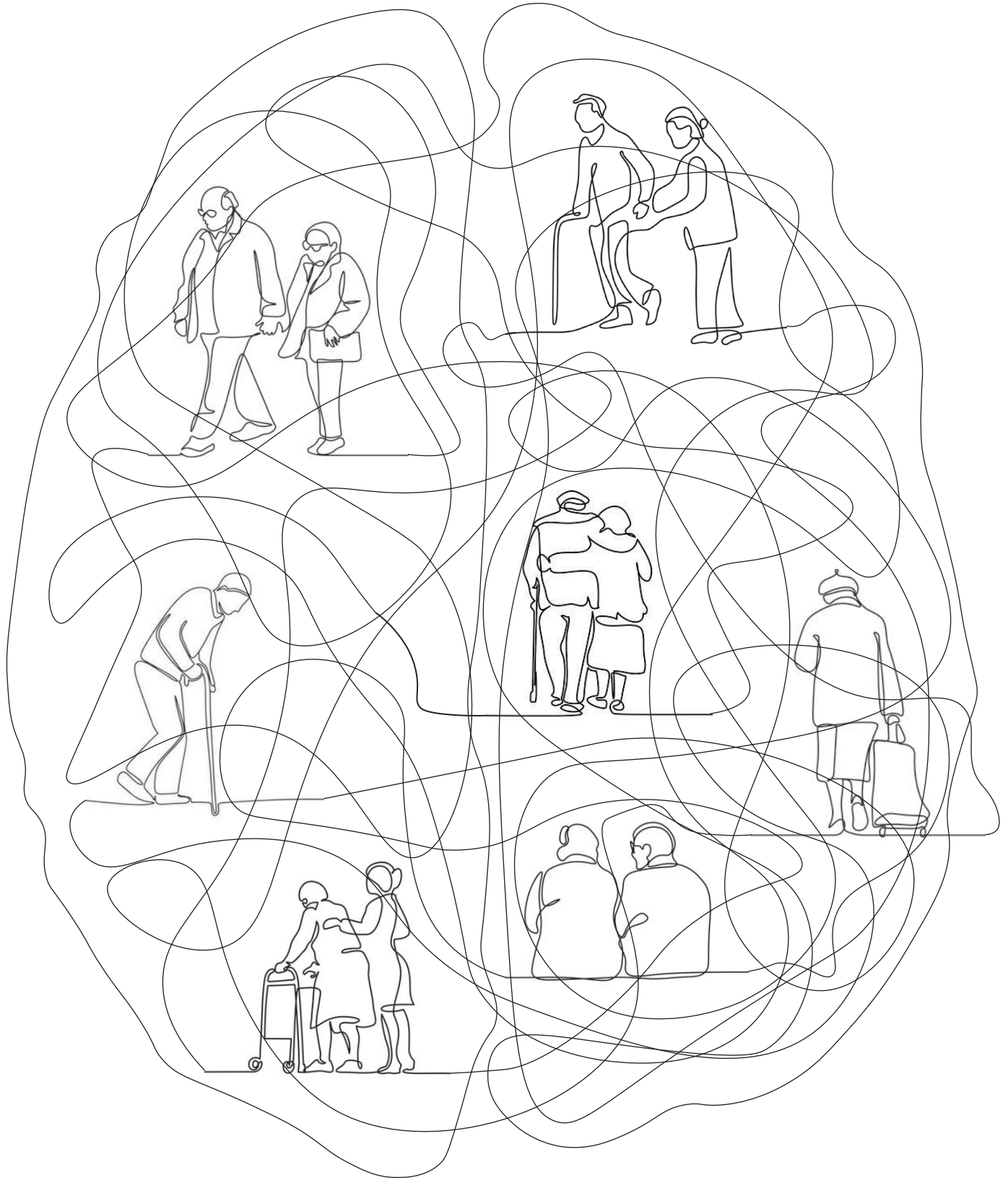


DESIGN FOR DEMENTIA

Research on the life of elderly with dementia in order to design a living environment that provides them with quality of life and the care they need



RESEARCH PLAN

Kim Houweling
5090342

7 november 2023

Delft University of Technology
Faculty of Architecture and the Built Environment

MSc Architecture
AR3AD110 Dwelling Graduation Studio
Designing for Care in an Inclusive Environment

Design tutor |
Birgit Jürgehake

Research tutor |
Leo Oorschot

Words | 2518

CONTENT

CHAPTER 1 | INTRODUCTION

1.1	PROBLEM STATEMENT	P.	4
1.2.	THEORETICAL FRAMEWORK	P.	5 - 6
1.3	DESIGN HYPOTHESIS	P.	7
1.4	RESEARCH GOAL	P.	7
1.5	RANGE	P.	7
1.6	RESEARCH QUESTIONS	P.	8
1.7	DEFINITIONS	P.	8 - 9
1.8	METHODS	P.	10
1.9	RESEARCH PLAN	P.	11
1.10	REFERENCES	P.	12 - 13
	APPENDIX A	P.	14 - 15
	APPENDIX B	P.	16
	APPENDIX C	P.	17 - 21

1.1 PROBLEM STATEMENT

The senior population (sixty years old and older) is increasing worldwide. From the year 2000 until the year 2050, the world's aging population will triple from six hundred million to two billion (World Health Organization: WHO, 2022). In the Netherlands the percentage of people above sixty-five years old will increase as well from nineteen percent in 2020 to twenty-five percent in 2050 (NIDI & CBS, 2020).

There is not just aging, but we can also speak of an upcoming, so called, double-aging, because the number of people over eighty years old is increasing in percentage terms more than the number of people over sixty-five (NIDI & CBS, 2020). The group of people above seventy-five in the Netherlands is expected to grow from 1,4 million in 2018 to 2 million in 2030. Within this group the amount of people above 85 years old will grow from 375 thousand in 2018 to 560 thousand in 2030 (De Klerk et al., 2019).

