

# RESEARCH PLAN

Designing alternative living for people with dementia to decrease the caregivers' burden and letting people stay at their own place longer.

Technical University Delft  
Faculty Architecture Dwelling  
Designing for care in an inclusive environment  
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## 1.1 Problem statement:

### 1.1.1 Dementia caregivers' burden & pressure on Dutch health system:

Dementia is a collective term of 50 brain diseases, which affect the ability to remember, think and make decisions. The number of people with dementia in the Netherlands will increase rapidly in the next twenty-five years. Currently, there are 300.000 people living with dementia in the Netherlands. This will increase to more than a half million people in 2040 and even 620.000 people in 2050 (Alzheimer Nederland, 2024).

People with dementia live on average for 6,5 years with the disease. This is often in different stages which have different effects on their lives. The different stages of dementia result in different care needs. Throughout these stages, the average informal caregiver (*mantelzorgers*) spends 39 hours per week caring for their community members. More than half of the informal caregivers experiences a heavy burden (Dementiemonitor mantelzorg, 2022). Different studies have shown that informal caregivers of people with dementia are likely to suffer from different types of health issues such as depression, anxiety, and physical illnesses (Etters, Goodall, & Harrison, 2008; Fonareva & Oken, 2014).

### 1.1.2 Rising pressure on informal caregivers

In the next twenty years, there will be an increasing pressure on the Dutch health system. The amount of informal care that is required cannot be fulfilled by the current informal caregivers. In 2018, per one care receiver of 75 and above living at home five informal caregivers were able to provide care. This is suspected to decrease to three informal caregiver per one care receiver in 2040 (Sociaal en Cultureel Planbureau, 2019). Next to the decrease of the potential of informal caregivers, there will be a larger shortage of formal caregivers (NU.nl, 2023). The decrease in informal caregivers and the shortage of formal caregivers means the caregivers' burden will be worse.

### 1.1.3 Housing challenges for people with dementia:

People with dementia often don't want to move to a new home and like to stay at their own place for as long as possible. In addition, 77% of the caregivers living with their care receiver finds the current housing options for people with dementia unsuitable (Alzheimer Nederland, 2021). But on the other hand 43% of the informal caregivers finds the current home of their care receiver not suitable. But moving people to a care home is not the solution. Care homes are seen as the final phase and often unpopular due to leaving the familiar environment and losing autonomy. This results in people staying at their unsuitable place leading to an even larger caregivers' burden and crisis hospitalizations. But even hospitalization does not always increase the burden on informal caregivers. More than half of the informal caregivers still experience the same or even a larger burden after their care receiver is hospitalized (Dementiemonitor mantelzorg, 2022).

With the increasing numbers of people with dementia, there is a need for better housing since the present housing schemes are not suitable. With this research I will focus on an alternative way of living for people with dementia. It will investigate the ways that partly replace care homes and make staying for people with dementia and their care givers at their own places possible.

### 1.1.4 Dementia in the architectural field:

Research about dementia and designing for dementia widely exist. The Dutch architecture firm Kroner Architecten provides guidelines and information that can be used while designing for people with dementia. But this research is mainly focussed on care homes and less on individual cases. Also informal caregivers of people with dementia have been studied thoroughly. For example the literature review by McCabe et al. (2016) which describes the needs of informal caregivers. Or Alzheimer Nederland which monitors and reports about the caregivers burden. These studies are

mainly coming from medical and psychological fields and are less present in the architectural field. Although the architectural research on dementia is very important, forgetting the informal caregivers makes it incomplete. Therefore this research will add to the research by focussing on dementia caregivers and their burden.

#### 1.1.5 Connection with the Tarwewijk:

Outcomes of this research will give the first design guidelines for an architectural design in the Tarwewijk in Rotterdam. While the research is useful on a national level, it is specifically connected to the Tarwewijk. Right now, only a small percentage of the Tarwewijk is seen as elderly (8%)(AlleCijfers.nl, 2024). Because this research focuses on the dementia pressure on the Dutch health system in the following twenty years, it is important to look at the age group aged 45 to 65 which will be 65 plus in twenty years. Right now, this age group exists of 2725 people. Although it is not possible to predict if these people will stay in the Tarwewijk, it is possible and important to give them an opportunity to stay. This can be done by building houses which are suitable to house people with dementia and informal caregivers.

