ANOTHER DEMANSION

Insight into the life of people with Young Onset Dementia and their relatives in order to design a care home facilitating them in their well-being

Nikita de Vette

ABSTRACT

Dementia is a familiar brain disorder, generally seen as a disease of the elderly and care homes are designed as such. However, also people between 30 and 65 can get dementia, called Young Onset Dementia and are overlooked now in architecture. Due to the different life stage in which the disease occurs, these mainstream facilities do not fit their needs, resulting in a decreased quality of life. It is already known how to design a dementia friendly environment, what the different course and impact of Young Onset Dementia is and which supporting facilities in the first stages at home are needed. Knowledge about architecture for later stages of Young Onset Dementia is lacking. This thesis therefore identifies the spatial needs of this target group and their relatives, in order to design a care home that facilitates them in maintaining their quality of life. Important outcomes of their spatial needs are having a purpose, physical activity, social interaction with peers, having a break and expressing dividual elements. These are not met in reality and the institutional setting of care homes are founded to be not suitable too. Provided guidelines for designing a care home for people with Young Onset Dementia therefore focus on dignity and activity. It is important for them to keep an as normal way of living, where young people with dementia and their relatives are brought together and to have a meaningful day and activities.

KEYWORDS

Young Onset Dementia, architecture, quality of life, care home, neuropsychiatry, health architecture, design guidelines

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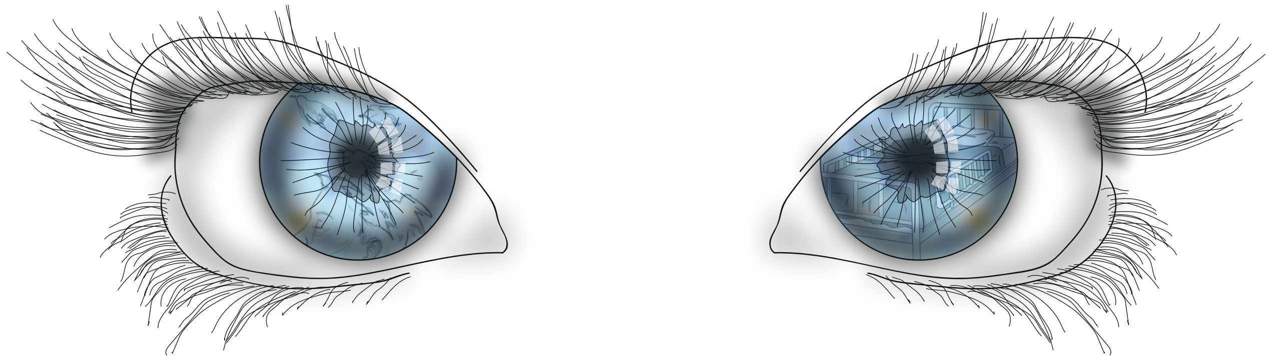
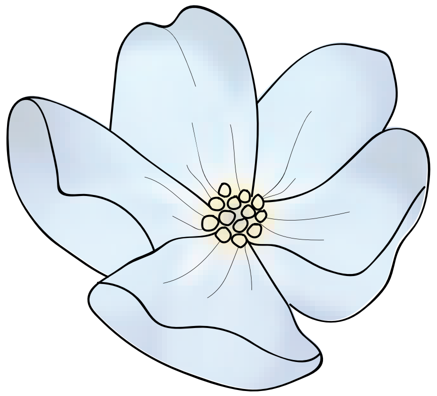


Fascination

I have seen with my own eyes what it means when a loved one has dementia at a young age and how important care is when someone gets lost mentally

My desire is to improve their life and well-being



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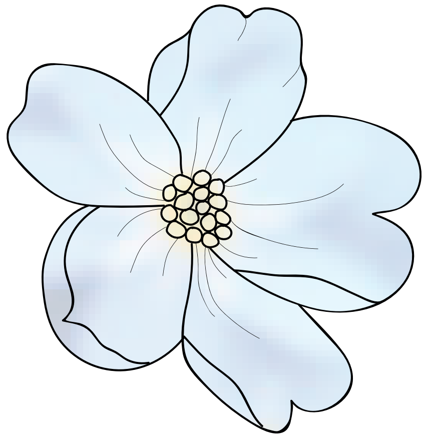
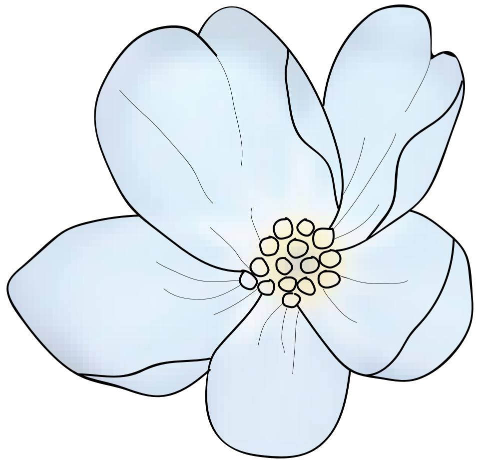




The introduction

1.1 BACKGROUND

Dementia is a generally familiar brain disorder, by now one out of 3 women and one out of 7 men will get it. Taking into account their surroundings, even more people come in contact with dementia in their lives. Due to our ageing society, this number is rising. When there were 50.000 people suffering from dementia back in 1950, this is currently already 290.000 and the prognosis is that this amount will increase to 620.000 in 2050 (Alzheimer Nederland, 2021).

Since dementia is typically regarded as an age-related disease, the occurrence of dementia at a younger age may be overlooked (Bakker, 2013). When younger people are diagnosed with dementia, it is called Young Onset Dementia; when the first symptoms manifest before the age of 65 (WHO, 2012). According to the World Health Organisation (2012), 6-9% of all dementia cases are a young onset form. It is estimated that there are today between 12.000 and 24.000 people with Young Onset Dementia in the Netherlands (de Vries & de Graaf, 2020). Due to late diagnosis, it is difficult to determine the exact number. As well as dementia in general, the number of young onset dementia is expected to rise, roughly doubling every 5 years (WHO, 2012). In 2017, Alzheimer Nederland measured this at 12.000, but more recent research showed an amount of 24.000 people with dementia between 40 and 65 (Vektis, 2019).

This thesis focuses on this population of Young Onset Dementia.

1.2 PROBLEM STATEMENT

The diagnosis of dementia has a big impact on those affected. According to doctors and researchers, dementia is the disease with the highest burden for the sufferer (Alzheimer Nederland, 2021). It results in an important loss of the health related quality of life (Bakker, 2013). Especially Young Onset Dementia is recognized as an important psychosocial and medical health problem with serious consequences for sufferers and their families. Caregivers experience even a higher level of caregiver burden than those of older dementia sufferers (Bakker, 2013).

Young Onset Dementia is not just dementia at a younger age, there are substantial differences with Late Onset Dementia (Mendez, 2017), which leads to different needs for these younger sufferers and their caregivers.

First of all, Young Onset Dementia has another clinical manifestation (Bakker, 2013; Smits, 2013; de Vries & de Graaf, 2020). Where the stereotype symptoms as memory problems and disorientation are more prevalent by Late Onset Dementia, the cognitive domains in the brain other than memory are often more affected by the younger people instead (Baptiste et al., 2016; Smits, 2013). They are therefore more likely to face problems such as deficits in language, visuospatial function and often have apraxia, which hamper functioning in daily life. Also behavioural problems and neuropsychiatric symptoms are more on the foreground in Young Onset Dementia, depression, psychosis and agitation are highly prevalent (Bakker, 2013; Smits, 2013; de Vries & de Graaf, 2020).

Second of all, young people with dementia are in a different phase of their lives and fulfil a more active role in society (Bakker, 2013; Baptiste et al., 2016). They are often part of a family and are a parent, even with whether or not dependent children living at home. According to a study in Norway, at least one out of four parents with Young Onset Dementia have children under 18 years (Gerristen, 2020). They are also still working and thereby usually a family provider, have a social life and are physically active.

Compared to older people with dementia, those symptoms and the greater loss of roles and responsibilities have a more profound impact on the quality of life of someone with Young Onset Dementia, as they are physically fitter, more active and often have a more preserved awareness of this (Bakker, 2013; Baptiste et al., 2016).

Despite these differences between Late and Young Onset Dementia, specialised care facilities for the younger are scarce in The Netherlands and their distribution is limited (Bakker, 2013). Hereby, specialised care often means more knowledge and care groups with young people, rather than a specific designed facility for them. Sufferers and their families are now forced to use the general dementia facilities, which are designed for and focussed on the elderly and thus do not fit the different needs of the younger. Therefore, it is difficult for them to integrate in those mainstream facilities, resulting in being pushed from pillar to post in order to find a suitable care facility (Bakker, 2013; Baptiste et al., 2016).

Most families are now providing informal care to their loved ones with Young Onset Dementia. At a certain moment they cannot take care of themselves anymore and families gradually take over the care till late stages of the disease, in order to prevent institutionalisation for as long as possible (Bakker, 2013). They have concerns about the quality of external care for their relatives, since they consider the mainstream facilities as not suitable. Although this far-reaching informal care, research shows that this only has a postponing result (Bakker, 2013). Institutionalisation is eventually inevitable, since at a certain moment it is not doable anymore.

Moving can already be challenging for the sufferers and can result in a, often temporary, fast decline in their process, since they lose all their familiar mechanisms. This can have a negative effect on their quality of life (Lambert, 2016).

In addition, it is known that unmet needs of people with Young Onset Dementia in care facilities can lead to or worsen their neuropsychiatric problems, and have an even bigger impact on their health related quality of life (Bakker, 2013). They thus end up in a downward spiral: due to their different symptoms as being sensitive for developing neuropsychiatric problems and the non-specialised care facilities, their needs are unfulfilled, causing more or worse neuropsychiatric problems.

Furthermore, another problem in those mainstream dementia facilities is the normalised use of psychopharmaceuticals. One out of three clients in The Netherlands get this medical treatment for their so called ‘unwanted and restless’ behaviour (van Marum et al., 2014; den Tek, 2022), which are typical neuropsychiatric symptoms people with Young Onset Dementia show, to get them quiet and calm. It has been shown that these antipsychotic medication and benzodiazepines have a low efficiency and harmful side effects, such as physical and cognitive decline and a state of sedation (Rochon et al., 2017; Wang et al., 2018). This again is a downward spiral and lowers their health related quality of life.

People with Young Onset Dementia, as well as their family, thus face consequences on their health related quality of life, because of the lack of specialised care facilities.

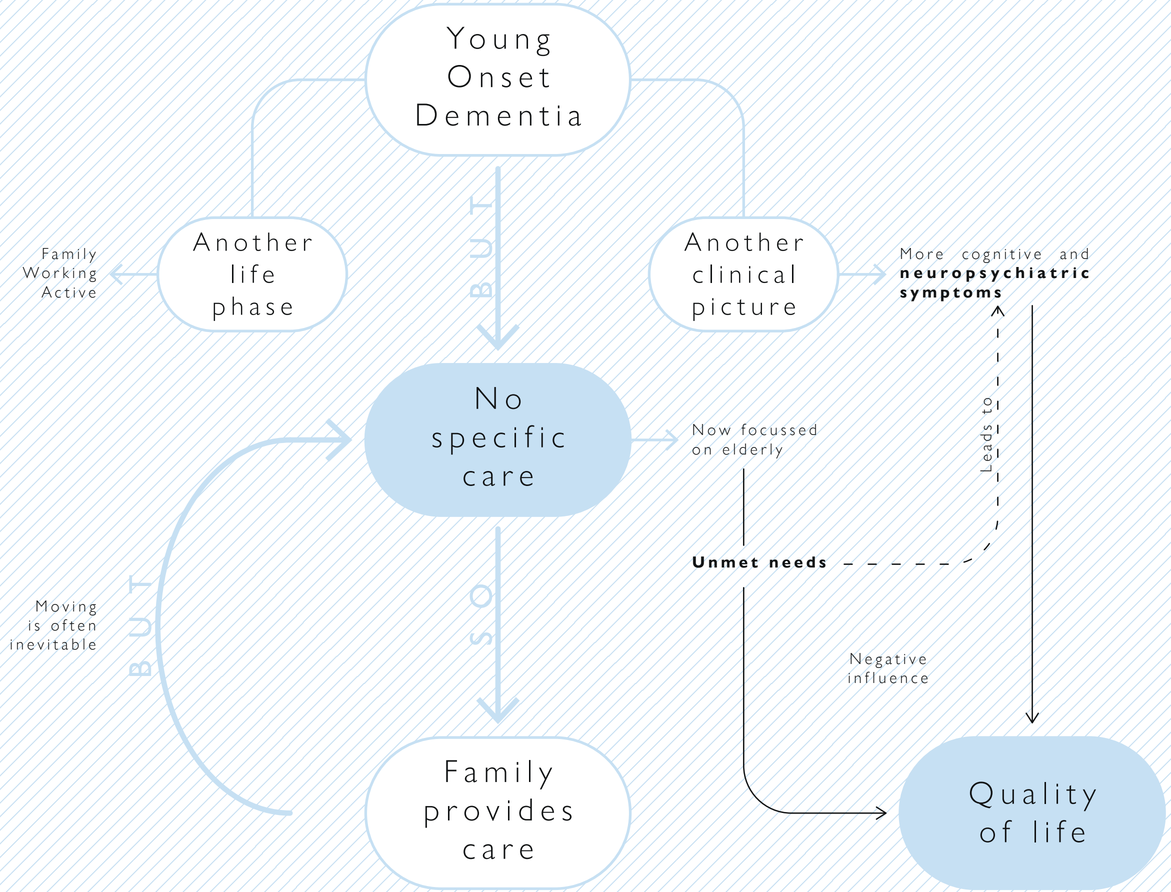


Figure 1 | Problem statement

1.3 GOAL

Specialised care facilities for people with Young Onset Dementia are needed. The main goal of this thesis is to create architectural guidelines for a care home for people with Young Onset Dementia, where they are able to live a meaningful life in an environment working in their (health) favour, in order to maintain their (health related) quality of life.

To achieve this, there are three research aims:

1) Insight in current design principles for environments used for people with dementia, to understand how to design a dementia friendly care environment

2) Insight in the spatial needs of people with Young Onset Dementia and their relatives, to understand how a care home should suit their life

3) Insight in the current care environments for people with (Young Onset) Dementia, to understand the care needs and see where they do and do not fit their spatial needs

1.4 THEORETICAL FRAMEWORK

Since dementia is a generally familiar brain disorder, it is already known what the symptoms are and what the course is. Based on those symptoms, it is also known how to design a **dementia friendly environment**, from an urban to an interior level. Fleming (2016, 2017, 2020), a clinical psychologist experienced in dementia, reviewed relevant literature about designing for dementia. Also the evidence based reviews of Bowes & Dawson (2019) and Marquardt et al. (2014) about dementia environments are used.

In the last decades there is more attention for Young Onset Dementia. More specialised, mostly medical, research has been done into the **course and impact of Young Onset Dementia**. Bakker (2013), Van Vliet (2012), Millenaar (2016) and Gerritsen (2020) wrote dissertations about the needs, experiences, impact and course in Young Onset Dementia which has resulted in the knowledge of what is needed as supporting facilities in the first stages of Young Onset Dementia for both the sufferer and their relatives in the home situation and in training programs for formal caregivers of people with Young Onset Dementia.