The older people get, the higher the risk on dementia. This double-aging will cause for approximately half a million people to have dementia by 2040, and this will probably go up to 620 thousand in 2050 (Factsheet Cijfers en feiten over dementie, z.d.).

The fact that the amount of people above eighty-five years old will keep growing from 2030 till 2050 is important for the care (Gopal et al., 2021). The demand for care will increase, but the number of people available to care for the elderly will decrease significantly over the years. The shortages of healthcare professionals are increasing further and the number of potential informal caregivers is also decreasing (De Klerk et al., 2019). This will also have its consequences for people with dementia that need care.

Caregivers already see problems in dementia care. Currently, eighty percent of the caregivers already thinks that the housing supply is not sufficient for the people with dementia (Van den Buuse & De Boer, 2021). Research shows that there is need for a new form of living between a normal house and a nursing home for people with dementia, where they feel at home, but with the care they need. Now several problems occur when people with dementia have to move; they are ripped out of their familiar and known surroundings, they lose freedom and control and they associate the nursing home with death (Van den Buuse & De Boer, 2021).

Designing for people with dementia

needs extra attention. For elderly people with dementia, the living environment can be a source of stress, uncertainty and confusion. Because a large part of our well-being and sense of familiarity has to do with our immediate environment, it is extremely important to pay a lot of attention to this (Wat is dementie, 2023).

To summarize, there are three important challenges:

1. Aging and double aging population causing an increase of people with dementia
2. Growing imbalance between people who need care and people who can provide care
3. No sufficient and supportive living arrangements for people with dementia

1.2 THEORETICAL FRAMEWORK

There has already been an extensive research on dementia friendly design (J. Nillesen et al., 2013; Halsall & Macdonald, 2015; Van den Buuse & De Boer, 2021; Aedes-Actiz Kenniscentrum wonen en zorg & KAW architecten, 2018).

The Dutch Alzheimer association also has an initiative for dementia friendly living. This proposal takes into account the whole spectrum of living environment. It goes from the coloring of the apartment, to lighting, to a recognizable front door, to the design of staircases in the building, to meeting spaces with other inhabitants, to walking routes outside. They built upon the idea of aging in place by answering to the need of elderly and elderly with dementia to not have to move again (Wat is dementievriendelijk wonen, z.d.). They did a research and questionnaire and came up with guidelines and conditions (image 1). This idea still is a vision and takes the ideal situation. The question remains how this can be implemented in the real world.

An overview of the literature about designing for people with dementia gives a lot of elements that are of importance (image 2). These elements can be divided among four main topics that should be looked in to in this research. These four being:

1. familiarity
2. Independence
3. Distintiveness
4. Biophilic

Of these four, biophilic design is a relatively new concept. This is proven to have a positive effect on health, healing and health promotion. Recent studies also relate this to dementia care facilities. Appropriate levels of thermal, acoustic, visual and air quality in buildings, has long been linked to occupants' satisfactory health, wellbeing, productivity and overall comfort. For example, adequate indoor air quality and thermal level controllability is of critical importance to human health, behavior, and wellbeing. In long-term-care residents, a non-supportive ambient indoor environment was identified as the principal source of behavioral disturbances among residents, disturbances caused specifically by poor acoustics, lighting levels, and inadequate ambient air quality-thermal conditions (Peters & Verderber, 2021).

The link between the biophilic aspects that add to quality of life for people with dementia, and the other key elements that contribute to this, is missing (image 3).

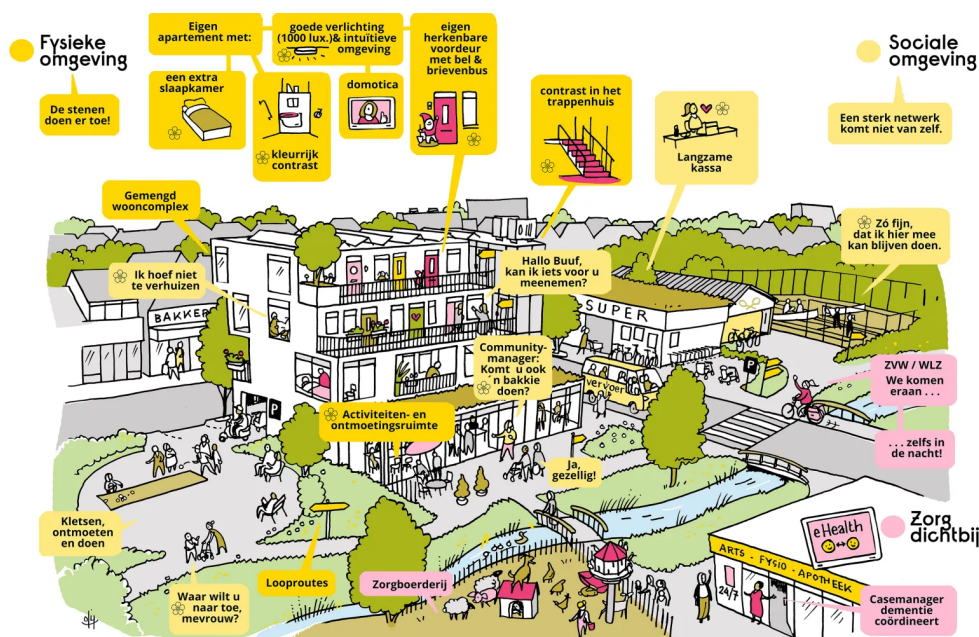


Image 1. Dementia friendly living. Derived from <https://www.alzheimer-nederland.nl/belangenbehartiging/standpunten/woonvormen-voor-mensen-met-dementie/wat-dementievriendelijk-wonen>.