The location for this design project will be the Polslandstraat and the Roggestraat. The current houses in these streets are in bad condition and will be demolished by the municipality. The plot is located central in the Tarwewijk, close to public green and a grocery store. Demolishing the current buildings frees up space for different housing typologies with a different density and different availability of care.

## 1.2 Theoretical framework:

In this section relevant studies on the topic of this research will be discussed. This way it becomes clear how this research can add to the existing research.

#### 1.2.1 Alternative ways of living:

In order to design an alternative way of living for people with dementia. It is important to investigate in already existing concepts. A literature review done by Speckemeier et al. (2023) investigates research about alternative housing types for people with dementia in the past decades. The research describes eleven different living concepts such as: shared housing arrangement (Germany), small – scale living (Netherlands) and group living (Sweden).

Speckemeier is a research assistant at the University of Duisburg at the Institute of Healthcare Management. This study will be used to explore the benefits and the drawbacks of the different housing typologies for people with dementia.

#### 1.2.2 Co-housing:

The co-housing typology is one of the eleven living concepts as discussed by Speckemeier, and already used as an alternative to the traditional care homes. Co-housing is a concept that has proven beneficial aspects such as a feeling of solidarity, mutual assistance and a sense of community (Labit, 2015, Jolanki & Vilkkö, 2015). Residents of co-housing concepts keep their own spaces but share common rooms such as kitchen and living room. Research about the benefits and drawbacks of co-housing in the Netherlands for elderly people goes more in depth on the problem of loneliness among elderly people (Rusinovic et al., 2019). Co-housing offers social activities and both emotional and instrumental support. Although this research is about co-housing for elderly in general and not about people with dementia, it is useful.

Research about co-housing for people with dementia in Modena also shows positive results. This research showed an improved informal caregiver's experience: a cost reduction for people living in a co-housing typology. Together with a decrease in caregivers burden and an improvement in quality

of life. Also people with dementia experienced an improved in quality of life and less risk to be hospitalized (Fabbo et al., 2020).

Fabbo works as Chief of Cognitive Disorders and Dementia Unit at Health Authority and Services of Modena in Italy. Topics of his research are: health psychology, clinical psychology and management of people with dementia. The research about co-housing for people with dementia shows positive results which can be used as a starting point for this research and as topic to discuss during interviews with informal caregivers.

Literature on designing for people with dementia is often guideline oriented. Telling the designer what needs to be taken into account and what not. It is focused on the needs of the user: people with dementia. But when the focus point for designing gets turned around it becomes a whole different approach. This is done by Feddersen and Lüdtkke (2014) by saying that we should design for people with dementia to benefit us all. Designing pleasant and appealing spaces for people with dementia through the use of colours, proportions, materials and acoustics will lead to pleasant and appealing space for carers and relatives.

The book *Lost in space* Feddersen and Lüdtkke is useful for this research not only because of the design guidelines, but also because dementia is discussed through different layers of society. Both authors are interesting because of their architectural backgrounds. Feddersen is a German architect and journalist on the field of housing for elderly and Lüdtkke completed her architectural studies after which she became a journalist on the topic of architecture, housing and health care.

Literature that is more focused on the design guidelines for people with dementia is the book *Dementia-friendly Hospital Buildings* by Büter and Marquardt (2019). Although the authors focus on designing dementia friendly hospitals which is a different environment than living rooms the information can still be of use. Ideas about colour, contrasts and daylight for dementia friendly hospitals can also be implemented in residential spaces. Also wayfinding and other orientation systems used in hospital corridors can be used in public spaces and walking routes in a residential building.

Both authors worked at the Chair of Social and Healthcare Building in the faculty of architecture at Technische Universität Dresden. Büter has a master's degree in interior design and her work focusses on designing architecture for people living with dementia. Marquardt is an architect and earned several academic awards for her dissertation on dementia-friendly architecture.