Another dimension in the research in Young Onset Dementia is required, focusing on the later stages of the disease where they cannot live at home anymore. Despite knowing that families consider external care as inappropriate and are facing worrisome problems with that, it remains unclear what people with Young Onset Dementia and their relatives need in their daily lives. Knowledge about the **spatial needs in the later stages** for a care home, specifically for young people with dementia and their relatives, is therefore needed.

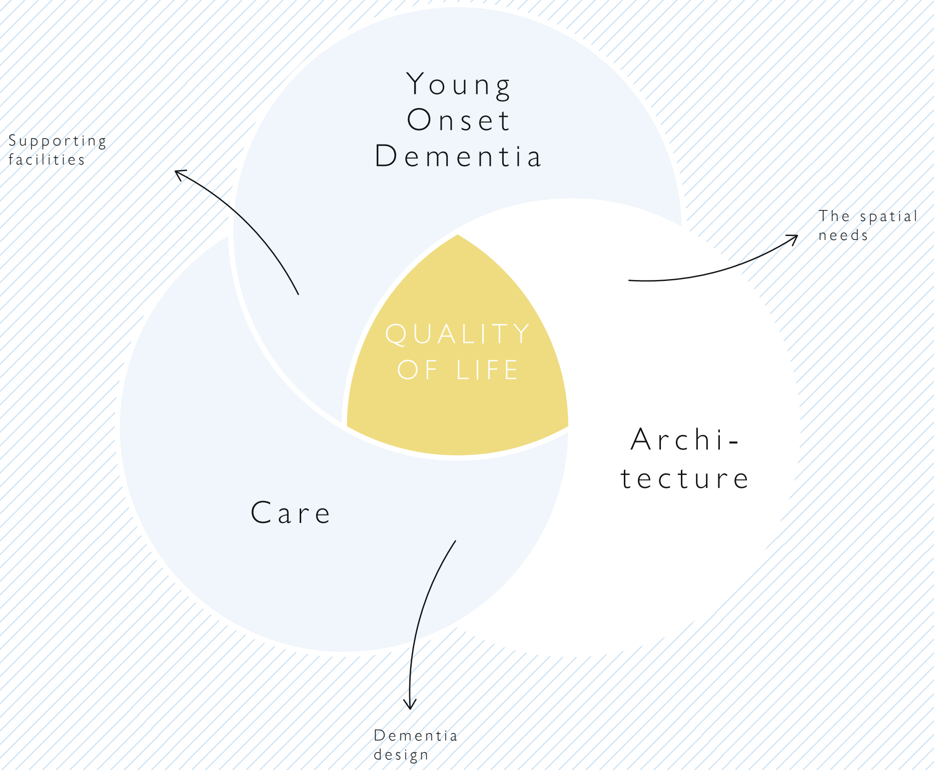


Figure 2 | Theoretical framework

1.5 DESIGN HYPOTHESIS

The design hypothesis of this thesis is that a care home for people with Young Onset Dementia should be a place for both the resident with Young Onset Dementia as their relatives, as it fits their specific life stage of being an active part of a family better.

1.6 RESEARCH QUESTIONS

The main research question of this thesis is:

How can a care home for people with Young Onset Dementia be designed in such a way that it facilitates them, and their relatives, in maintaining their quality of life?

The sub-questions of this thesis are:

1) Which design principles are used for people with dementia?
2) What are the spatial needs of people with Young Onset Dementia?
3) What is the perspective of relatives on the spatial needs in daily life?
4) How do current care homes for people with Young Onset Dementia look?

1.7 RESEARCH LIMITATIONS

This research only focuses on people with Young Onset Dementia and care facilities in the Netherlands and only involves an architectural level and thus not medical examination, organisational policies and supporting services.

1.8 DEFINITIONS

A **care home** is a build residential institution where care is provided on a permanent base to people with mental or physical diseases or infirmities

Care facilities are built and supporting care services.

Dementia is a collective name for around 50 brain diseases, causing progressive brain damage, which hampers the brain in processing information properly (Alzheimer Nederland, a.d.; Dementie.nl, a.d.).

Design guidelines, principles and solutions are three consecutive notions. A design guideline is a written recommendation of a certain performance. This can be translated into different design principles, which are the practical operations. The design solution is the final form in how it is applied.

Health is, according to the WHO (1946) "*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*" The fundamental difference in this thesis is that despite having a disease or infirmity, a person should still be able to experience health.

Therefore health is seen as being able to integrate physical, mental and social challenges in life by maintaining or developing a state of well-being (Huber, 2014; van der Stel, 2016).

Health-related Quality of Life (HRQoL) is based on the relation between health and the QoL. It evaluates how a health status is perceived and reacts to nonmedical aspects of human life (Lin et al., 2013).

Late Onset Dementia (LOD) is the most common form of dementia, afflicting people aged above 65.

Spatial needs are essential qualities of a physical living environment, from an urban to a building level.

Quality of Life (QoL) refers to the goodness of life as a whole, covering all aspects of human life by evaluating the perspective on well-being and satisfaction (Lin et al., 2013).

Young Onset Dementia (YOD) is dementia at a younger age, with symptoms manifesting before the age of 65. This number is rather an indication of the different life phases based on the general retirement age. In this thesis, the age rage is set between 30 and 65, although in some literature the rage between 40 and 65 is used (Lambert, 2016).

The term Early Onset Dementia, which has the same meaning, is the medical term for this disease and also widely used in literature. However, this term can be misinterpreted as an early stage of dementia and is therefore not used in this thesis.

1.9 METHODS

This thesis is an anthropological research, it has an human-centred approach, so qualitative methods are therefore used.

By two **personal cases**, first hand experiences are used to gain basic insight into faced problems with dementia in daily life and in a care home. Case 1 is a young man with dementia who lived in a care home, case 2 is a young woman with dementia who lives at home.

By **observations and informal talks**, the persons behind Young Onset Dementia get to know, in order to understand the clinical picture and how a care centre could support young people with dementia and their relatives. This is done by physical fieldwork in two care homes for people with dementia, referred to as fieldwork place 1 and fieldwork place 2, and one in a specialised care home for people with Young Onset Dementia, referred to as fieldwork place 3. Fieldwork place 1 is based on a year inside experience of case 1. Fieldwork place 2 consisted of a guided tour through the building by a staff member and observations of daily activities in and with residents from two wards. Fieldwork place 3 also consisted of a guided tour through the building by a staff member and observation in a ward during different parts of the day.

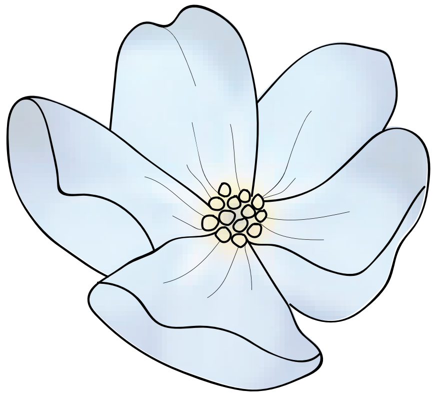
Since it is not possible to interview the people with dementia themselves, the experiences of caregivers are used to get a more thorough understanding, by having informal talks. In fieldwork place 1 is spoken informal with caregivers. In fieldwork place 2 is spoken with two activity supervisors and a caregiver. In fieldwork place 3 is spoken with two caregivers and a hostess.

By **media**, a broader picture of the persons behind Young Onset Dementia is gained, in order to understand the general influence on their and their relatives life.

The documentaries *Frank & Alzheimer, Magreet: jonge mensen met dementie* and *Gezichten van dementie*, the tv-programme *Restaurant Misverstand (seasons 2 and 3)*, the Youtube series *Muziekherringeringen* and *Herinneringen voor het leven* of Alzheimer Nederland, the blog of *Margreet Mantel*, a partner of a young person with dementia, and newspaper and magazine articles with personal stories have been used.

By **case studies** is investigated which kinds of specific build care facilities there are and how they work, in order to get an overview of the program and spatial organisation of existing care facilities and their architectural principles.

An inventory of the facilities for people with Young Onset Dementia is made and described to give a general overview. The case studies are chosen by typology, with priority for the ones where fieldwork is carried out and where young people with dementia live, in order to get an understanding of how such a facility functions in practice for my target group. Since there are not many care facilities specifically designed for young people and facilities focussed on elderly are often used, they are taken into account as well. The case studies chosen are fieldwork place 1 and fieldwork place 3, due to the different typologies, a courtyard and a ward. The characteristics of those facilities are analysed, such as sizes of living groups, patient rooms, outdoor spaces, additional facilities and the spatial organisation.



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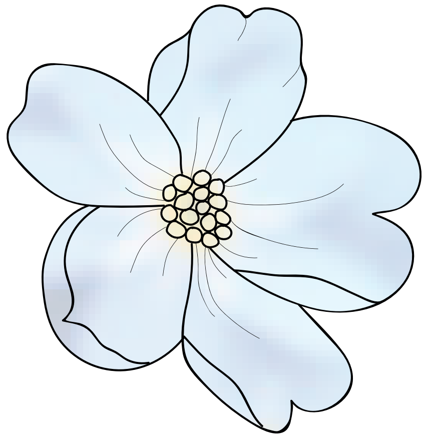
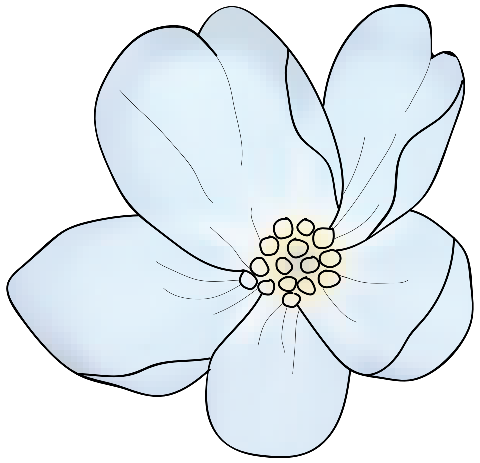




The literature

2.1 TYPES OF DEMENTIA CARE

Home care is care given at home, whereby the person with dementia resides in his own home during the day and night. Generally, this care is given by informal caregivers, which are the relatives living in the same home. However, it is also possible to hire external personal care, for basic assistance at set moments or for longer periods.

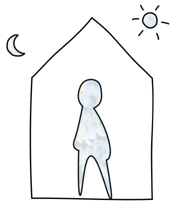


Figure 3 | Home care

Respite care is a temporary replacement of care, whereby the person with dementia resides in an external facility during the day and night for a few days. It is an additional support of the care at home. This can be on a structural basis on set days in a month or week, to get some rest as an informal caregiver, or on an incidental basis, when the informal caregiver is not able to take care or needs a break.

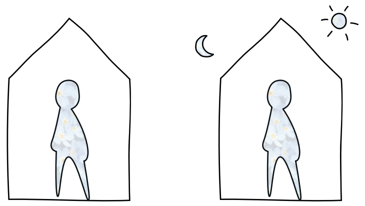


Figure 4 | Respite care

Daycare is an external form of care, whereby the person with dementia goes to an external facility during the day, where they can do activities and eat together. It is an additional support of the home care for a few days a week. Usually, people go there after breakfast and return home before dinner. During the night they reside at home and care is given by the informal caregivers.

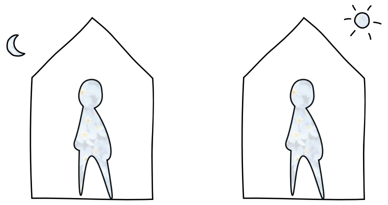


Figure 5 | Daycare

Long-term care is a total replacement of care, where the person with dementia moves permanently to an external care facility.

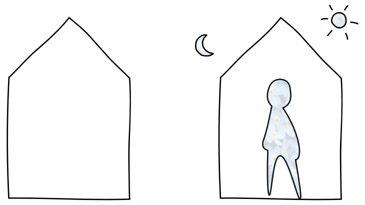
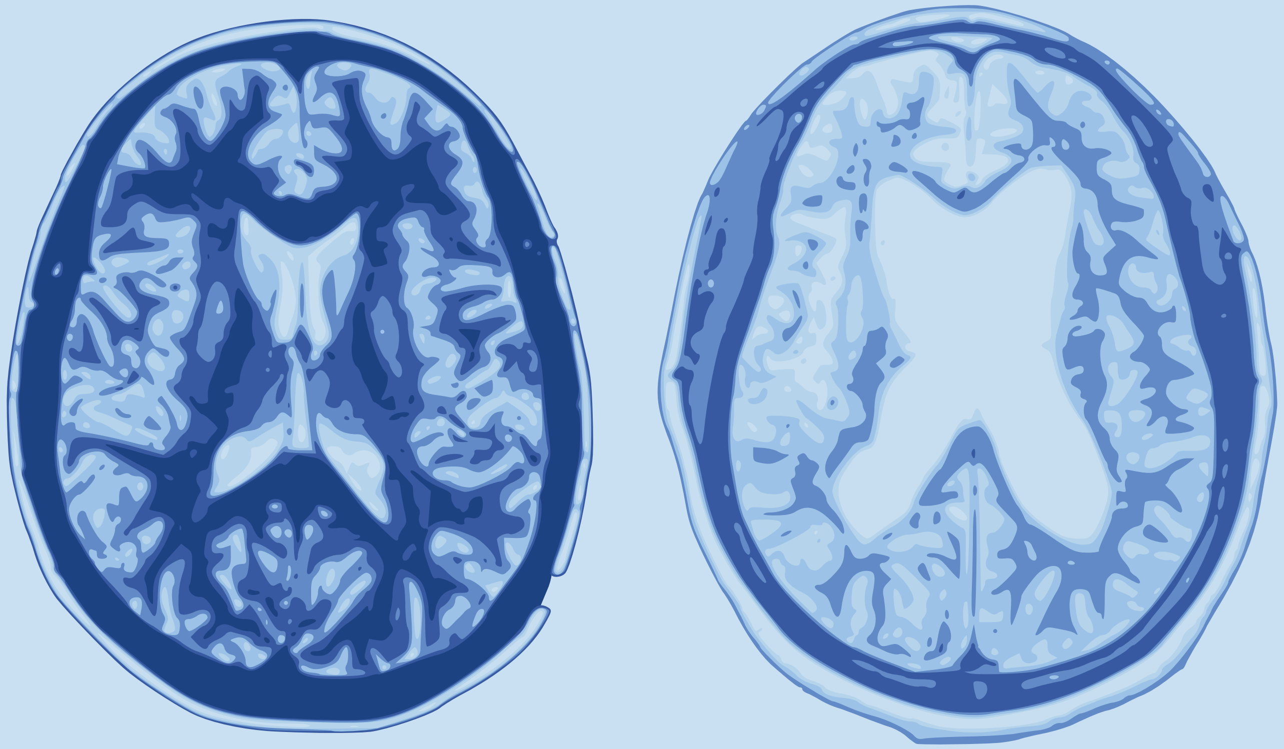


Figure 6 | Long-term care

Figure 7 | Places of care homes for YOD in The Netherlands, based on information of Kenniscentrum Dementie op Jonge Leeftijd (n.d.)