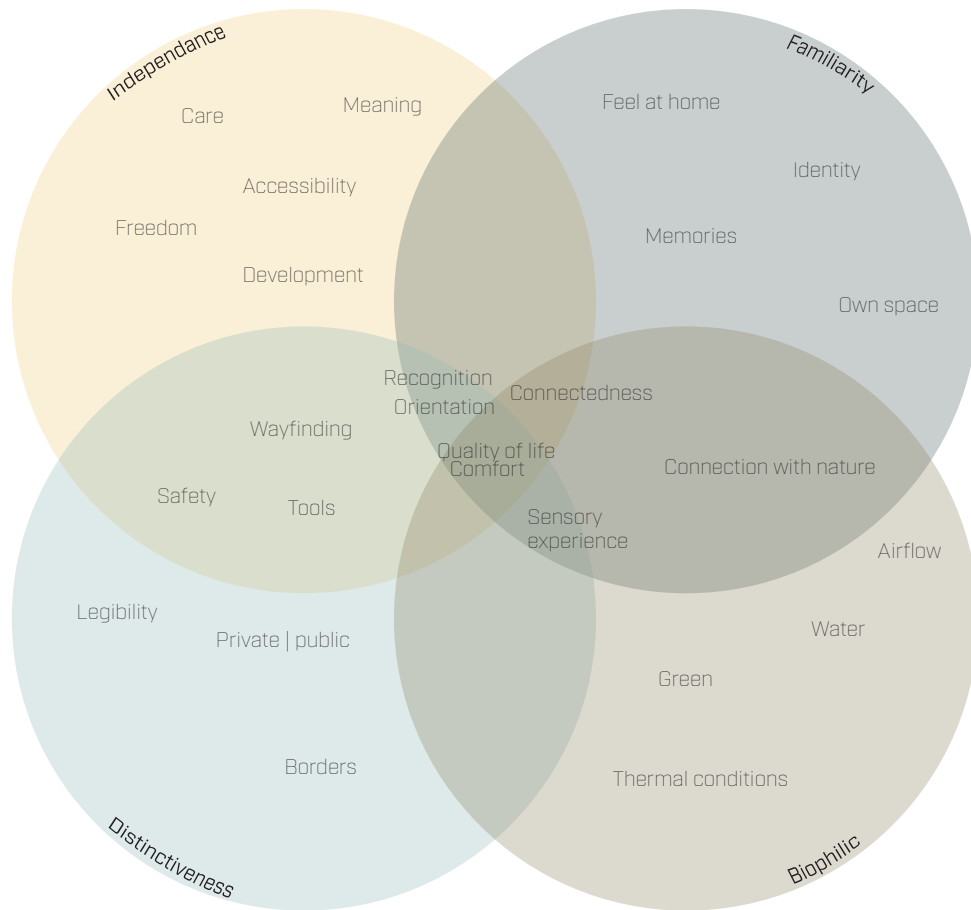


Image 2: Topics that are of relevance when designing for people with dementia subdivided in four main topics(own image).

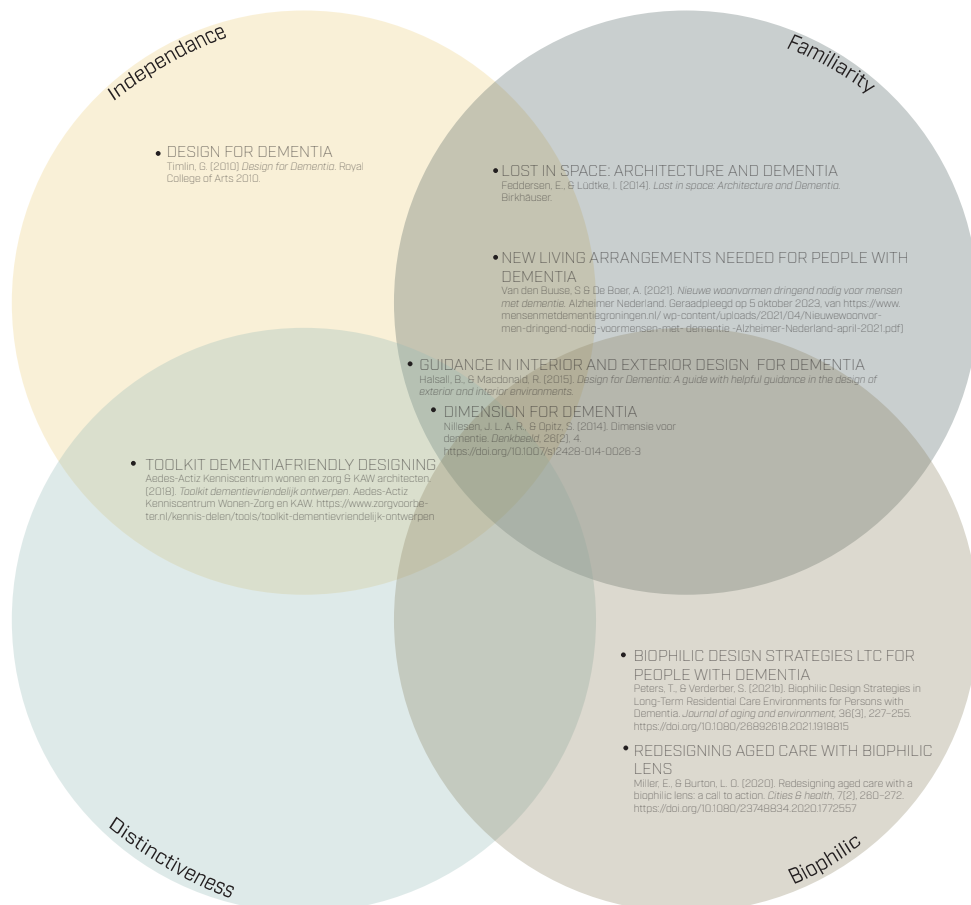


Image 3: Literature overview on designing for people with dementia, categorized in four main topics(own image).

1.3 DESIGN HYPOTHESIS

By bringing together the fields of dementia, dementia care and architecture, a qualitative living environment can be created for people with dementia (image 4). A higher quality of life will contribute to the efficiency of care and a

decrease in the demand for care. In this way, people with dementia can still get the care they need in a society where the imbalance, between those who need care and those who can provide care, is growing.