Both books are important when designing for people with dementia. And will be used in the design process. But when designing for informal caregivers of people with dementia the literature does not to provide answers. Although the intention of Feddersen and Lüdtkke is already more broad then only providing design guidelines for people with dementia the literature fails to include the needs of informal caregivers.

### 1.3 Research questions:

The research question comes from two different problems. The first problem is about caregivers staying at home with their care receiver in unsuitable houses, experiencing heavy burden. The second issue is about care receivers not willing to move to care homes and the caregiver's burden that stays even when their care receiver is hospitalized. There is a need for alternative housing that decreases the caregivers' burden and makes it possible for caregivers and care receivers stay at their own place even when formal care is needed. Alternative means that it is different from the present houses people with dementia and their informal caregivers live in and different from the traditional care homes. This leads to the research question: **How can alternative living decrease the dementia caregivers' burden and make residents stay at their own place?**

Since the problem statement is coming from a prediction and expectation based on the present lacking housing situation for people with dementia the output of this research is for a future target group who might get dementia. Giving them opportunities to a longer stay at their homes with an increase of the informal caregivers' burden.

#### 1.3.1 First sub-question:

The research question will be answered with sub questions. First it is important to get an overview of dementia and how it relates to living at home. The first sub question will be: **what are the different types and stages of dementia and how does this effect living on your own?** To limit the research, literature will be studied from an architectural view. What is needed to know as a designer. Only dementia stages are investigated which allow people to stay at home. This can be both with or without additional care from formal caregivers.

#### 1.3.2 Second sub-question:

When designing for people with dementia, it is important to know their needs and how this is translated in a design for a residential home. The second sub question is: **how to design for people with dementia?** A lot of the research about designing for people with dementia is about care homes. This will set the base for creating design guidelines for people with dementia and their informal caregivers living on their own.

#### 1.3.3 Third sub-question:

Next it is important to gain more knowledge about different types of existing ways of living. This shows the benefits and drawbacks of these alternative ways of living. The third sub question is: **what can be learned from existing alternative ways of living for people with dementia?** To get a broad knowledge about existing alternative ways of living for people with dementia, it is important look at examples both in and outside the Netherlands. Although context may differ with the Dutch health system, examples outside the Netherlands can still be useful.

#### 1.3.4 Fourth sub-question:

Lastly it is also necessary to research the possibilities of architecture on reducing the informal caregivers' burden. The final sub question is: **how can an architectural design help reducing the informal caregivers' burden?**

## 1.4 Methodology:

#### 1.4.1 First sub-question:

To get an answer to the first sub-question I will be studying studies such as on how different stages of dementia effect the way of living. Both Edwards et al. (2024) and Górska et al. (2016) have written on the experiences of living with early stage dementia. The film Human Forever (2023) will give more insight in the different stages of dementia. While analysing the different stages of dementia will provide a broader view on the disease. It is also important to get in touch with informal caregivers of people with dementia. During interviews I will research how their daily routines of living at home gets disrupted by an increasing care need of their dementia family member.

#### 1.4.2 Second sub-question:

The second sub-question will be answered by analysing the books mentioned at chapter 1.2 Theoretical Framework. I will also look into the design guideline of Kroner Architecten on designing for people with dementia. To focus more on how to design for people with dementia in residential buildings, I will be investigate research written by Alzheimer Nederland on the needs of people with

dementia. This way the sub-question will be answered from both an architectural as an user viewpoint.

#### 1.4.3 Third sub-question:

The third sub-question is focusing on alternative ways of living for people with dementia both in the Netherlands as outside the Netherlands. A part of answering this research question will be done by comparative research. This will investigate concepts such as co-housing and small scale living. This is mainly based on the literature review by Speckemeier et al. (2023).

At the same time my architectural practice will be used. The idea of alternative living is also about designing new floorplans which allow a longer and burden decreasing stay at people their homes. Investigating the current floorplans will explain why residents need to move. Therefore I will be looking into current typologies of the Polslanstraat and the Roggestraat in the Tarwewijk.