Average brain

Dementia brain

Figure 8 | MRI scan average brain and dementia brain

2.2 SYMPTOMS OF DEMENTIA

Dementia is a collective name for around 50 forms of brain diseases that hamper the processing of information. The brain cells or the connection between them break down, due to the process of accumulation of protein plaques or small strokes (Alzheimer Nederland, a.d.–h; Dementie.nl, a.d.). This makes the brain shrink (figure 8) and lose its functions gradually, resulting in an impaired daily functioning.

Symptoms are related to cognitive functioning, as memory and visual spatial, and physical functioning, also of the body itselves as immune response. Neuropsychiatric symptoms, which are psychiatric complaints due to a neurological disorder, can occur as a consequence. These can manifest in nervosity, anxiety, depression, restlessness, agitation, delusions and psychosis.

The course of dementia is progressive and there is no cure. It differs per person which symptoms occur and in which order, as also the duration can differ (Kennisplein Zorg voor Beter, 2022b). The average lifespan after diagnosis is 8 to 10 years (Alzheimer's Society, 2021). However, in Young Onset Dementia the disease even deteriorates faster, meaning having a shorter lifespan. Eventually, someone becomes so weakened, being only able to lie in bed, and will die due to another infection or because swallowing is no longer possible (Kennisplein Zorg voor Beter, 2022b).

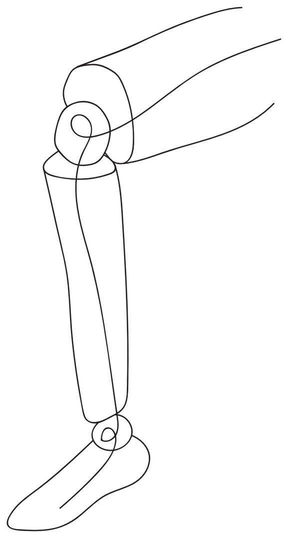


Figure 9 | Body control

Coordination

Coordination is the ability to have control over the movements of the body. The muscles required for those movements are regulated by the brain. It interprets the spatial perception and makes a response by translating it in detailed instructions for hundreds of muscles to contract at the right time (Van Den Heuvel, 2022).

The brain of people with dementia slightly lose the ability to make these responses, resulting in ataxia. This is the uncoordinated and incoherent course of movements, which is not caused by a loss of muscle strength (Hersenstichting, 2022b). They therefore face difficulties with keeping their balance when walking, often characterised as walking when you are drunk, moving smoothly as they can shiver, miss out if they want to grab something and getting difficulties with swallowing.

Having this impairment means it becomes difficult to move yourself from one place to another and might eventually result in having to walk with a walker or using a wheelchair. Also taking care of yourself becomes more challenging if you cannot control your body with washing, changing or eating (Hersenstichting, 2022). An environment should therefore form no obstructions or risk to move in, by preventing falling and facilitated independent movement, so that moving is stimulated and safe.

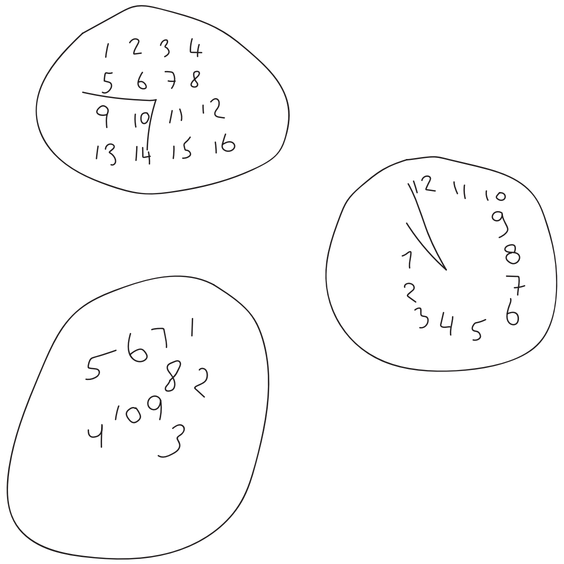


Figure 10 | Clocks drawn by dementia patients

Sense of time

The perception of time is essential to keep people grounded in reality and to orientate oneself within time and space. Time is an abstract concept, which is perceived by knowing successions and durations events (West & Fraisse, 2009).

People with dementia lose this sense of time. Already in an early stage, they are not able to draw a clock and time, which is therefore a strong indication for dementia (Alzheimer Nederland, n.d.-e).

The abilities of the brain to regulate the experience of time and the innate body clock are compromised. They lose the awareness of the passage of time, being no longer familiar with the duration of a year, month, week of even a minute (Munson, 2021). When looking at a clock, they are also not able to tell the time anymore, resulting in not knowing where they are during the day (Munson, 2021). Even the concept of today, yesterday or tomorrow can be confusing. In addition, their body clock can be off kilter, so instinctively they also do not know where they are within the 24-cycle, leading to switching morning and afternoon or even day and night (Munson, 2021).

Losing sense of time can thus make the daily functioning of people with dementia challenging and leads to confusion, since the track of the day is lost, which can result in anxiety and anger.

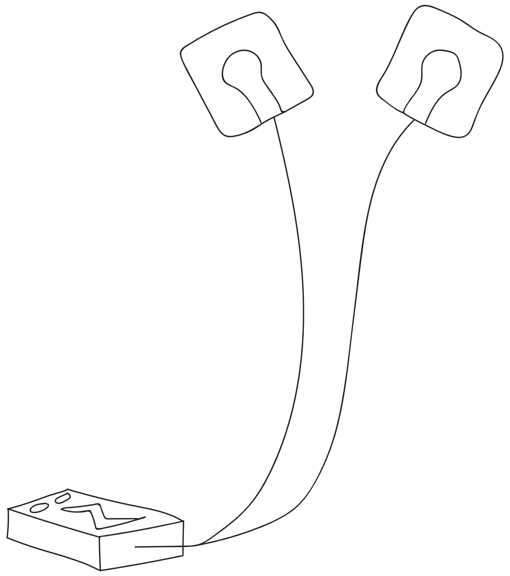


Figure 11 | Getting intensive stimuli

Stimuli

Throughout the whole day people are exposed to stimuli, both conscious and unconscious, of which external stimuli are perceived through the senses. All this information is filtered in the brain, the important is perceived consciously and the minor fades into the background (Hersenz, 2023).

This filter is broken in the brain of a person with dementia. All information is perceived consciously at once with the same importance, resulting in overstimulation, making it almost impossible to understand the information (Hersenz, 2023;). One clear stimulus is therefore enough (Raemaekers, 2022). Another occuring impairment is that the person cannot stimulate itself anymore, resulting in understimulation. This is called apathy, occurring by half of them. This manifests in lack of initiative, emotions or social contact, which reduce independent functioning.

Over- and understimulation can result in misunderstood behaviour. Overstimulation can lead to agitation, resulting in nervous or aggressive behaviour. Both also lead to physical complaints like headache, tiredness and an increased heart rate (Hersenz, 2023). With understimulation, someone is likely to produce their own stimuli, resulting in shouting, tapping and wandering (Raemaekers, 2022). In contrast, someone can also get passive and sleep much. Both behaviours are meant to fill the void and prevent boredom. An environment should therefore provide stimuli (Kennisplein Zorg voor Beter, 2022a) and balance it at the same time.

ARCHITECTURE BALANCING **STIMULATION**

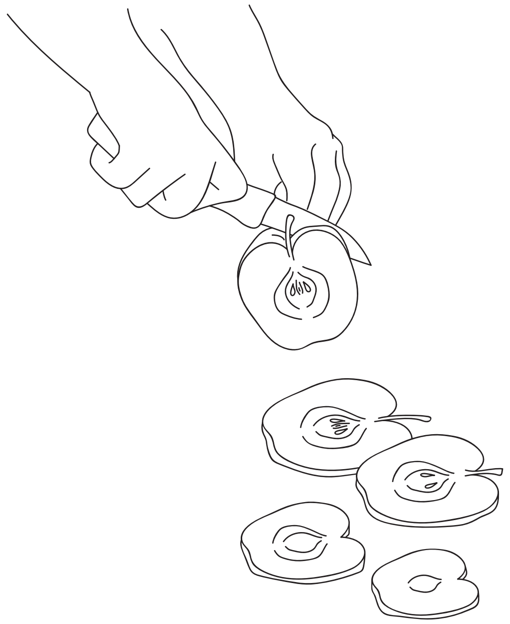


Figure 12 | Cutting an apple the wrong direction

Daily tasks

Our whole day consists of a sequence of common everyday actions, like dressing up, making a sandwich and tying our shoelaces, which enables us to function on a basic level and take care of ourselves. Most of these daily tasks are learned in childhood and are executed automatically.

For people with dementia, this is no longer the case. Although their autopilot remains intact for a long time, they gradually have to think more consciously about what they are doing, resulting in getting difficulties with executing those daily tasks, which is called apraxia (Alzheimer Nederland, n.d.-f). When they have to do something, it remains clear to them what they have to do, but not completely how. This manifests itself in two ways (Hersenstichting, 2022a). They might not be able to execute the movements belonging to the task properly, or they swap the order of movements, like taking a shower and washing their hair first without water. Eventually, they are not able to execute certain tasks at all.

Personal care and daily functioning become more challenging, they become more dependent on help from their environment and lose a certain amount of autonomy (Hersenstichting, 2022a). Although, an environment should stimulate this execution of those daily tasks to keep them as good as possible.

ARCHITECTURE HELPING TO **REMEMBER**

Figure 13 | Short-term memory

Forgetfulness

The short-term memory is a mechanism of the brain that enables us to retain a certain amount of recent information for a short period of time, like remembering the order of a few roads on a road map (Alzheimer Liga Vlaanderen, n.d.). This amount is limited to seven elements and after half a minute, this information is lost when it is not repeated consciously (Cognifit, n.d.). Only then, this information can be transported to our long-term memory.

The short-term memory mechanism is affected by people with dementia, they can no longer store new information and almost forget it immediately (Alzheimer Liga Vlaanderen, n.d.). Their learning ability is therefore impaired. New instructions or situations cannot be adopted properly anymore, it requires constant repetition. This way, they can learn a new routine after a long time, but this will eventually become impossible (Alzheimer Nederland, 2023).

Moving to a new environment can thus be challenging for people with dementia (Lambert, 2016). Almost all they know is lost and they have to adapt to a new situation and learn new routines, which appeals to their impaired learning ability. Therefore, they might find it difficult to recognise the place, learn where their room is or how a coffee maker works (caregiver, fieldwork place 3). This can result in a confusing situation, an environment should therefore be easy to understand.

ARCHITECTURE HELPING TO UNDERSTAND **SPACE**

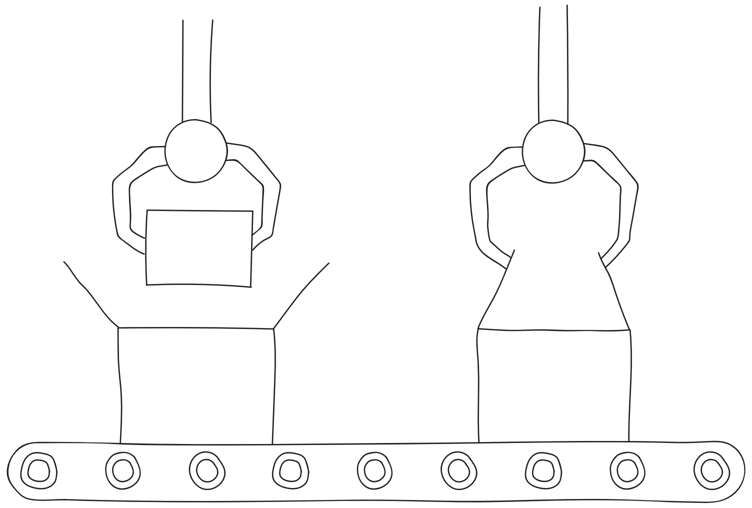


Figure 14 | Long-term memory

Fixed patterns

The long-term memory is a mechanism of the brain that enables us to retain information for a long period of time. There is a strong connection with the short-term memory, information that is repeated or has an importance shift to the long-term memory. It contains consciously accessible factual knowledge, unconsciously controlled skills and habits, and through our senses obtained emotional related memories. We are therefore able to remember events from the past, execute controlled skills without thinking and associate certain smells or sounds with memories (Stangor & Wallinga, 2014).

This long-term memory of the brain remains intact for a long time by people with dementia and are therefore capable to rely on its three abilities, in contrast to many other functions (Priory Adult Care, 2022). Objects from their past remain familiar, they will recognise a certain shape of a chair, but not a new modernistic chair. Skills that became a routine by repetition can be executed on automatic pilot, such as walking into the right direction of the toilet without conscious thinking and they show a strong reaction to music, for example still being able to sing the words or execute corresponding dance movements. An environment should therefore rely on fixed patterns and habits that recall the past.

ARCHITECTURE RECALLING THE **PAST**

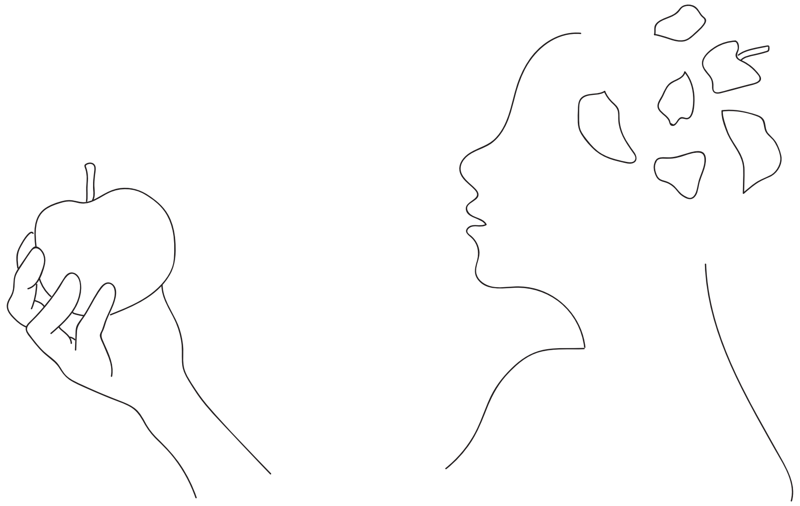


Figure 15 | Not recognising objects

Recongition

The world around us is perceived through our senses. The brain has the ability to form an understanding from this, so that we can respond to it appropriately. This visual information makes us aware of what we see and how objects and spatial relationships are interpreted.

By people with dementia, this processing of sensory information in the brain is impaired. This results in not being able to perceive the world how it actually is, the brain misinterprets what is seen through the eye (Alzheimer's Society, 2022). They have difficulties with recognising objects, called agnosia (Alzheimer Nederland, n.d.-a). Familiar utensils, sounds or relatives might not be identified anymore or even seem completely new, resulting in not knowing what to do or how to respond. Recognising their own reflection can also be an issue, leading to confusion and anxiety (case 1, fieldwork place 3).

Misinterpretation also causes problems with the perception of space. People with dementia cannot judge depth anymore, resulting in difficulties with for example climbing stairs (Alzheimer's Society, 2022). They also might not see the differences between different objects.

Not knowing what is perceived through the senses can lead to problems with daily functioning, resulting in getting dependent on help and can lead to anxiety and feeling unsafe. An environment should therefore be easy to understand and not mislead their visual spatial perception.