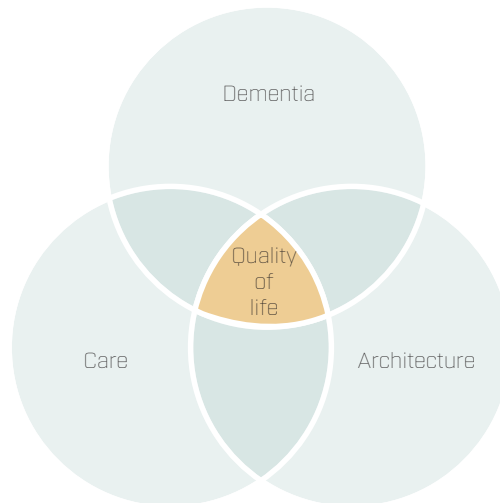


Image 4: Research plan to achieve quality of life for people with dementia (own image).

1.4 RESEARCH GOAL

The aim of this research is to define design guidelines that provide people with dementia with sufficient housing and a qualitative living environment through all stages of dementia. And to see if this can contribute to the efficiency

in care, so that people with dementia can still get the care they need. The goal is to create a living environment that comforts and supports the life of people with dementia.

1.5 RANGE

This research will only focus on elderly with dementia, and therefore exclude the early onset dementia.

This research will only focus on the situation in the Netherlands. Although some principles might be universal, the living arrangements are based on Dutch principles. The fieldwork, observations and questionnaires will all be done with Dutch people.

This research will include all stages of dementia. From the early stage, with more independence and less care demand to the severe stage, with a 24-hour care demand.

Because all forms of dementia are progressive, this research will exclude the concept of a healing environment. And focus more on a healthy environment, that supports and might slow down the process.

Considering the living environment, this research will focus on all scales; from room, to apartment, building and neighbourhood.

This research is user-based. Its main focus is the perspective of the person with dementia, but it will also include their partners, family and caregivers.

1.6 RESEARCH QUESTIONS

Research question |

Which living environment features provide people with dementia with quality of life and the care they need?

Sub questions |

1. What living environment features can contribute to the quality of life for people with dementia
2. Which living arrangements are there already for people with dementia
3. What living environment features are wanted by people with dementia
4. What architectural features contribute to providing care for people with dementia

1.7 DEFINITIONS

Dementia

There are many different types of dementia. They have in common to be progressive; people with dementia will get worse over time. They get problems with memory, thinking, perception and behavior. At some point they need a lot of assistance with daily living. Dementia can be explained in three stages; early, middle and late stage, or mild, moderate and severe. These stages differ per person and may overlap (The progression, signs and stages of dementia, 2021).

Adding to this, people with dementia also perceive their surroundings differently. Despite the subjectiveness of the topic, are there some general aspects. For example, the brain of one with dementia cannot stimulate itself but it must be given stimuli, orientation and organization become problematic, they have no conscience of what is 'behind' them, so they can't comprehend sounds and movement behind them, which causes confusion and fear (J. Nillesen et al., 2013).

Quality of life

"Referring to an overall sense of well-being with a strong relation to a person's health perceptions and ability to function. On a larger scale, quality of life can be viewed as including all aspects of community life that have a direct and quantifiable influence on the physical and mental health of its members." (Healthy Places Terminology, 2009)

Domains of quality of life that are important for people with dementia are: Physical functioning, daily activities, mobility, social

interaction, interaction capacity, bodily well-being, sense of well-being, sense of aesthetics and overall perceptions (Brod et al., 1999).

Well-being

Related to this are the domains of well-being. The Eden Alternative is a philosophy that seeks to address loneliness, helplessness and boredom and it serves as a template for driving successful culture change in long term care facilities (image 5). It is focused not only on the care of the human body, but also on the human spirit and the well-being of residents in nursing homes (The Eden Alternative, 2023).

The notion of well-being consists of two key elements: feeling good and functioning well. Feelings of happiness, curiosity and engagement are characteristic of someone with a positive sense of themselves. Having positive relationships, control over your own life and a sense of purpose are all attributes of functioning well (Huppert, F., & So, T. (2013).

Living environment

"The living environment is represented by the space in which organisms (biota) live and interact with each other or with the non-living environment (the abiota)" (Living environment, z.d.). The non-living environment is in this research defined as architectural features on different scales. From the details in the room to apartment, to building, to neighbourhood.

Biophilic design

Biophilic design is an approach to architecture that seeks to connect building occupants more

closely to nature. Biophilic designed buildings incorporate things like natural lighting and ventilation, natural landscape features and other elements for creating a more productive and healthy built environment for people (Seven Principles of Biophilic Design SageGlass, 2016).

Care

Caregiving is the process of protecting someone or something and providing what that person or thing needs (Care, 2023). Or "caregiving is providing care for the daily needs of someone that is unable to care for themselves (About caregiving, z.d.). This broad definition can have many interpretations. In this research, when spoken about care, it is medical care and help that support the impairments that come with dementia. But cleaning for example is excluded.

Healthy environment

A spatial setting that does not have a bad influence on one's health.

Health promotive environment

Spatial and architectural elements that stimulate a person to live healthier.