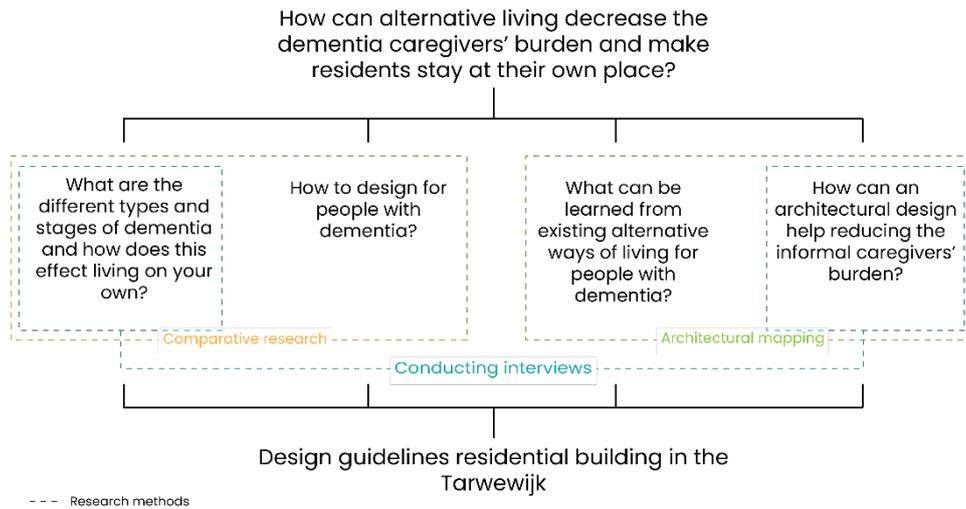
#### 1.4.4 Fourth sub-question:

For the final sub-question I will be doing interviews with informal caregivers. This can either be people who live with and care for their relatives. Or people who lived with their relatives but decided it wasn't doable anymore. This will be combined with the first sub question on how dementia effects living at home. The interviews will help understand the caregivers' burden and give insights in how architecture can decrease this burden. This sub question is strongly connected with the previous sub question because of the architectural analysing method. Mapping floorplans of houses of people with dementia and their caregivers live in will be useful for coming to a conclusion. Therefore it is needed to interview at least five to ten informal caregivers.

#### 1.4.5 Fieldwork:

During the research period, fieldwork will give more insights into alternative housing for people with dementia. I will be staying for three days at the care farm Reigershoeve in Heemskerk. At this care farm live 27 persons with dementia. Although the residents don't live at home anymore this place will be important for my research. Observations and talking to the residents will give insights into benefits and disadvantages of the fieldwork location. The fieldwork is also useful to better understand the dementia disease. Finally it is a chance to get in contact with informal caregivers and relatives.

Flowchart:



Time planning:

Sub-questions:

- What are the different types and stages of dementia and how does this effect living on your own?
- How to design for people with dementia?
- What can be learned from already existing alternative ways of living for people with dementia?
- How can an architectural design help reducing the informal caregivers' burden?

Methods & data:

- Studying literature, Edwards et al. (2024) and Górska et al. (2016) on the experiences of living with early stage dementia. The film Human Forever (2023) by Teun Toebes + interviewing informal caregivers
- Studying literature: Lost in space by Feddersen and Lütke (2014) & Dementia-friendly Hospital Buildings by Büter and Marquardt (2019) + analysing reports Alzheimer Nederland
- Studying literature on alternative typologies by Speckemeier et al. (2023) + investigating floorplans of the current typologies in Polstrandstraat and Roggestraat
- Interviewing informal caregivers + mapping floorplans

Week:

What to do:	1	2	3	4	5	6	7	8	9	10
Data collection sub-question 1.1		Studying literature								
Data collection sub-question 1.2	Conducting interviews									
Data collection sub-question 2		Studying literature								
Data collection sub-question 3		Studying literature								
Data collection sub-question 4	Conducting interviews									
Data analysis										
Draft version										
Final version										

Fieldwork: [ 1 2 ]

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