ARCHITECTURE HELPING TO UNDERSTAND **SPACE**

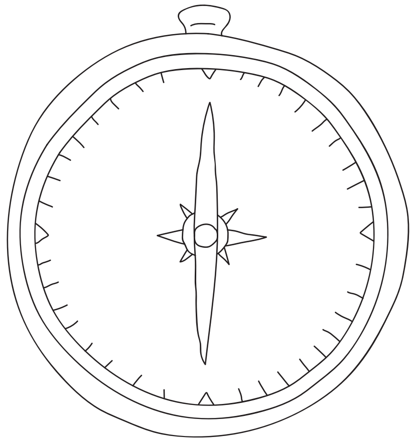


Figure 16 | A broken compass

Orientation

Spatial orientation is important to be able to navigate successfully through an environment. It is the ability to locate oneself in relation to objects and space (van den Berg & Ruis, 2017).

This ability is impaired by people with dementia, resulting in getting disorientated in space. They might get lost on their way, as streets and buildings are not recognised anymore, even if they are in a familiar environment (Alzheimer Nederland, n.d.-b). The same can happen at home, where they might not find certain rooms.

The risk of getting lost outdoors or indoors can form a risk and unsafe situations and might lead to anxiety to the person self. Moving to a new environment is thus challenging for people with dementia, since it is unfamiliar. It becomes extra difficult to find your way. It is therefore important that an environment is designed as such that it relies on familiar and recognizable patterns.

ARCHITECTURE HELPING TO **ORIENTATE**

2.3 TYPES OF DEMENTIA

Alzheimer is the most occurring form of dementia. The first affected area in the brain is the hippocampus, the memory area, in the temporal lobe. Protein plaques manifest between the brain cells and hamper their functioning. Preliminary signs are therefore difficulties with remembering new information. These plaques spread gradually to the temporal lobe, which contains the functions of recognition, visual perception and language. resulting in a progressive loss of those skills (Alzheimer Nederland, n.d.-i).

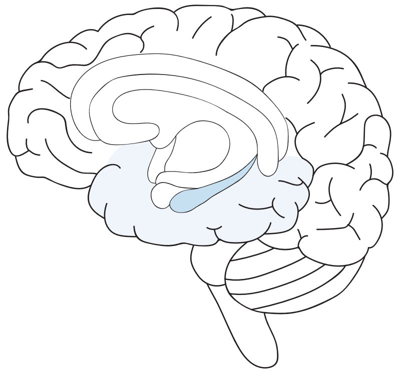


Figure 17 | Location of Alzheimer

Vascular dementia is the second most occurring form of dementia. It is caused by small strokes, which can occur in all areas of the brain, resulting in damaged connections between brain cells. This leads to the characteristic sign of slowness in speaking, thinking and acting. Also the brain cells themselves can be damaged, resulting in the sudden loss of functions. In contrast with other forms, the start is acute and there is no gradual decline in contrast. A new decline occurs after new small strokes, in between are periods with some degree of stability (Alzheimer Nederland, n.d.-g).

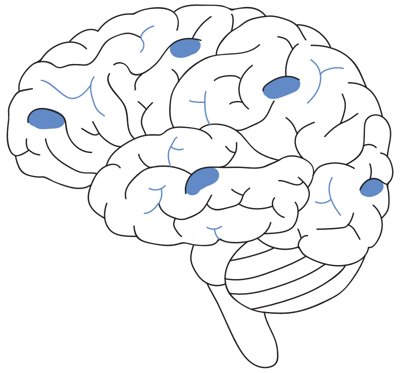


Figure 18 | Location of vascualr dementia

Frontotemporal dementia (FTD) is four times more present in YOD. It is caused by protein plaques, which manifest in the frontal lobe. This area is responsible for planning and behaviour. The preliminary and most dominant signs are a change in personality and behaviour, which often gets uninhibited. The plaques can also reach and affect the temporal lobe. The course of this form is gradual, but unpredictable, the decline can come with smaller as well as bigger steps (Alzheimer Nederland, n.d.-c)

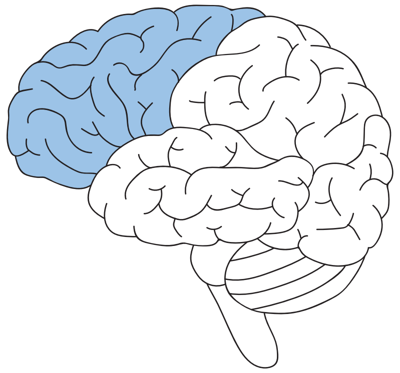


Figure 19 | Location of Frontotemporal dementia

Lewy Body dementia is the least occurring form in YOD. The brainstem is the first area that is affected by accumulation of protein plaques, called 'lewy bodies', on nerve cells of the brain, hampering the transfer of information. The first sign is having concentration problems, followed by memory problems. Other characteristic signs are hallucinations and Parkinson's symptoms such as losing control over the body, resulting in difficulties with moving and trembling. These plaques can spread as well to other areas of the brain (Alzheimer Nederland, n.d.-d).

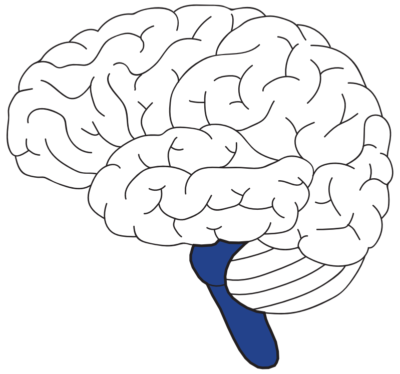
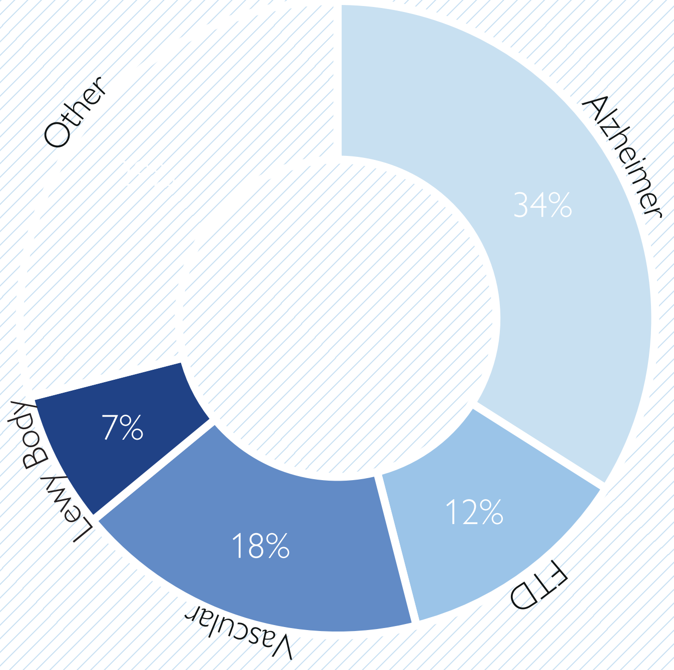
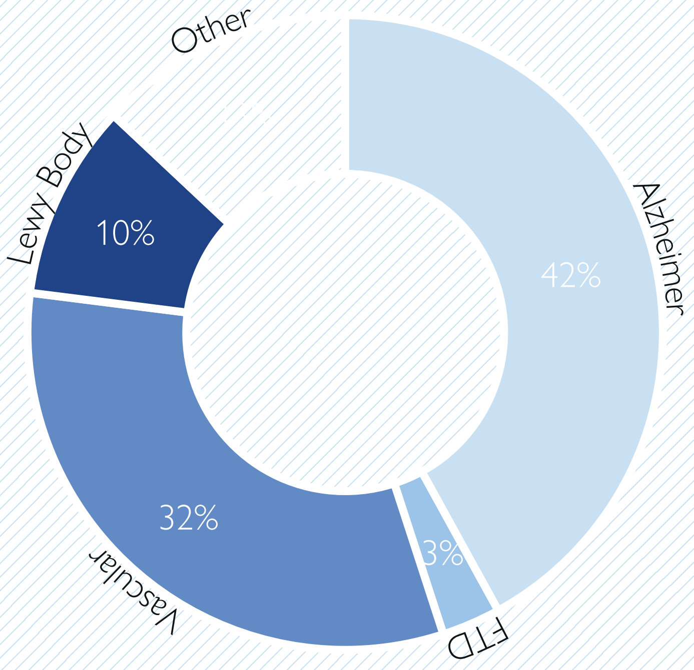


Figure 20 | Location of Lewy Body dementia



Types Young Onset Dementia



Types Late Onset Dementia

Figure 21 | Types of dementia YOD compared to LOD based on Bakker et al. (2013) Harvey et al. (2003) and Pijnenburg et al. (n.d)

2.4 STAGES OF DEMENTIA

There are different categorisations of the stages of dementia, on with three and one with seven scales However, **there is not one course of dementia, the duration of stages and the corresponding symptoms differ per person and are rather an indication.**

The three-scale contains early, middle and late stage dementia, where early contains partly the pre-diagnostic period, the middle stage lasts a few years and the late stage contains mainly the most severe stage before dying (Alzheimer Nederland, 2023).

Since there is too much differentiation within the middle stage of this three-scale, the scale of Reisberg (Reisberg et al., 1982) with seven scales is used as basis in this thesis, to provide a clearer overview of the course of dementia in this longest lasting stage. The first three stages contain no to mild cognitive decline, where only the very fist symptoms occur, and is pre-diagnostic. These are combined in this thesis as 'no dementia', since the focus is on the later stages. The last stage contains very severe cognitive decline and is the last stage before dying, in this thesis as 'severe dementia'. The three stages in between are comparable with the middle stage of the three-scale, containing moderate to severe cognitive decline. All used in this thesis as 'early, mild and moderate dementia'.

STAGE		SYMPTOMS	CARE
No dementia	Pre-diagnostic, first decline noticeable	First changes in behaviour noticeable, like lack of emotion, tired and passive. Slight problems with short-term memory. Mild decline in cognitive functions, including trouble with focusing, working, or organising.	No
Early dementia	Difficulties in daily life, assistance with complicated tasks	Decreased memory of recent events. Cognitive difficulties with problem-solving, finances, planning, speaking and not being able to work anymore. Might withdraw from social situations and places, as they are challenging.	Home *Daycare*
Mild dementia	Reduced independence, requires some assistance with many activities of daily living	Memory loss is more prominent. Further decline of cognitive functions, daily activities become a challenge. Coordination and recognition are impaired, not being able to drive anymore.	Daycare *Care Home*
Moderate dementia	Dependent on care, full assistance with activities of daily living	Poor short-term memory and also decline in long-term memory. Ability to speak is declined, not being able to have a substantive conversation anymore. Not being able to handle their own affairs and to do daily activities alone.	Care Home
Severe Dementia	Final stage of life, requiring assistance with all activities.	Impaired mobility, not able to walk anymore. Lost ability to speak or communicate. Incontinent and cannot do any daily activity themselves.	Care Home

FOCUS

A **familiar** environment enables people with dementia to function independently and gives them a 'sense of 'home' and makes them enjoy the place where they are more (Van Hoof, 2010; Fleming et al., 2017). With moving, they lose all familiarity as their place, stuff and habits, resulting in losing their sense of belonging (Fleming et al., 2020). Adapting is difficult for them, causing a, often temporary, decline. A familiar building design therefore helps them to understand the space better by rooted memory and provides a smoother transition to a new environment, with maintaining as much of their competences and sense of belonging (Fleming et al., 2017). Multiple studies have shown that a 'homelike' environment is beneficial for them (Bowes & Dawson, 2019) as it reduces agitation, anxiety, depression and contributes to the maintenance and engagement of activities (Fleming et al., 2017). Also residents as their families and caregivers often mention that this is preferred over an institutional character. The build environment can influence this experience of 'sense of home', however there is no general definition, there are components adding to this.

Archetypes
The building design can recall our memory by using archetypes. These are shapes that are deeply linked to our collective memory and therefore are familiar. The canopy with a sloping roof was found to be positively associated with the past (Nute & Chen, 2018). This characteristic form is a widely recognised symbol of a shelter pointing to heaven and protecting the heart, the second archetype. It is associated with the connection between heaven and the earth and the centre of primal human shelters.

Homelike setting
A homelike setting can be created by using basic spaces of a general house. The living room, kitchen and dining room, which are inscribed in our memory as fixed patterns, are often combined and form the heart of our house where social interaction takes place. Adding those rooms in a similar way creates the opportunity for a domestic way of living. Kitchens for example stimulate participation in cooking (Fleming et al., 2020) and family-style mealtime settings have a positive effect on eating behaviour (Bowes & Dawson, 2019).

Long corridors on the other hand reduces a 'homelike' feeling, since it does not correspond with our idea of a house.

Personalistation
The furnishing also plays an important role in creating a 'sense of home'. The introduction of plants, animals or children brings in more life (Fleming et al., 2020) and using similar furniture as residents have at home creates a 'homelike' feeling. The opportunity for personalisation of the own room is also associated with creating a homelike environment (Fleming et al., 2020, Marquardt et al., 2014). Being able to bring your own belongings, as furniture, decoration or objects with sentimental value add to the recognition and sense of belonging.

