrouw. Er was eerst ook nog een ander stel waarmee ze soms dingen samen mee deden. Nu niet meer, ze zijn ondertussen overleden. Mevrouw Driessen geeft aan dat het fijn was om met hen af te spreken omdat je in dezelfde situatie zit en daarover kunt delen. Ze zou het leuk vinden om met meerdere stellen op een afdeling te zijn.

De dochter komt vaak langs om haar ouders te bezoeken. Zij is niet te spreken over de situatie van haar ouders. Ze zegt dat er ontzettend veel vrijheid wordt ontnomen, en dat de menselijkheid van mensen niet wordt gezien. De mens achter de ziekte wordt niet erkend. Er is een gebrek aan zachte zorg; eerst konden mensen nog hun eigen keuzes maken, maar nu niet meer. Dit komt onder anderen-

door het personeelstekort. Deze behoefte aan keuzevrijheid is iets wat vaker in het gesprek terugkomt. Ze hebben nu de situatie waarbij meneer Driessen verplicht een middagdutje moet doen omdat hij te onrustig is. Dit willen de dochter en vrouw eigenlijk helemaal niet, want in de middag gaan ze altijd wat samen doen. Ook hebben ze ook niets meer te zeggen over hoe hun kamer eruit ziet, omdat meneer Driessen meer ruimte nodig heeft om in zijn bed te komen, moeten er spullen weg, zo ook de fotoboeken volgens de dokter, vertelt de dochter. Daarnaast zijn ze allebei nu al 4 weken niet buiten geweest, dit wil meneer wel maar dat mag niet.

De zorg drukt zwaar op de dochter, zij is veel bezig met het welzijn van haar ouders en zet zich voor hen in. Zo ging ze altijd vaak met haar ouders naar buiten voor een wandeling. Niet alle bewoners hebben familie die regelmatig op bezoek komt. Zo kan het dus gebeuren dat zij maandenlang niet buiten komen, omdat niemand ze meeneemt. Het zorgpersoneel heeft hier geen tijd voor.

Op de kamerdeur van meneer en mevrouw Driessen hangt een briefje met de vraag om te kloppen. Zorgmedewerkers en anderen kwamen eerst zomaar binnenlopen, terwijl dit gewoon hun woning is. De dochter omschrijft het als volgt; "je hebt een heel leven gehad, en nu wordt je zomaar opzij geschoven".

De dochter en mevrouw Driessen geven aan dat aandacht voor de interesses van een bewoner heel belangrijk is, en ook communicatie, ook als dat soms moeilijker is met iemand met dementie.





Image x: Kamer meneer en mevrouw Cornelisse



Image x: Zorginstelling waar meneer en mevrouw Cornelisse wonen

## 6. Partner - Pieter

### *Woont nog samen met echtgenote*

Pieter en Agnes zijn al tientallen jaren getrouwd en wonen samen in het rijtjeshuis waarin ze ook hun kinderen hebben opgevoed. Agnes heeft dementie en woont nog thuis. Leo zorgt voor haar; hij helpt haar met omkleden in de ochtend en brengt haar iedere week naar een dagopvang.

Ze krijgen hulp van buitenaf, zo hebben ze een casemanager en er komt hulp langs om het huis schoon te maken. Het is echter de vraag hoe lang deze situatie nog houdbaar is. Pieter vertelt bijvoorbeeld dat Agnes weleens het gas aan laat staan.

Vooraf emotioneel is het voor Pieter erg zwaar. Agnes erkent hem niet meer als haar man, maar haar vriend. Dit vind hij heel moeilijk om te horen van haar. Maar ze hebben ook nog mooie en grappige momenten met elkaar vertelt hij.

De dagopvang ontlast hem ontzettend. Agnes heeft het leuk daar en het geeft hem de mogelijkheid om iets voor zichzelf te doen, zoals in de tuin werken of gaan biljarten met vrienden. Hij vind het ook fijn om mensen te spreken die in dezelfde situatie als hem zitten. Bij de dagopvang kunnen de partners zonder dementie aan het begin een kop koffie met elkaar drinken en zo verbinding zoeken met elkaar. Pieter heeft ook een vriend die ook een vrouw had met dementie, daar spreekt hij ook graag mee af.

Pieter heeft kamertje voor zichzelf met een bureau en een bed waar hij soms in de nacht naartoe gaat om te slapen. Dan kan hij beter rust krijgen. In de nacht kan Agnes onrustig zijn en ze is ook weleens naar buiten gelopen om vervolgens wel weer terug te komen. Pieter benoemt dat hij een veilige omgeving belangrijk vindt voor Agnes, dat ze niet zomaar de

wijk in kan lopen. Maar dus ook dat er geen gasstel is wat ze aan kan zetten.