Aging in place

"The ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level." (Healthy Places Terminology, 2009)

Health

"A state of physical, mental, and social well-being and not merely the absence of disease and infirmity." (Healthy Places Terminology, 2009)

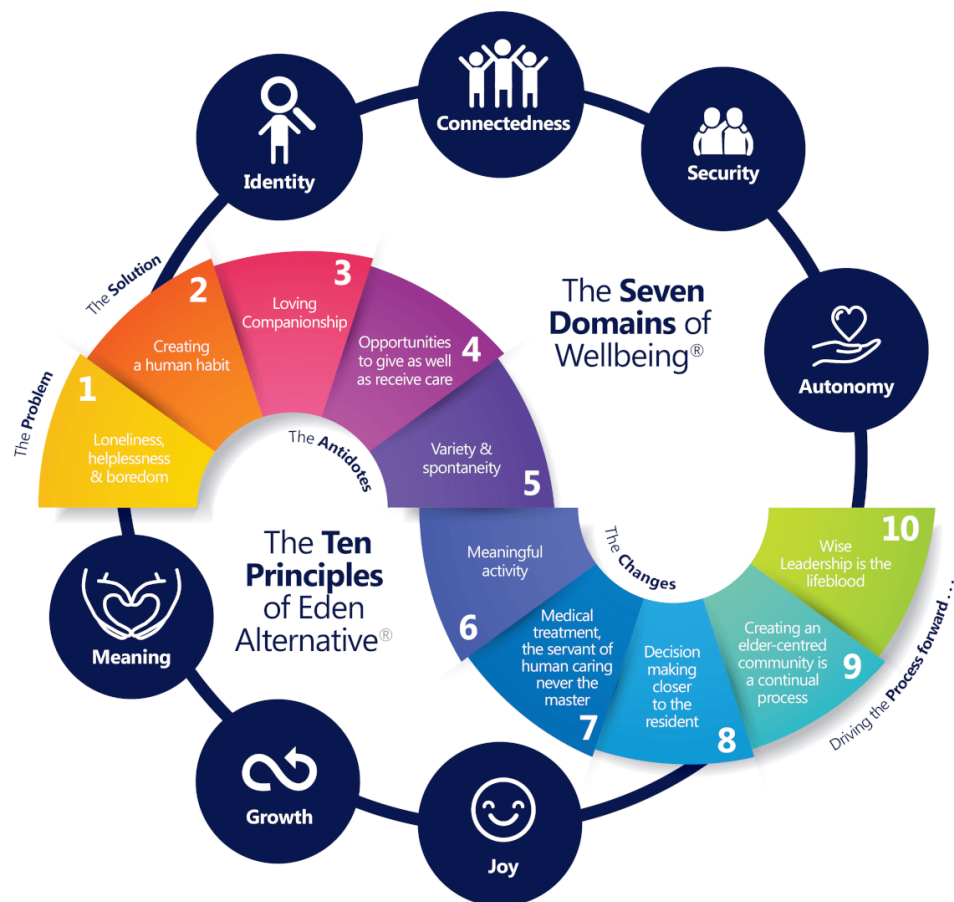


Image 5: Domains of well-being and the ten principles from Eden Alternative. Derived from <https://edeninoznz.com.au/framework/>

1.8 METHODS

Literature

Literature study will be done on existing toolkits and design principles for people with dementia. As mentioned in the theoretical framework, there has already been an extensive research on dementia friendly design (J. Nillesen et al., 2013; Halsall & Macdonald, 2015; Van den Buuse & De Boer, 2021; Aedes-Actiz Kenniscentrum wonen en zorg & KAW architecten, 2018). Different theories on different scales will be combined to get the whole picture on where architecture can contribute and support the living environment for people with dementia.

There are also previous studies and questionnaires done regarding this target group, their living arrangements and their care. These will be used as extra data, to broaden the input from the target group (Aedes-Actiz Kenniscentrum wonen en zorg & KAW architecten, 2018; Halsall & Macdonald, 2015). The literature suggested above is just a starting point, there is much more like this to find that will be used.

Fieldwork

There will be fieldwork for five days in an elderly and dementia care facility. This is a mixed living group with vital elderly but also people with severe dementia. The building also has a function for the neighborhood. This week will be used to get to know the daily life of people in different stages of aging and different stages of dementia. Especially to see what spatial and architectural features influence their life. But also to find out what living environment features they are still lacking or wishing for. This information will be gained first of all through observation.

The four points (distinctiveness, familiarity, independence, biophilic), as mentioned in the theoretical framework, will be the guidelines for the observation and also the interviewing.

Focus points in observation will be:

- daily schedule
- movement through the building
- movement outside
- what spaces are used/ not used
- floorplan
- outdoor space
- communal area

These observations will be caught in sketches and drawings on floorplans (see appendix A). Photography will be used to capture:

- Tools for orientation

- Things that make it feel like home

Another method to get information is interviewing. The people with dementia will be interviewed in a more informal way by just listening during meals and talking with them in during their normal activities. If possible it is nice to visit their homes and ask them about what they like and dislike.

Their caregivers will also be questioned. This is to find out what care people with dementia need in different stages of dementia, and how their life changes. Especially regarding their built environment, what becomes more important or less important. In this case the interview should also be focussed on their independence and possibilities for that.

This is also to find out how the built environment features helps them with their job. What is supporting them and what is not working well, and do they have suggestions in changing this for the better. Since they see the people with dementia on a daily basis they might have input on what gives their live meaning and is important for them as well.

Lastly the family members and others around them will also be interviewed. To see why they choose a certain facility and what things about the building they like and dislike (for questions see appendix B).