Familiar

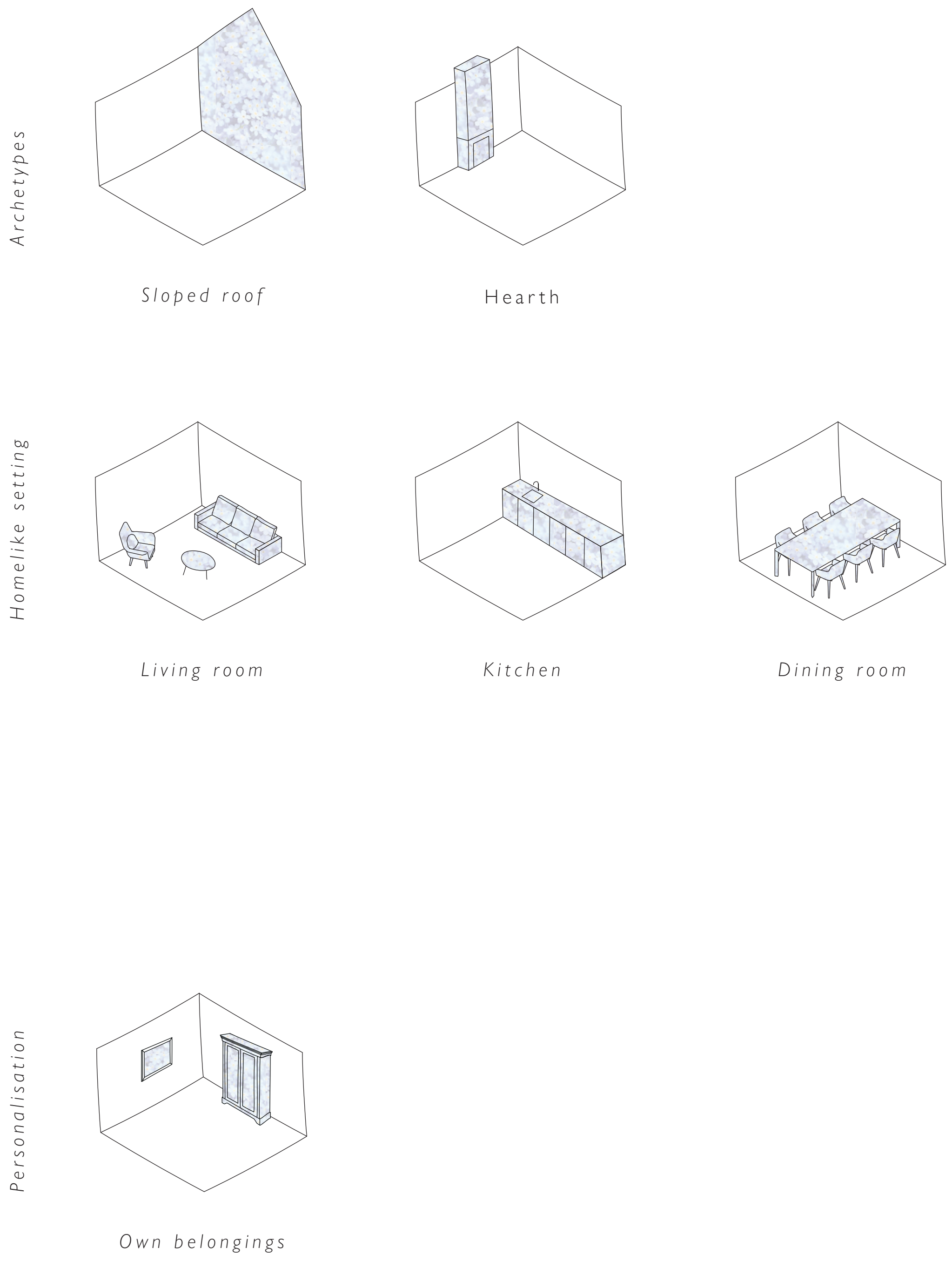


Figure 22 | Guidelines familiair environment

Wayfinding is important for people with dementia to be able to navigate independently through an environment. Their impaired memory and learning abilities makes it difficult to find their way in a new environment (Bowes & Dawson, 2019). They often face issues with finding their room or other areas, since they do not clearly understand their position and the position of their destination within space anymore, leading to confusion, frustration and anxiety. It is shown that an improved wayfinding reduces this. One aspect of wayfinding is creating a familiar environment, as described before, but is not enough. The built environment should have such a spatial organisation that people can move from one place to the next, without having to remember a whole route (Fleming et al., 2020).

Landmarks
Repetitive elements make it difficult for people with dementia to read the space and locate oneself, since it is lacking a clear distinction between different places (Fleming et al., 2020). An environment is better understood when clear landmarks are used, one can then identify the place, locate where they are in the bigger picture and navigate from landmark to landmark.

Routing
Naturally guiding routes can help people with dementia to navigate through an environment, without having to think consciously of where to go and how to come back and enables them to just wander around. Relying on such a route prevents stress and gives them trust on their way. Circular routes ensure that they come back and pass important places. Short distances and the absence of the typical long corridors with dead end locations are found to be particularly helpful indoors (Bowes & Dawson, 2019). Literature contradicts on which shape is best instead, some mention L-shaped hallways, while others suggest straight hallways.

Wayfinding

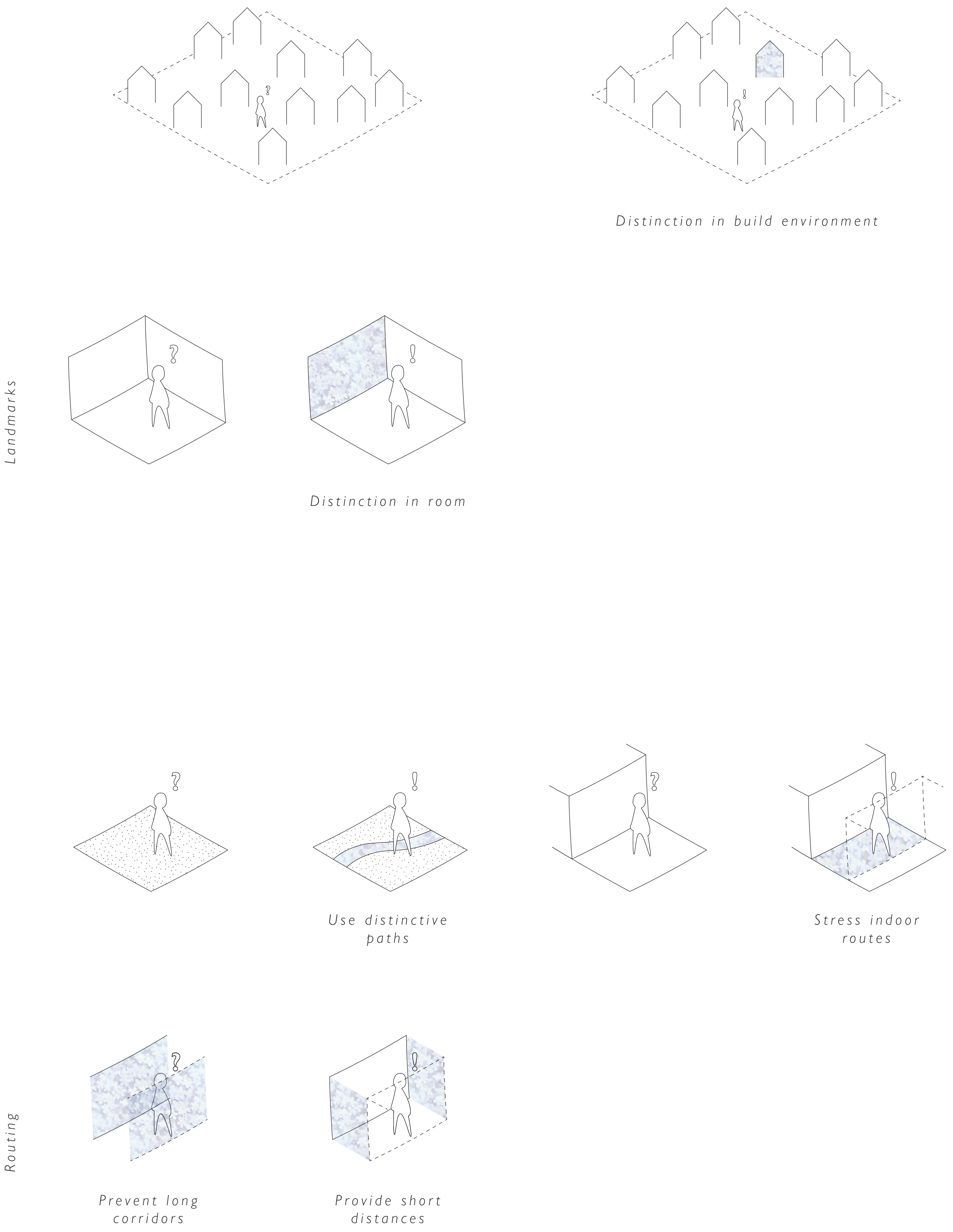


Figure 23 | Guidelines wayfinding

Visibility

Having multiple decisions is difficult and confusing for people with dementia. They cannot decide in advance what is behind a closed door or around the corner of a new hallway. Such decision points should therefore be avoided. There should be visual contact with the main places within the whole area instead. Being able to see a destination provides a more clear understanding of the existing places they can go and how to get there (Bowes & Dawson, 2019, Fleming et al., 2020). This prevents having to make decisions or having to seek for it, which can cause stress. Combined kitchen, dining room and living room seemed to be better found (Fleming et al., 2016). On the other hand, not seeing often means not existing for them, resulting in not finding it at all. This visual contact between spaces can be created by opening up one to another (Fleming et al., 2020).

Cues

Differentiation of places can be enhanced by adding visual cues, like signs, pictures or colours, or allowing sensory cues, like sound and smell, making the build environment even more clear. Signs can indicate the route and point destinations or mark places. People with dementia show to be still able to recognize their picture, name or other personal belongings at their front doors and can help by finding their own room (Bowes & Dawson, 2019, Fleming et al., 2020). Colours as well help with being able to distinguish places. Sound and smell stimulate our unconscious mind and give internal cues for finding the kitchen, by hearing cutlery or smelling food, the bathroom by smelling soap or their room by hearing one owns music or seeing their personal belongings (KAW & Aedes-Actiz Kenniscentrum Wonen-Zorg, 2017).

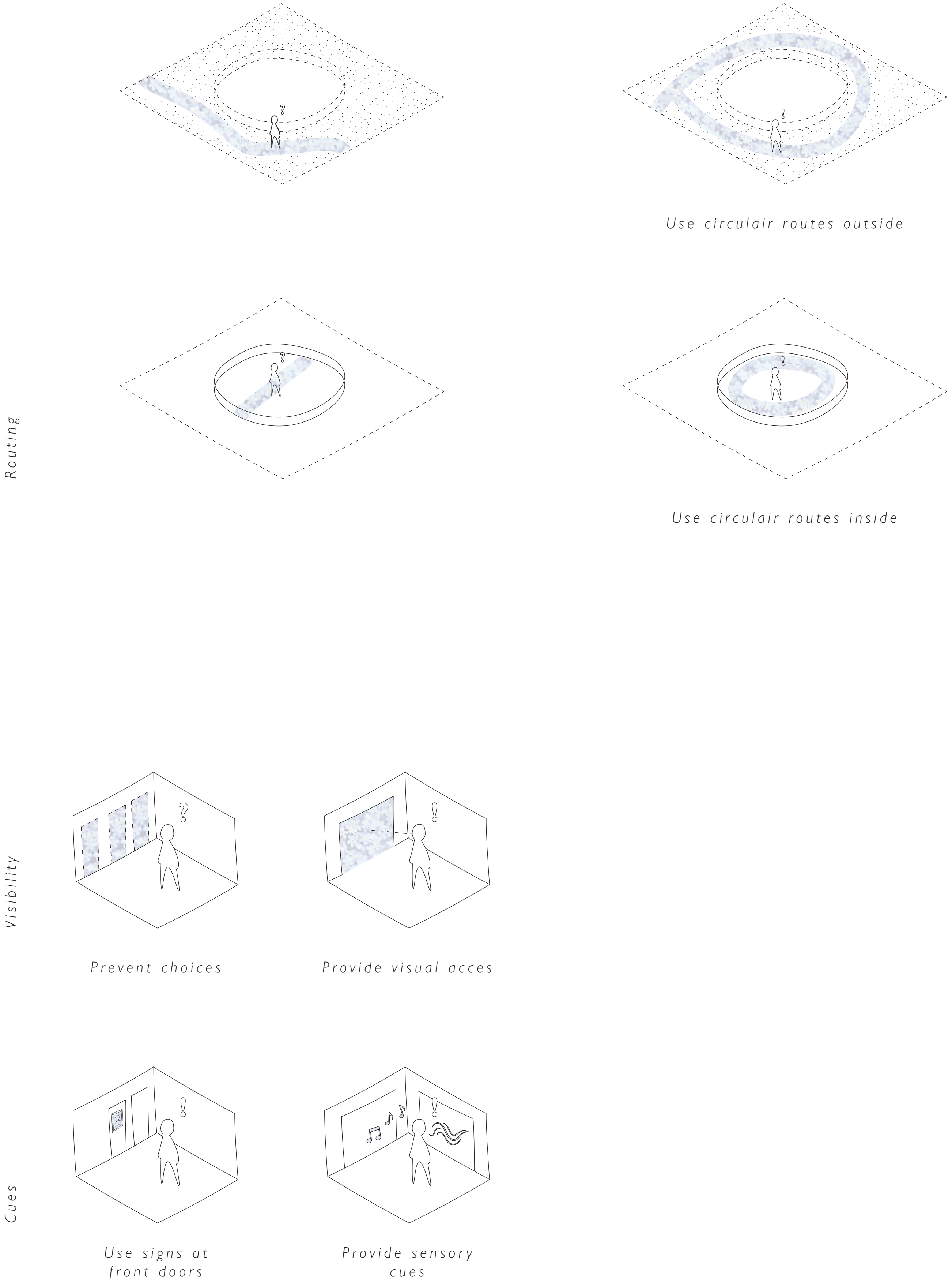


Figure 23 | Guidelines wayfinding

Readability of the environment is important for people with dementia to orientate themselves in space. Knowing what you see, where you are and what to do results in feeling relaxed and calm. Their impaired visual-spatial abilities make it difficult for them to read an environment and due to their learning abilities it is difficult for them to adapt to another environment easily. The build environment should therefore be easy to understand and form no barriers in their visual perception.

Contrast
Repetitive patterns are difficult to read and distinguish for people with dementia, while contrasting patterns or colours stand out for them. A contrasting background can help them with the identification of different places and objects (Fleming et al., 2017; Fleming et al., 2020; Bowes & Dawson, 2019). However, floors with coloured geometric patterns have a negative influence on the readability, as they are seen as steps or holes and leads to more disorientation and anxiety (Fleming et al., 201; Fleming et al., 2020; Bowes & Dawson, 2019).

Zoning
Well defined spaces with different functions makes the environment more comprehensive (Fleming et al., 2017). Open floor plans are correlated with being more dependent, likely due to the lack of a legible meaning of those open and interconnected spaces (Fleming et al., 2020).

Transition
Creating transitions between different spaces highlight the change of function, making the environment even more comprehensive. In-between spaces can provide a smooth transition and make a link between different functions. Partitions as colours, material, ceiling heights, arches or brighter spaces can also help as cue to form such transitions (Marquardt et al., 2014, Fleming et al., 2020).

Structure is important for people with dementia to orientate themselves in time and eventually also in space. Life is made out of rhythms, which gives something to hold on to when you are lost. The build environment should thus provide rhythms to make it understandable.

Light
Having enough daylight is important to synchronise the circadian rhythm with the ambient time of the day. Different research shows that exposure to typical daytime light levels strengthens this rhythm, leading to improved sleep patterns of people with dementia (Fleming et al., 2017, Van Hoof et al., 2010, Fleming et al., 2020, Bowes & Dawson, 2019).

Outdoor experience
To orient oneself with the time of the day and year, experiencing the outdoor situation is important. Seeing daylight helps them with being aware of the time of the day and the weather helps them understand the season (Fleming et al., 2020, Van Hoof et al., 2010). Pictures or murals of natural scenes on the other hand can cause confusion, since it can show autumn trees while it is summer (Van Hoof et al., 2010).

Rituals
Having a common thread throughout a day or week helps people with dementia orient and feel at ease. A continuation or rituals, as activities and events, connected to set places works best for them. Eating, drinking and sleeping are the most considerable rituals during a day (Van Hoof et al., 2010). Waking up and going to sleep can be the moments with the most disorientation.