Wanneer ik vraag hoe hij de toekomst ziet met Ria, mocht ze meer zorg nodig hebben, dan vertelt hij dat hij het liefst met haar mee verhuist naar dezelfde woning. Hij zou ook wel willen vrijwilligen, door bijvoorbeeld in de tuin te werken. Ook kan hij best omgaan met andere mensen met dementie zegt hij, dus hij hoeft niet altijd alleen met zijn vrouw te zijn. Contact zoeken met anderen is voor hem heel belangrijk. Er is nu ook een gemeenschapshuis in de buurt waar hij graag naartoe gaat met Ria om koffie te drinken of andere activiteiten, zo werd er bijvoorbeeld een kerststal opgebouwd. Maar het is ook belangrijk voor Pieter om soms 1-op1 contact te zoeken met mensen zonder Ria erbij zodat hij zijn ei kwijt kan.

Een flexibele gemeenschapsruimte zou volgens hem handig zijn om om te hebben in een wooncomplex. Hij noemt een voorbeeld waarbij dat op de begane grond is en dat mensen daar boven wonen, wat hem wel zou bevallen.

Pieter zegt dat hij zich niet schaamt voor Agnes. Hij vertelt dat hij met haar door de supermarkt loopt en iedereen mag het weten. Iemand vroeg eens in de supermarkt of Agnes pillen nam, ja zegt ie, toen zij ze; dat is maar goed, want anders is ze al helemaal onhoudbaar. Terugkijkend op deze situatie zegt Pieter dat mensen er maar aan moeten wennen dat er mensen zijn met dementie.

## 7. Partner - Joost

*Woont sinds 3 jaar niet meer samen met echtgenote*

Ik heb een man geïnterviewd waarvan de vrouw dementie heeft. Zij woont nu sinds 3 jaar in een verzorgingstehuis. Daar zijn 3 groepen van ongeveer 8 mensen waarbij iedere groep een eigen kamer heeft, en er is nog een gezamenlijk deel waar alle ongeveer 25 bewoners samen kunnen komen. Zij zit in een rolstoel wat haar erg beperkt. Joost komt iedere dag langs, dit vindt hij normaal. Hij voelt zich schuldig als hij dat niet doet, ookal zou Sara het waarschijnlijk niet merken.

Ze hadden een casemanager die uiteindelijk zei dat het niet meer verder kon zoals het nu ging. Sara was slecht ter been en moest geholpen worden om de trap op te gaan. De hulp die langskwam kon dat niet doen, dus moest Joost het doen. Zelf is hij ook fysiek niet meer helemaal fit, dus dit was een kantelpunt om te beslissen dat het zo niet meer kon. Ook was Gerrit 24 uur per dag bezig om Sara te verzorgen, wat te veel werd.

Als ik vraag of hij nog bij Sara zou willen wonen als daar een plek voor was, zegt hij van niet. Dat zou hij niet meer kunnen, omdat het te zwaar is.

Zelf gaat hij nu verhuizen naar een appartement wat midden in het centrum van het dorp ligt. Hij zou eerst naar het blok naast waar Sara woont verhuizen, maar daar had hij geen goed gevoel bij. Het was te ver van alles, en er was niet veel te doen. Het appartementencomplex was ook apart van waar Sara woont. Je zou nog door een hek of poort moeten gaan om daar te komen. Zou het dan uit maken als dat wel kon? Ja zegt hij, al weet hij natuurlijk niet zeker of hij dan een andere keuze had gemaakt. Het is dus belangrijk om je partner makkelijk te bereiken wanneer je niet samen woont.

# Visit Gastenhuis Vleuten

08-01-2024

Tijdens mijn bezoek aan het Gastenhuis in Vleuten (bij Utrecht) ben ik rondgeleid door het gebouw, en een van de zogmedewerkers heeft me verteld over hoe de bewoners hier wonen. Wanneer je aankomt, moet je eerst een hek door, hier zit geen slot op. Buiten staat een fietsenstalling voor een duofiets, waarmee ze weleens met een bewoner op pad gaan. Sowieso zijn ze veel buiten bezig; iedere dag wordt er gewandeld met de bewoners. Toen ik er was, ging een vrijwilliger met ze wandelen. In de zomer zitten ze veel buiten op het terras, of zitten de bewoners in hun eigen achtertuin. De bewoners mogen naar buiten wanneer ze willen. De voordeur is in principe altijd open, dus mensen zouden mogen gaan wanneer ze willen. Het is daarom ook niet een volledige zorginstelling. Het is echter wel fijn voor het zorgpersoneel dat er een zachte groene grens om het terrein is, zodat het niet te vaak gebeurt dat ze iemand moeten terugbrengen.