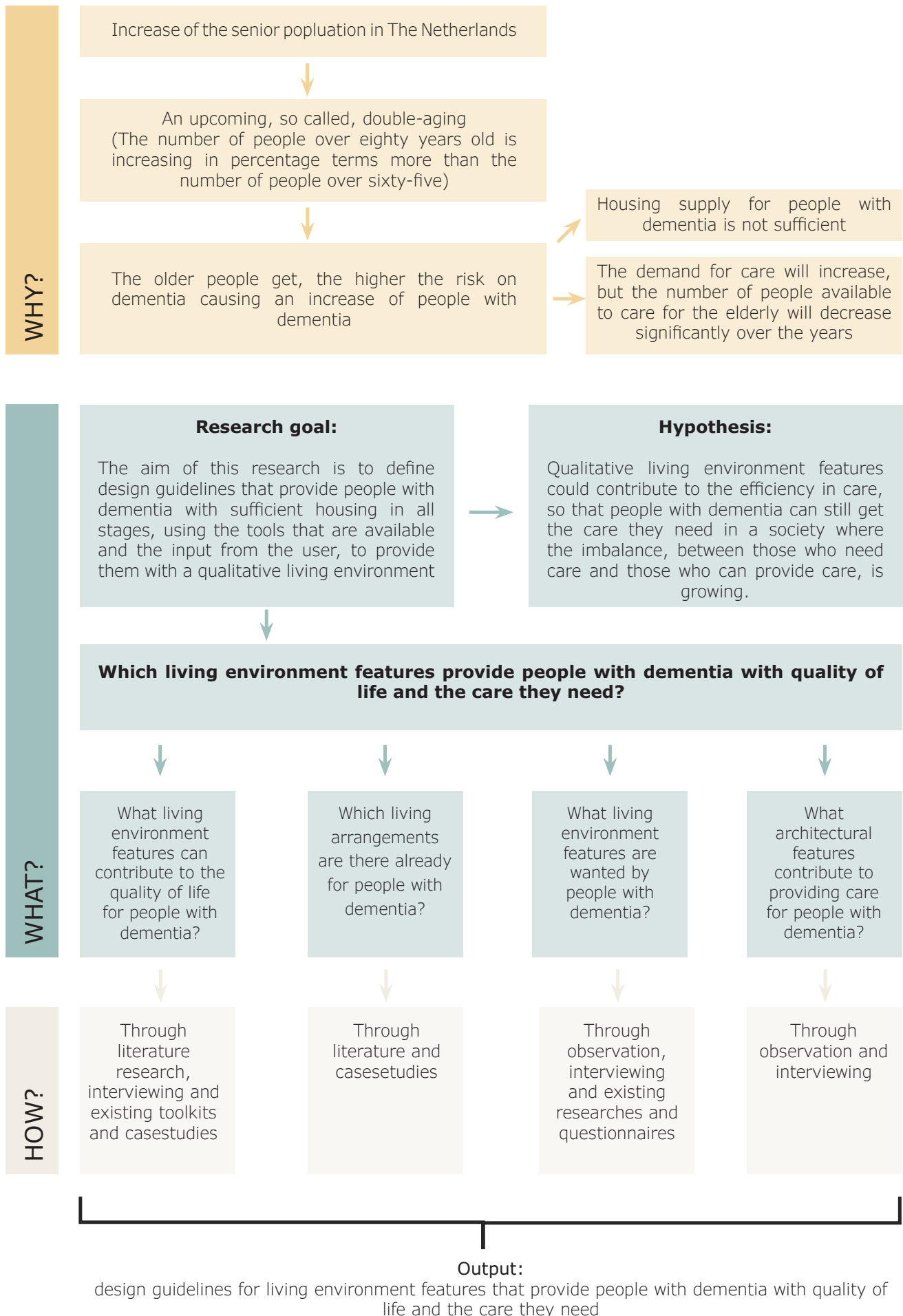
A final method used during the fieldwork is a form of workshop. The people with dementia and other elderly will be shown images of already developed designs for people with dementia, to get their input on what they like and dislike about it. To see what they would think of such a place and what works for them and not. The pictures will focus on biophilic, distinctiveness, familiarity and independence. This will give input from their perspectives on designs (see appendix C).

Case studies

Case studies include the building as well as the people and the interaction between both. They will be used to research earlier implementations of certain key elements in designing for people with dementia. Criteria for these case studies:

- Focused on dementia care specifically
- Based on research
- They all together grasp the whole range from room to neighborhood

1.9 RESEARCH PLAN



1.10 REFERENCES

- About Caregiving. (z.d.). <https://www.tntech.edu/cis/caregivingcenter/about-caregiving.php>
- Aedes-Actiz Kenniscentrum wonen en zorg & KAW architecten. (2018). *Toolkit dementievriendelijk ontwerpen*. Aedes-Actiz Kenniscentrum Wonen-Zorg en KAW. <https://www.zorgvoorbeter.nl/kennis-delen/tools/toolkit-dementievriendelijk-ontwerpen>
- Brod, M., Stewart, A. L., Sands, L. P., & Walton, P. (1999). Conceptualization and Measurement of quality of life in dementia: The Dementia Quality of Life Instrument (DQOL). *Gerontologist*, 39(1), 25–36. <https://doi.org/10.1093/geront/39.1.25>
- Care. (2023). In *Cambridge Dictionary*. <https://dictionary.cambridge.org/us/dictionary/english/care?q=care%29>
- De Klerk, M., Verbeek-Oudijk, D., Plaisier, I., & Draak, M. D. (2019). *Zorgen voor thuiswonende ouderen*. Sociaal en cultureel planbureau. <https://www.narcis.nl/publication/RecordID/oai%3Aascp.nl%3A0cb5bc5d-a1e6-4281-b15e-43676b5a8d59>
- Factsheet Cijfers en feiten over dementie | Alzheimer Nederland*. (z.d.). Alzheimer Nederland. <https://www.alzheimer-nederland.nl/factsheet-cijfers-en-feiten-over-dementie>
- Gopal, K., De Kort, J., Lickens, D., Marchal, B., & Van Veen, A. (2021). *Houdbaarheid ouderenzorg tot 2050*. ABF Research. <https://www.actiz.nl/sites/default/files/2022-02/Eindrapport%20ABF%20Research%20-%20Houdbaarheid%20ouderenzorg%20tot%202050.pdf>
- Halsall, B., & Macdonald, R. (2015). *Design for Dementia: A guide with helpful guidance in the design of exterior and interior environments*.
- Healthy Places Terminology*. (2009). Centres for disease control and prevention. <https://www.cdc.gov/healthyplaces/terminology.htm>
- Huppert, F., & So, T. (2013). *Flourishing across Europe: Application of a new conceptual framework for defining well-being*. Social Indicators Research, 837–861.)
- Living environment*. (z.d.). StudySmarter UK. [https://www.studysmarter.co.uk/explanations/environmental-science/living-environment/#:~:text=and%20mobile%20app-,Definition%20of%20the%20living%20environment,living%20environment%20\(the%20abiota\)](https://www.studysmarter.co.uk/explanations/environmental-science/living-environment/#:~:text=and%20mobile%20app-,Definition%20of%20the%20living%20environment,living%20environment%20(the%20abiota)).
- NIDI & CBS. (2020). *Bevolking 2050 in beeld*. <https://publ.nidi.nl/output/2020/nidi-cbs-2020-bevolking-2050-in-beeld.pdf>
- Nillesen, J., Opitz, S., & Plaats, J. J. (2013). *Dimensie voor dementie: kleinschalige woonvormen voor dementerende ouderen*.
- Peters, T., & Verderber, S. (2021). Biophilic Design Strategies in Long-Term Residential Care Environments for Persons with Dementia. *Journal of aging and environment*, 36(3), 227–255. <https://doi.org/10.1080/26892618.2021.1918815>
- Seven Principles of Biophilic Design | SageGlass*. (2016, augustus). <https://www.sageglass.com/industry-insights/seven-principles-biophilic-design>
- The Eden Alternative. (2023). *Our framework - the Eden Alternative*. The Eden Alternative - Improving the Lives of Elders. <https://www.edenalt.org/our-framework/>