Readability

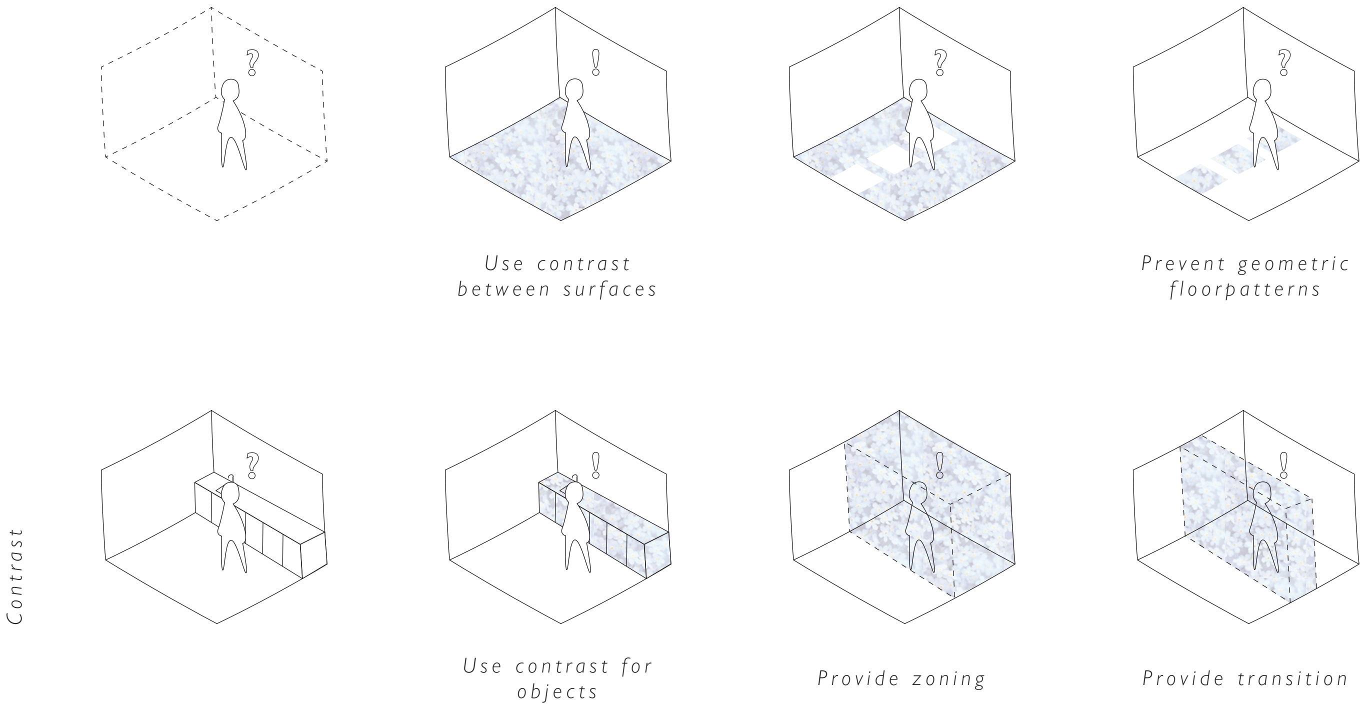


Figure 24 | Guidelines readability

Structure

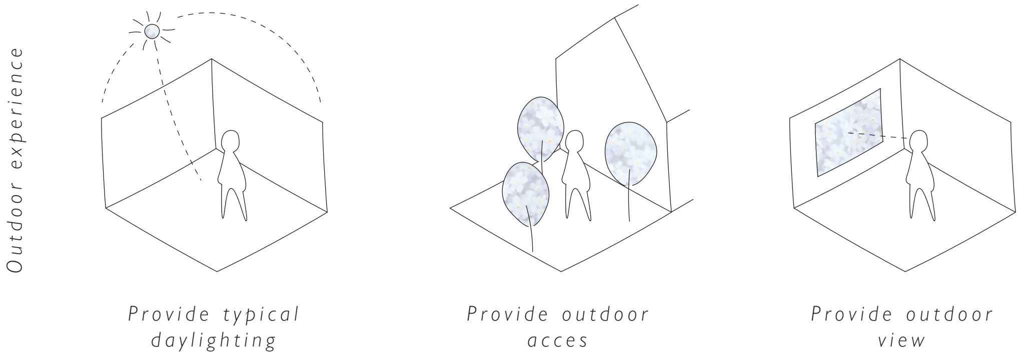


Figure 25 | Guidelines structure

A **small scale** is mentioned repeatedly as beneficial for people with dementia and is transitioning as the new standard in the institutional setting (Van Hoof, 2010). The scale of an environment can affect their behaviour negatively as it can be intimidating and make them lost in space, resulting in feeling anxious and being agitated (Fleming et al., 2020, Fleming et al., 2017). It has been observed that a smaller scale reduces this and improves their performance and independence, mainly because of the simplicity of the environment (Fleming et al., 2020, Bowes & Dawson, 2019, Marquardt et al., 2014). It is also associated with greater comfort, familiarity and safety (Fleming et al., 2017). The build environment could thus add to their feeling of security and experience of comfort by providing them a human scale.

Group size

In smaller groups, patients, caregivers and relatives know each other better and are associated with more social interaction between them (Marquardt et al., 2014). Making sure there are only a few familiar people in their space makes them more comfortable and feel more at ease (Fleming et al., 2017). Also family visits seem to take place more often (Nillesen & Optiz, 2014, Fleming et al., 2020). Although no number of the ideal group size has been investigated with security as purpose, the studies measuring effects of small groups who have reported positive effects had a range of 8 to 10 beds in a cluster (Fleming et al., 2020, Bowes & Dawson, 2019).

Compact design

Having a compact build environment makes it easier for people with dementia to manage and oversee their own everyday life (Fleming et al., 2020). When everything is within short distances and visible, by ensuring less doors, rooms and corridors, an environment is easier to understand, leading to a better wayfinding.

Privacy is important for people with dementia, as it gives them the possibility to withdraw in their own world if 'the outside' becomes too intimidating (Fleming et al., 2017). More privacy is associated with less agitation and eventually more social interaction (Bowes & Dawson, 2019, Fleming et al., 2020). Graduations in private and public spaces give them more personal control and the possibility to choose on purpose whether to interact with people or not (Fleming et al., 2017, Fleming et al., 2016). The build environment should thus provide spaces for oneself and the opportunity to choose.

Single rooms

Having a place for oneself, with personal belongings, provides the possibility to be alone and do your own thing, without having the feeling of others looking at you and is adding to a more homelike and secure feeling. Single bedrooms are nowadays preferred over shared rooms, as well by residents, caregivers and families, as they seem to improve sleep, leads to less conflicts between residents and are a place for families to be together as one (Fleming et al., 2017, Fleming et al., 2020).

Small scale

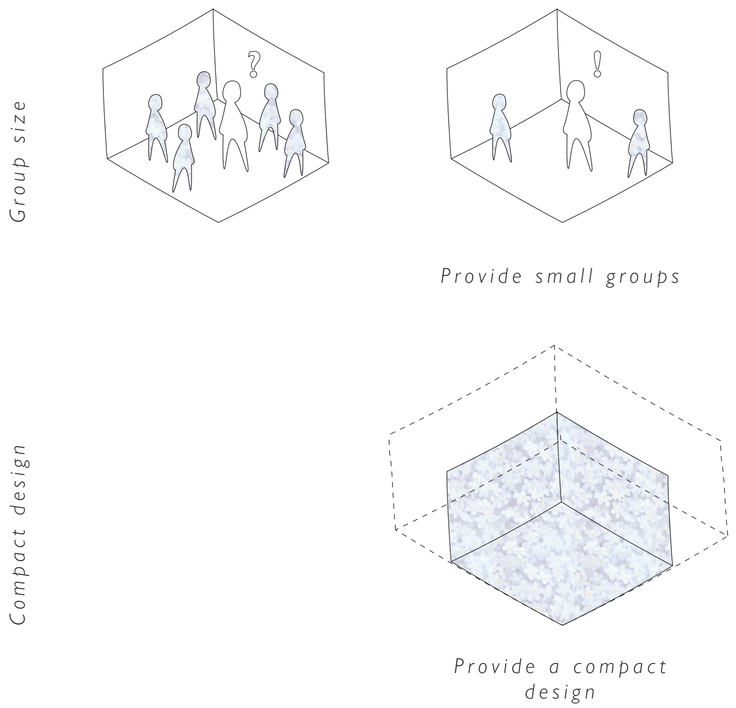


Figure 26 | Guidelines small scale

Privacy

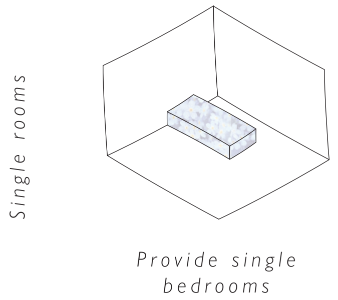


Figure 27 | Guidelines privacy

Safety contains two components: feeling safe and being safe. Feeling safe has to do with being able to oversee the situation one is in. Being safe mainly has to do with reducing risks for them. People with dementia should be able to move around in their environment independently without coming to harm and feel or be restrained (Fleming et al., 2017). The latter can lead to frustration, agitation and depression (Shiells et al., 2020; van Liempt et al., 2022). Those negative responses are found to be mitigated by using unobstructive safety features (Bowes & Dawson, 2019, Fleming et al., 2016). A built environment should thus provide the feeling of freedom, while being kept secure from harm.

Exit design

People with dementia have the habit to open doors and make attempts to escape their wards and walk into unsecured areas (Marquardt et al., 2014), which can be a safety concern for some of them. Visual barriers were tested and camouflaged doors, with for example painted murals, views or patterns, seemed to reduce those exit attempts, since they do not recognise it as a door and do not see it as impeded freedom anymore (Bowes & Dawson, 2019, Marquardt et al., 2014, Fleming et al., 2020, Fleming et al., 2017). Also silent exit locks seem to reduce this feeling (Marquardt et al., 2014, Fleming et al., 2020, Fleming et al., 2016). However, it has been under debate whether or not to lock exit doors in wards (Fleming et al., 2017), since it can be seen as a form of physical restraint. Their own safety used to be often chosen above more freedom, but the new law ‘Wet Zorg en Dwang’ has been tightened up and contains a part of freedom of movement, which now has to be considered individually.

Objects

Everyday objects can form a risk for people with dementia, since they do not always know what they see or what the danger might be. Especially a kitchen can form risks with stove tops, hot water, sharp kitchenware and appliances (Fleming et al., 2020).

Fall prevention

Falling when walking is a safety concern for people with dementia (Fleming et al., 2020). It is important to prevent it where possible and reduce the impact. Preventing falls with walking can be done by avoiding obstacles as steps and loose carpets, and by providing enough space, grab bars and lightning (Fleming et al., 2017).

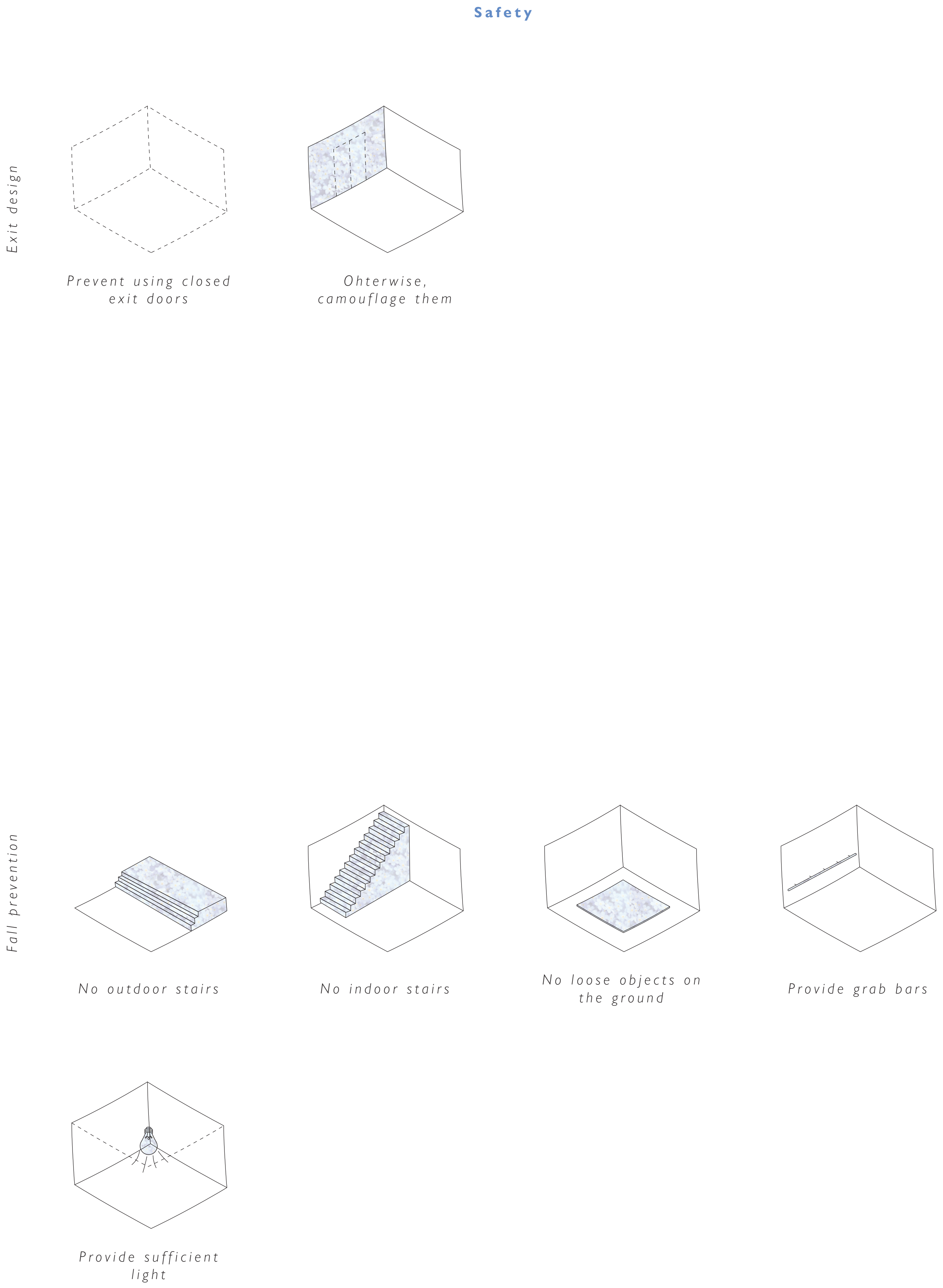


Figure 28 | Guidelines safety

A **balance in stimuli** is important for people with dementia, in order not to get over- or understimulated. All senses should be considered, as visual and auditory stimulation can be as stressful. They should be able to register sensory stimuli consciously that give them cues about where they are to help reduce confusion and lead to greater independence and less apathy (Fleming et al., 2020). The build environment should thus be designed to minimise unhelpful stimuli and optimise helpful stimuli.

Noise
High levels of noise or different sounds at the same time can be overwhelming for people with dementia (Bowes & Dawson, 2019, Fleming et al., 2020). Especially in care settings, they are exposed to sounds from television, phones, intercoms, doorbells or alarms, disturbing their needed aural stimulation (Marquardt et al., 2014, Van Hoof, 2010). Also sounds from open kitchens, spreading through the environment can be overstimulating (Van Hoof, 2010). It is found that noise results in less social interaction and disruption in sleep (Fleming et al., 2020). Positive sound on the other hand, as the sound of birds singing in bathrooms, has a calming effect (Marquardt et al., 2014).