In totaal wonen er 20 bewoners met dementie. Er zijn 2 kamers die groot genoeg zijn voor een stel om te wonen. Zij moeten wel allebei dementie hebben. Iedere dag zijn 3 zorgpersoneel, en eventueel een vrijwilliger. Volgens de medewerkster is deze verhouding goed te doen. Ze helpen mensen met opstaan en naar bed gaan als dat nodig is, en zorgen voor het eten en activiteiten. Er is een ochtend- middag- en nachtschift. Niet iedereen is opgeleid tot zorgverlener. Zo is er bijvoorbeeld iedere dag een kok, die hier niet voor opgeleid hoeft te zijn en die ook weleens iemand helpt om naar bed te gaan. Hetzelfde geldt voor de schoonmakers die langskomen. Er wordt verteld dat het personeel altijd klopt op de voordeur voordat ze naar binnen gaan. Ze hebben respect voor de privacy van de bewoners, het is tenslotte hun woning.

Wanneer je binnenkomt, is er een entree zoals je die ook bij een normaal huis hebt. Er is

een gang met een bankje en een trap naar boven. Links zijn gedeelde wc's, rechts is de woonkamer en keuken, en als je verder links de gang in loopt, zijn daar de appartementen. Alhoewel het een mooie dag was, valt het op dat er heel veel licht de kamers binnen valt. De gangen zijn echter wel vrij donker. Ook zijn de voordeuren niet erg goed van elkaar te onderscheiden. De gang is volledig wit, ook de deuren. Er hangt wel een foto van de bewoner bij de voordeur. Meer persoonlijke elementen of een specialere voordeur zouden de bewoners kunnen helpen om hun woning makkelijker te vinden.

Er is een open keuken waar gekookt wordt samen met de bewoners. Iedereen mag binnenlopen voor het ontbijt wanneer ze willen. Iedere dag is er een menu voor de lunch en het avondeten, dit staat geschreven op een bordje op het aanrecht. Ook wanneer er een bewoner jarig is wordt hier iets speciaals voor gebakken. Het personeel eet ook altijd mee. Bewoners helpen ook met de tafel dekken en afruimen. Alhoewel ze dus nog wel meehelpen, benoemt een bewoonster dat ze wel nu minder verantwoordelijkheid heeft, wat fijn is. Er wordt bijvoorbeeld wel besloten wat er op het menu staat en wat het dagprogramma is. De woonkamer heeft verschillende tafels waar mensen zich over verspreiden.

In de woonkamer is een spelletjeskast, maar er wordt ook gesjoeld, geknutseld, er zijn filmavonden en iedere twee weken worden nagels gelakt. Ook komt er iemand langs om binnen te gymmen met de bewoners. Er is een wat rustigere woonkamer verbonden aan de gemeenschappelijke ruimte met keuken. Hier staat een televisie en piano. Nu werd die niet veel gebruikt, maar er was eens een groep die het leuk vond om samen naar sport te kijken. Er komt ook weleens een kinderdagverblijf langs, dit is een hele goede match met de bewoners.

Wanneer je naar boven loopt, valt het op dat er geen paaltje staat voor de trap, zoals je dat weleens bij andere zorginstellingen ziet, zodat rolstoelen niet de trap af kunnen rollen. De familieleden van de bewoners accepteren ook voor deze risico's, zoals ook dat ze vrij naar buiten kunnen lopen. De bewoners zijn allemaal fysiek nog erg mobiel, er is maar één bewoner in een rolstoel omdat die de heup gebroken heeft. Die heeft ook een bewegingssensor in zijn kamer, maar dit is wel in overleg. Iedere maand wordt gecheckt of het nog steeds nodig is.

De bewoners hebben ruime kamers die ze allemaal anders hebben ingericht. Ze nemen eigen meubels en spulletjes mee, wat een gezellige huiselijke sfeer geeft. Iedere woning heeft een keukenblokje waar veel bewoners koffie of thee maken, maar niet wordt gekookt.

Er zijn twee ruimere appartementen waar echtparen kunnen wonen. Zij moeten wel allebei een zorgindicatie voor dementie hebben. Deze woningen hebben een aparte slaapkamer, en ruimte woonkamer. De bewoners die ik sprak vonden het fijn om er te wonen.

Er zijn ook bewoners waarvan hun partner ze komt bezoeken. Een man komt zelfs iedere dag. Er is een parkeerplaats waar ze hun auto neer kunnen zetten.

Ik was er maar voor een uurtje, maar de bewoners waren allemaal ontzettend vrolijk en lief, en totaal niet angstig. Ze mogen doen waar ze zin in hebben, niets moet.



Image x: common room of Gastenhuis Vleuten



Image x: living room of one of the inhabitants of Gastenhuis Vleuten



Image x: ground floor hallway of Gastenhuis Vleuten



Image x: kitchen of one of the habitants of Gastenhuis Vleuten



Image x: bathroom of one of the habitants of Gastenhuis Vleuten