The progression, signs and stages of dementia. (2021, februari 24). Alzheimer's Society. <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/progression-stages-dementia>

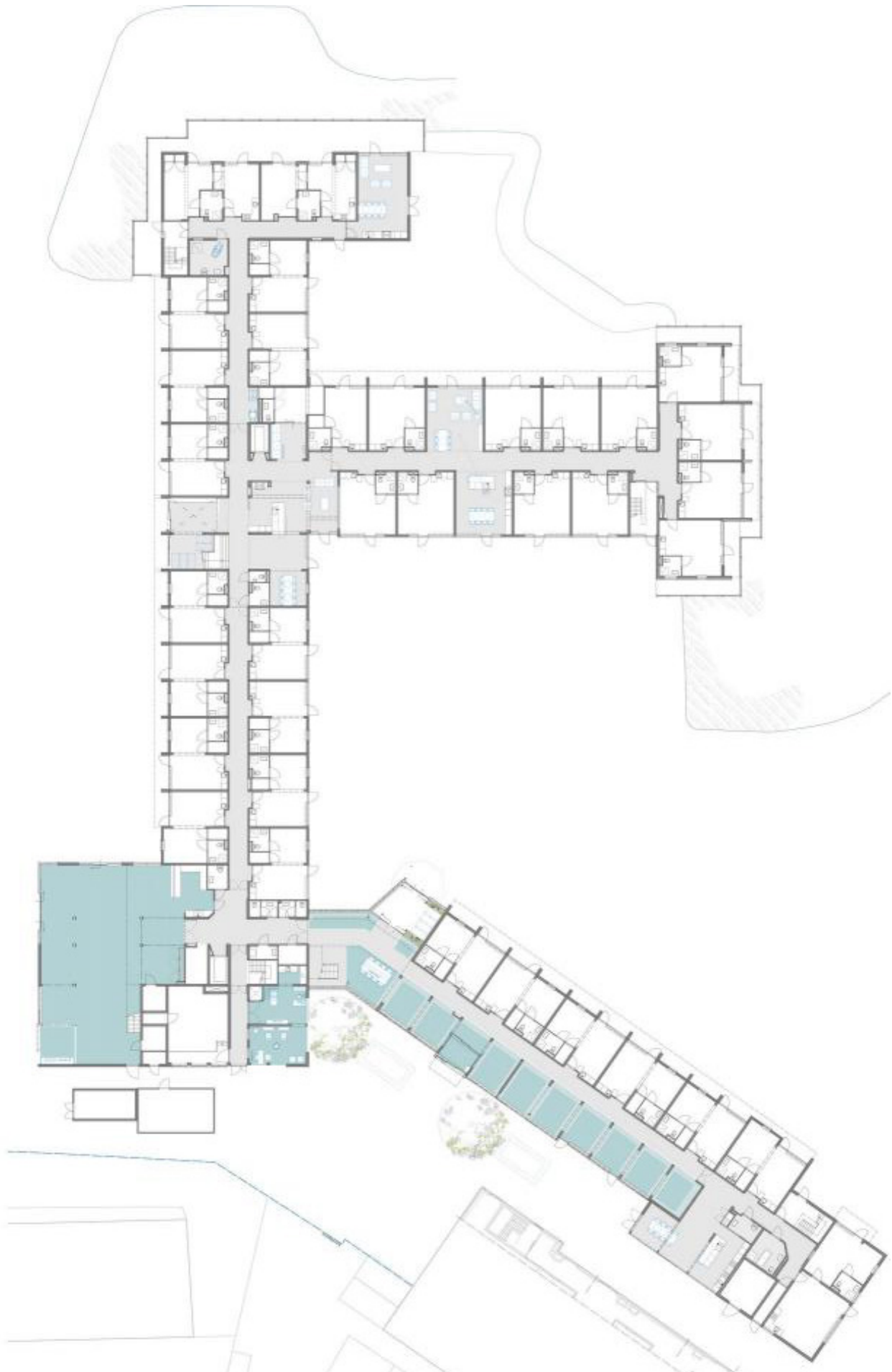
Van den Buuse, S., & de Boer, A. (2021, april). *Nieuwe woonvormen dringend nodig voor mensen met dementie.* Alzheimer Nederland. https://www.alzheimer nederland.nl/sites/default/files/directupload/Rapport%20onderzoek%20woonvormen_Alzheimer%20Nederland_april%202021.pdf

Wat is dementie? (2023). Ontwerpen voor dementie. <https://www.ontwerpenvoordementie.nl/wat-is-dementie/>