Clutter
Visual stimulation, as cues, help people with dementia with finding their way. Too much visual stimulation, like posters, decoration or different colours and patterns, can create clutter. This will cause overstimulation, resulting in not being able to distinguish the helpful cues (Fleming et al., 2020). Such cues thus need to be designed as such that it does not become part of the clutter.

Smell
Strong or unpleasant smells, like urine of cleaning products, are found to result in overstimulation (Marquardt et al., 2014).

Group size
How larger the group of people, how higher the level of overstimulation is, mainly due to noise and movements (Fleming et al., 2020). A smaller group size, or even a smaller division of the group during activities can therefore help people with dementia to remain calm (Fleming et al., 2017).

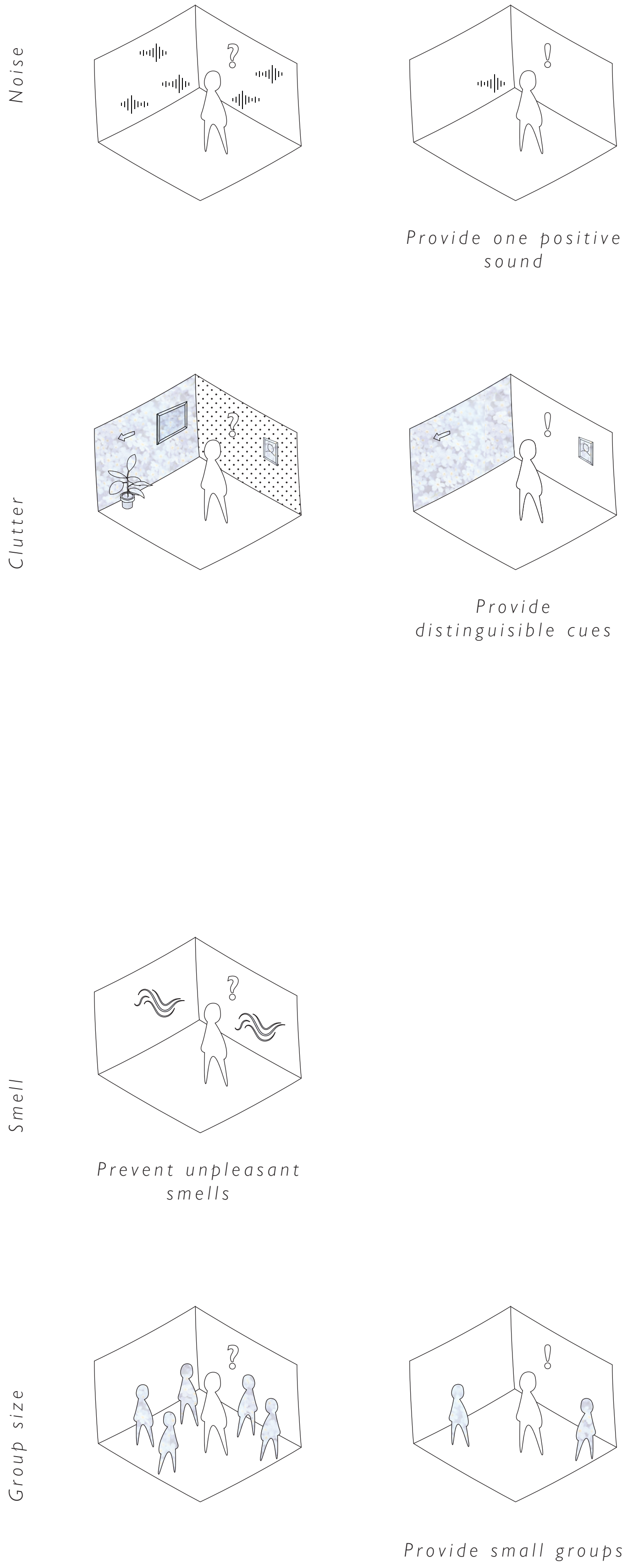
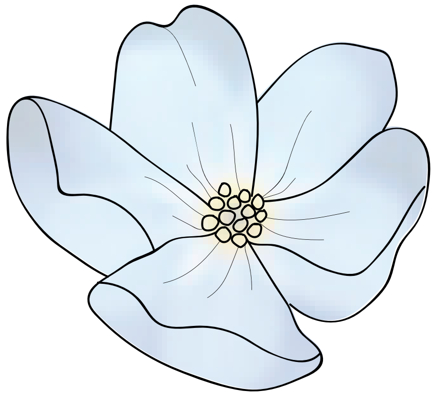
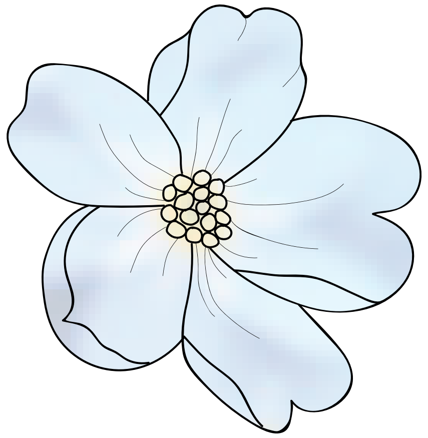


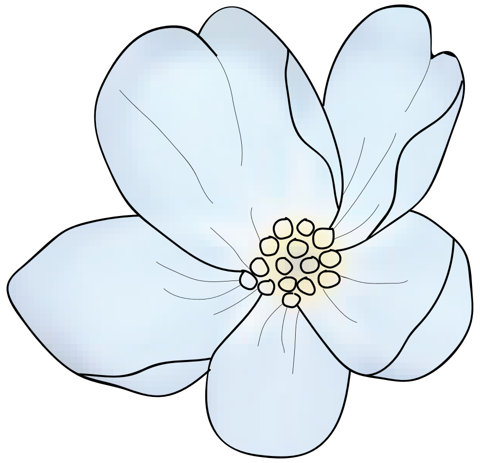
Figure 29 | Guidelines balance in stimuli



CHAPTER 03

The target group





3.1 NEEDYD STUDY

There is already research done to what families with Young Onset Dementia need in the first stages of the disease, where they live at home. The Dutch NeedYD study, meaning Needs in Young Onset Dementia, was the first prospective study in the field of Young Onset Dementia. It is a collaboration between several Alzheimer organisations in the Netherlands and researchers. The aim of this research was to map the functioning and (care) needs of young people with dementia and their relatives and to investigate the course of neuropsychiatric symptoms, in order to give them the best possible support in their home situation, so institutionalisation could be postponed or even be prevented.

215 people with Young Onset Dementia and their families were followed for two years initially. Van Vliet (2012) and Bakker (2013) focus on the pre-diagnostic phase and on the (un)met needs and use of (in)formal care respectively. Millenaar (2016) and Gerritsen (2020) focussed on the impact on the sufferer and their relatives and on the course of the disease respectively. Together give insight into the characteristics of the disease and the difficulties which are faced in the time before the diagnosis and after. Examples mentioned include misunderstanding, conflicts with family and work, changing behaviour, neuropsychiatric problems, taking care and finding help and support for that. Also the impact on the relatives and their lives, such as dealing with the loss, managing their own life, having new responsibilities, experiences of burden and concerns. These studies thus provide understanding of the challenges faced with Young Onset Dementia within the Dutch context.

Although, the dissertations mainly face the psychological impact, rather than the practical needs. Corresponding with the research aim, resulting solutions focus on awareness, information and external support of professionals and fellow sufferers, to get mental support for dealing with the situation at home in the first stages of the disease facing diagnosis and giving informal care to light formal care. When it comes to the patient, the NeedYD study is based on closed and rating questions, which can be shallow. Also further research and relationships between outcomes in the dissertations are mainly based on statistical and quantitative research, with only one personal case study. Also the (care) needs of young people with dementia in later stages of the disease, where most of them do not live at home anymore, is not researched.

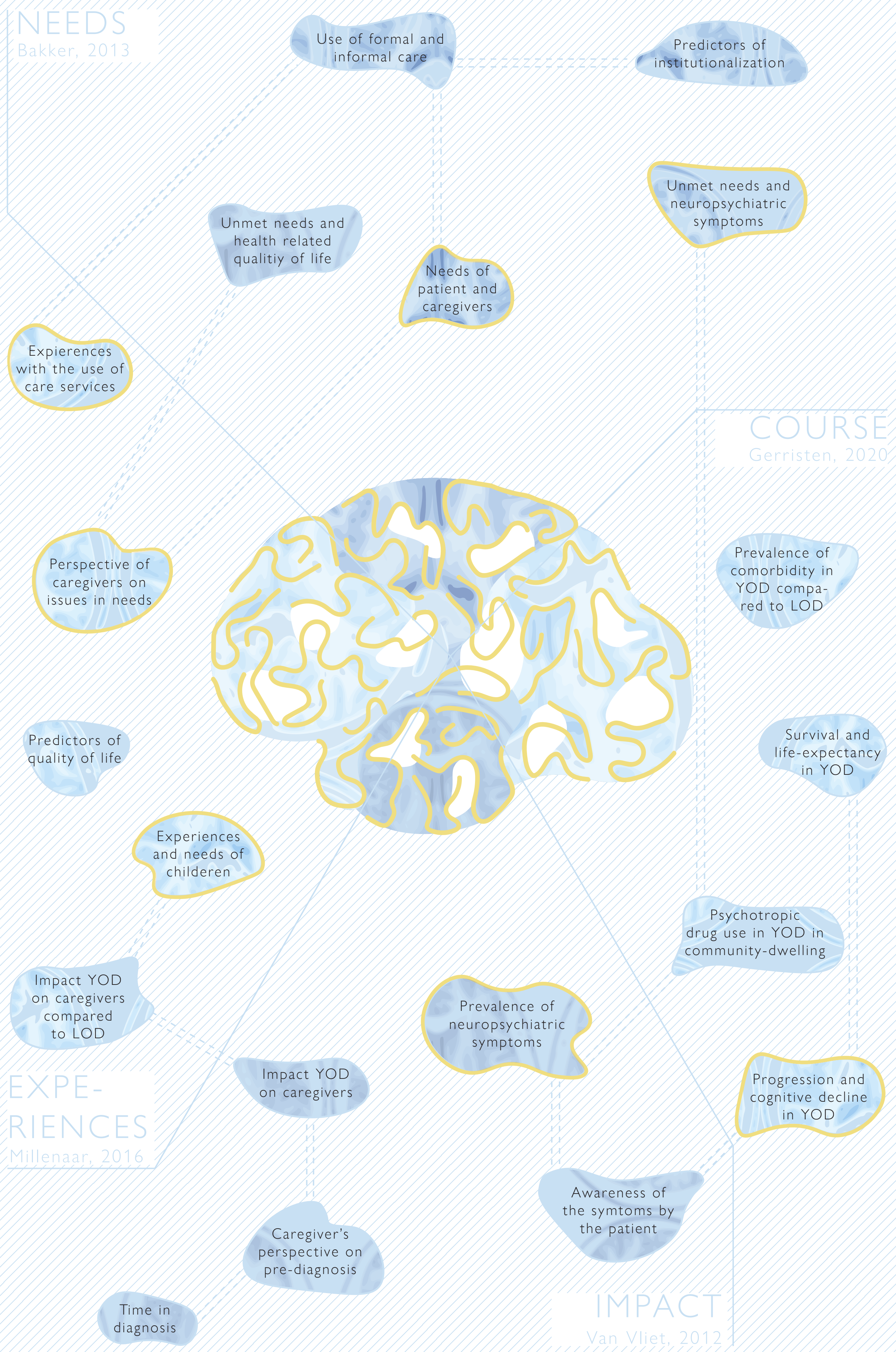
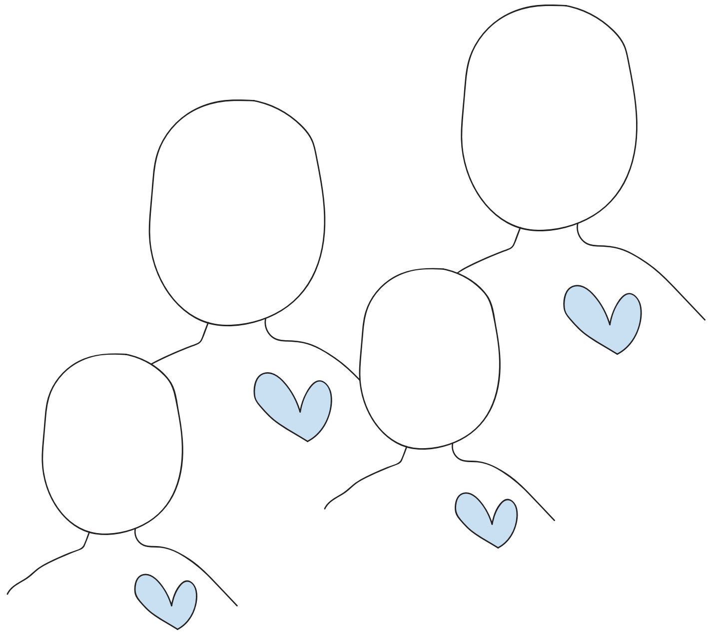


Figure 30 | Research context scheme



All relatives have dementia

Dementia at a young age affects all the relatives and could be seen as a family disease, of which the implications are not comparable with those in older stages of life (Gerritsen, 2020).

Late diagnosis The period before the diagnosis in Young Onset Dementia is longer than in Late Onset Dementia, where the average time is 2,8 years compared to over 4 years (Gerritsen, 2020). The first occurring symptoms, like changing behaviour, lack of emotions, difficulties with language and problems in their job, are often linked to mental complaints or a burn-out at first, since dementia at a young age is rare and not thought of (MAX, 2022; *Op je 47e tussen de bejaarden,* 2022; Bailliu et al., 2021; Alzheimer Nederland, 2018; *Margreet - Jonge Mensen Met Dementie* 2, 2022).

Conflicts Due to misunderstanding of the situation, this pre-diagnostic period can cause tension and anger in their family situation, which is reported by 33% of the caregivers (Van Vliet, 2012). Sometimes this even leads to, almost, divorces (Van Vliet 2012; (Alzheimer Nederland, 2017a).

Also conflicts in the work situation occur, since they cannot function properly anymore. They are getting fired and are often unable to find or keep a new job, which can lead to financial difficulties (Van Vliet 2012; Bakker, 2013; Alzheimer Nederland, 2018).

Getting apractical After the situation is getting worse, the right diagnosis is given. At that point they are almost not being able to function in a job anymore, ending up at home with a sickness benefit. Also managing their own daily life becomes challenging, needing more help with planning, taking care of themselves and household tasks, they need to be taken care of (Alzheimer Nederland, 2019a; Alzheimer Nederland, 2016a).

Changing roles Marital and parental relationships change, as the relative with dementia is no longer able to fulfil the role of a partner or a parent. Partners are becoming informal caregivers, which can lead to emotional problems (Gerritsen, 2020). Children also get more responsibilities in the care and get a parental role for their parent instead of getting parental care (Millenaar, 2016; Alzheimer Nederland, 2019a), which can also lead to emotional difficulties (Millenaar, 2016; Alzheimer Nederland, 2018).

Losing life The life of someone with Young Onset Dementia is different from that of someone with Late Onset Dementia. They already live a more quiet life, do not work anymore and are already more at home, while at a younger age, they suddenly face all this unintentionally.