Wat is dementievriendelijk wonen? (z.d.). Alzheimer Nederland. <https://www.alzheimer-nederland.nl/belangenbehartiging/standpunten/woonvormen-voor-mensen-met-dementie/wat-dementievriendelijk-wonen>

World Health Organization: WHO. (2022, 1 oktober). *Ageing and health.* <https://www.who.int/news-room/fact-sheets/detail/ageing-and-health#:~:text=At%20this%20time%20the%20share,2050%20to%20reach%20426%20million.>

APPENDIX A





APPENDIX B

Questions people with dementia who live there

- Do you feel at home, what elements in your apartment help with that?
- How long have you been living here, are you happy with this place and why?
- Why did you choose this facility/place over other places?
- What is your favorite place in your apartment?
- What do you like about the apartment?
- What do you miss in your apartment?
- What is your favourite place in the building?
- What do you like about the building
- What do you miss in the building?
- Where do you like to go?
- What is your daily routine like?
- Is there something you would like to do, that is not possible now?
- Are there things you can no longer do?
- Is the building and apartment helping with your conditions?
- Do you get care or help with things?
- What do you still do on your own?
- What can you still do on your own but is not possible in this building?
- Is it easy to find your way around in the building?
- Did you move here by yourself or with others?
- Do you have people coming over often?
- What is your least favorite place in the building and why?
- What things are necessary for you to be happy in the building?
- Are there elements in the building that can be improved?
- What makes you happy?

Questions for caregivers

- What can you tell about the different stages of dementia?
- How independent are people with dementia
- Is this mixed living helping with the efficiency in care?
- What elements in the apartment help you with your work?
- What elements in the building help you with your work?
- Can people go outside?
- Do they do that often?
- How far do people with dementia go?
- What do you think of a closed facility?
- What do you think will help to avoid accidents?
- What do you think would help against

wandering or feeling lost?

- Are there sometimes accidents or is there confusion or fear or sadness among people with dementia?
- What makes them happy?
- Do they fill their own day or is there a schedule?
- What in the building will make your job easier?
- Are there elements in the building that can be improved?
- Can partners of the people also move with them?
- Are the apartments adjustable when the care demand changes?
- Do they wander a lot or get lost? What would help with this?

Questions for family and relatives

- Why did you choose this facility for your partner/parents/etc. Or did they choose it themselves?
- What stage of dementia is he/she in?
- Was moving here difficult? what made it easier, or would make it easier?
- Do they feel at home here?
- What do you think of this apartment, this facility?
- Is your family member happy here? What makes it so?
- What would you like them to do or have in the apartment or building?
- How would you like to get old?
- Are there elements in the building that can be improved?
- What makes them happy?
- What do you think about their freedom? Or do you want borders?
- What activities are important for them?

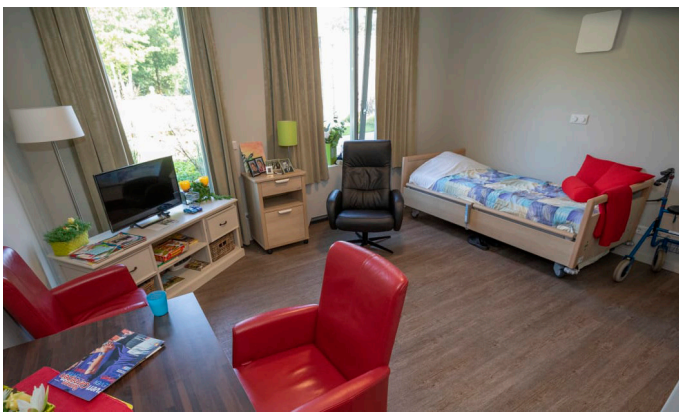
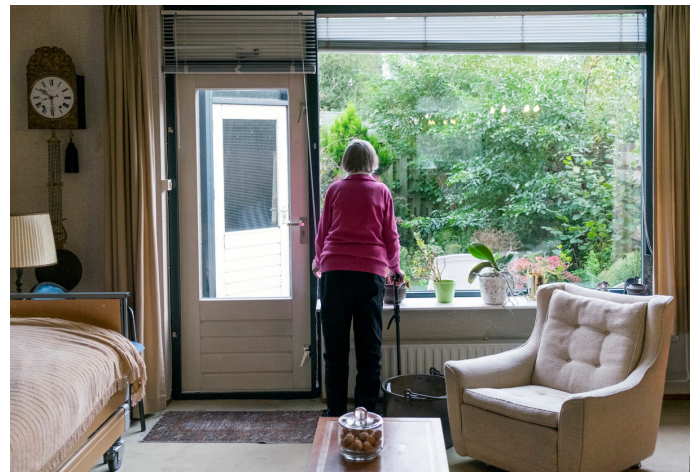
APPENDIX C*



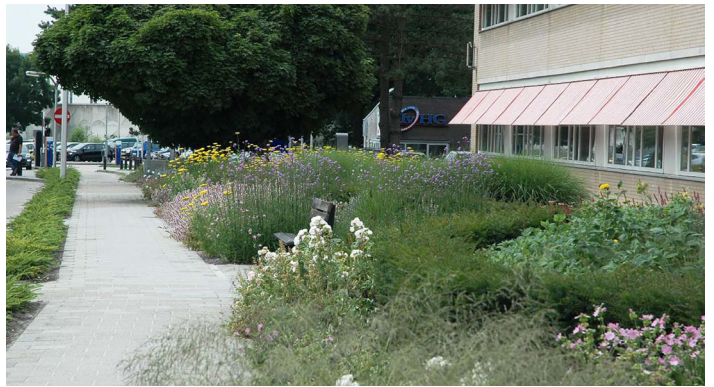
* Print in larger format taking poorer visibility of subjects into account



** Print in larger format taking poorer visibility of subjects into account*



** Print in larger format taking poorer visibility of subjects into account*



* Print in larger format taking poorer visibility of subjects into account



** Print in larger format taking poorer visibility of subjects into account*