In Young Onset Dementia, the proposed picture of the future changes immediately with the diagnosis, knowing you will only have a few years left, in which you lose yourself and your capabilities a little more every day (*Margreet - Jonge Mensen Met Dementie* 2, 2022). It is described by families as a long grieving process, while they are still alive (Alzheimer Nederland, 2017b; Alzheimer Nederland, 2016b; Alzheimer Nederland, 2019b).

Nobody at home The difference with Late Onset Dementia is that there is, in almost all cases, always somebody at home, since the partner is retired. There is therefore always somebody there to assist, to keep company and to keep an eye on. In Young Onset Dementia, the other partner is still working and cannot afford to stop or work and care at the same time. They are therefore juggling between their work and caring responsibilities for their relative and in some cases for their children (Armstrong, 2021). If there are older children living at home, they are also at school or at work during the day and cannot take care.

Being home alone can lead to unpleasant or unsafe situations. The relative with dementia can become anxious, since they do not know what to do, how to do something, how late it is, when to do something and how long it takes before someone comes home (case 1, 2). Eventually the situation at home is not doable anymore, and they have to move somewhere else where there is specialised care for them the whole day.

He was 63 when the first symptoms of Alzheimer occured

"My partner actually got it too,
although she does not have it herself, she got it anyway

I find that very painful"

(Talpa Network, 2021 (S2E5))

Looking back, his symptoms of Alzheimer occurred
when he was 40 years old.

He lost his job where he worked for 15 years. After he hopped from job to job, after a probationary period he was fired each time.

Eventually, he was 50 when he could not get work anymore.

(Case 1)

Her partner is 61 and has dementia

"I have to tell him that he needs to shower,

I have to tell him that he needs to brush his teeth,

I need to prepare his clothes.
Some time ago he put a t-shirt on under his normal t-shirt and over it a vest and another vest."

(Hoppe,2022)

He is 45 years old and diagnosed with Alzheimer

"I have played volleyball my whole life. The rules were recently changed, but it is too difficult for me to learn them again.

This annoys me, because I cannot keep up with my teammates anymore"

(Margreet - Jonge Mensen Met Dementie 2, 2022)

He was 51 years old when he got the diagnosis of Alzheimer

"If at this age you have to say goodbye to something that you have been doing from a young age with great pleasure and passion all these years ...,

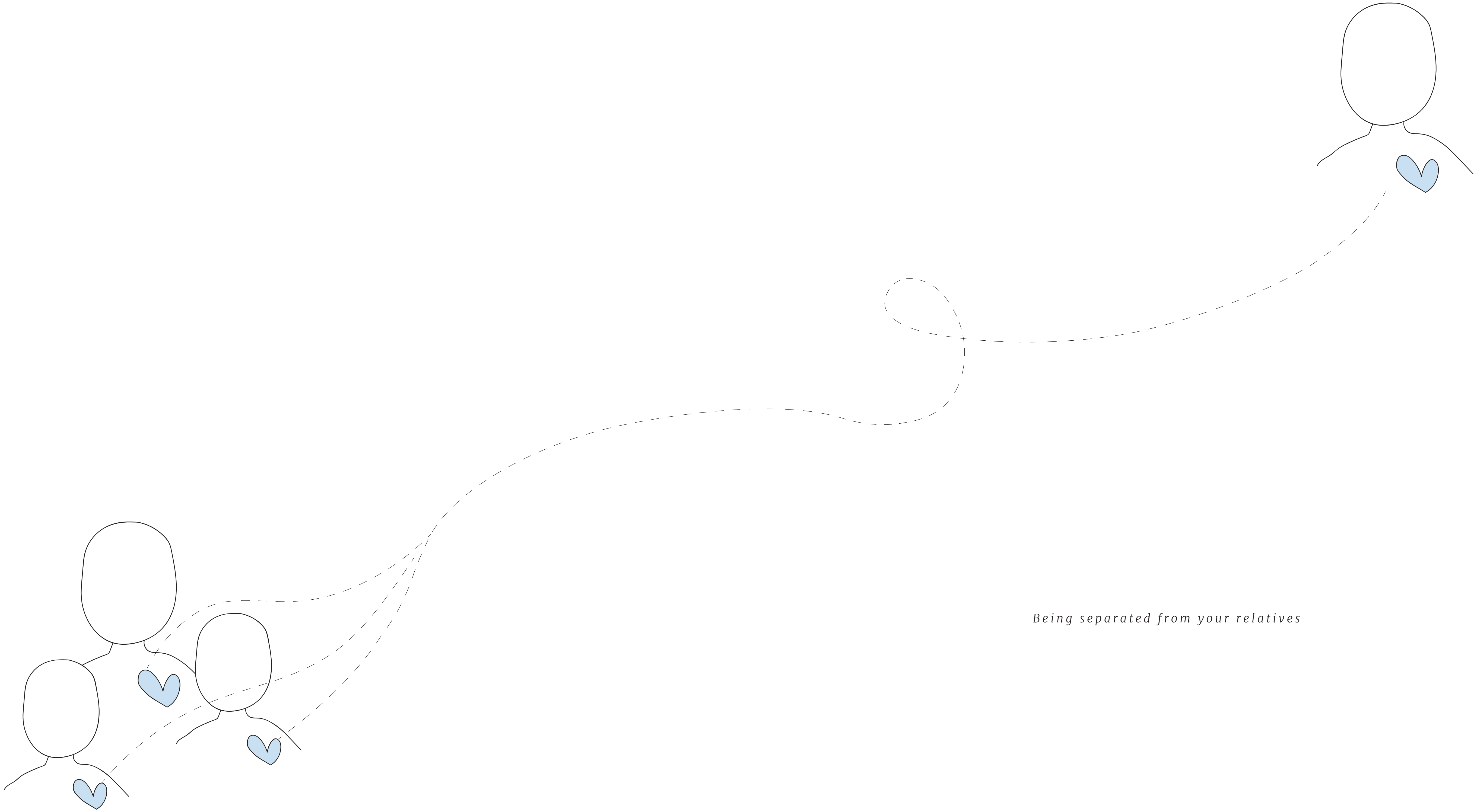
that is intense, yes,
it is not always easy to deal with that."

(Talpa Network, 2021 (S2E4))

He was 35 when he was diagnosed with Alzheimer. Our kids were 3, 6 and 8.

"The situation at home is almost impossible with three young children, then he also became incontinent. The children could no longer be left with him, even if I was upstairs. It is clear to me that I was not going to make it." (Partner)

(MAX, 2022)



Being separated from your relatives

Alone Moving to a care home is a big shift for people with Young Onset Dementia. Where they used to be part of a family or household, and still are, their worlds separate and are suddenly living alone in a new environment with new people around them. When being in the care home, they are very aware that they are there and their relatives are not, as their sense of reality is still intact (case 1).

Restless They also can become restless as a result of feeling alone or too much or too little stimuli, while they used to be very calm at home (case 1; Hoppe, 2022). The difference between how someone was at home and how they are in the care home can be big. Two young men were constantly calling, or even shouting, their partners name. Only if they were with them, they felt soothed.

"Because of the stimuli, he was screaming and shouting all the time.

It was really painful to go there.., to see how much he was not himself, and he would oly be put in his room.

But to be sitting at home and thinking that you father sits in his room all day long, that was very difficult"

(Hoppe,2022)

In the beginning he really missed us and was sad sometimes, because we were not there.

He could stand in front of the window, looking out for our car and hoping that we came.

Sometimes he also wanted to go upstairs, because he thought there were the bedrooms or his relatives like at home.

(Case 1)

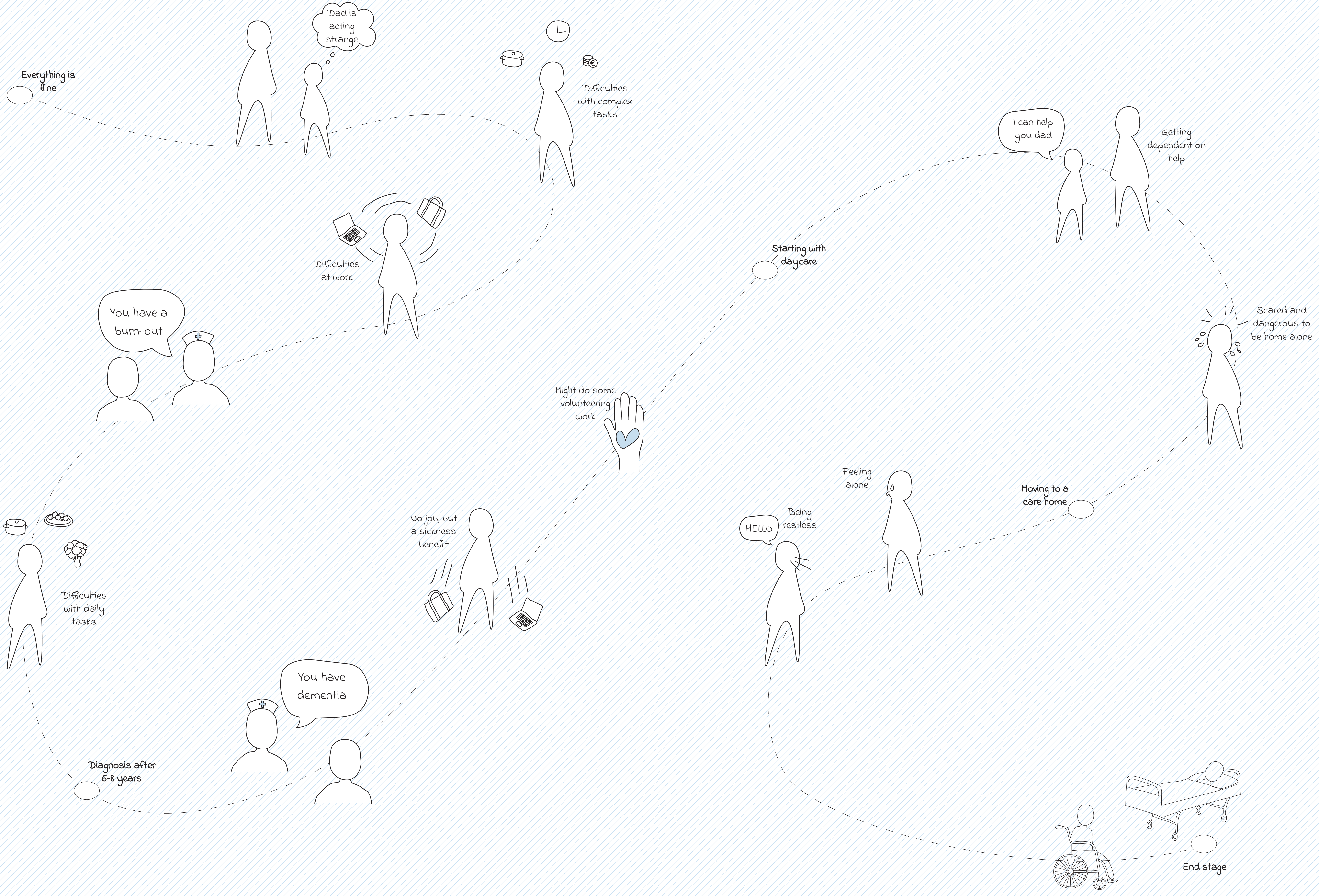
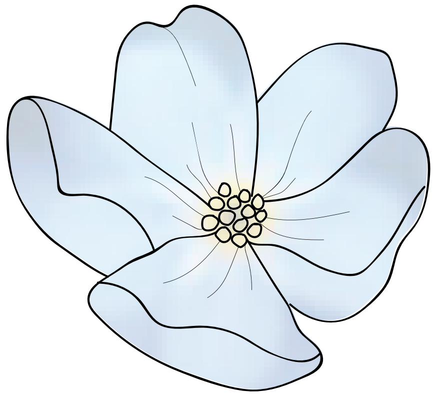


Figure 31 | Patient journey (global indication)



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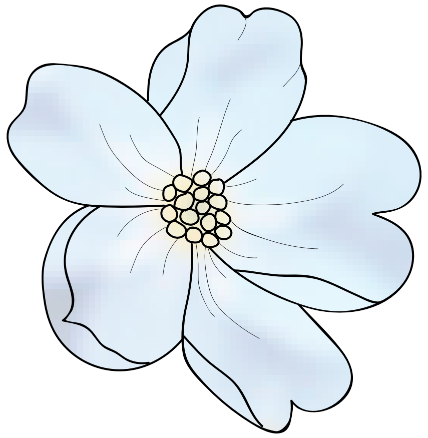
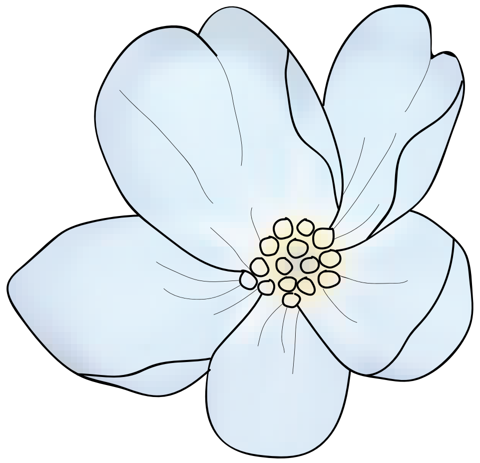




The spatial needs

4.1 NEEDS OF SUFFERERS

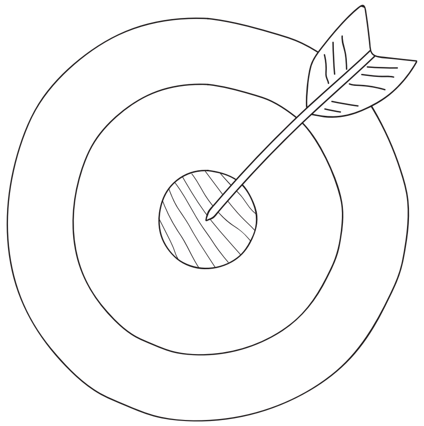


Figure 32 | Purpose

Having a purpose in society

With the diagnosis of dementia, younger people lose all of those roles and responsibilities. This results in not having a purpose in life anymore, while others around them still have, which can make them feel useless and lose their self-esteem (Talpa Network, 2023 (S3E1); *Margreet – Jonge Mensen Met Dementie* 2, 2022).

People with Young Onset Dementia often mention wanting normality. They want to be seen as fully-fledged and remain an active part of society (Talpa Network, 2022 (S2E3); *Margreet – Jonge Mensen Met Dementie* 2, 2022). Without challenges in daily life, the dementia will deteriorate faster (Vught in Talpa Network, 2022 (S2E6)). They are capable of doing more than is generally thought and having a purpose and something to add to the society is shown to give back their self-esteem and bring more pleasure. Typical for almost all young people with dementia is their motto "look at possibilities, not at impossibilities" (Talpa Network, 2021, 2022).

Despite not being able to work anymore, they still try to participate in society by volunteering. Some are helping a few days a week in a thrift store, with making bikes and sorting products, which they enjoy doing (case 1, 2). Two participants of Restaurant Misverstand became friends and did voluntary work at Natuurmonumenten, helping with forester tasks. Another woman was volunteering at a restaurant, where she assisted with making and serving food (*Margreet – Jonge Mensen Met Dementie* 2, 2022).

A care home should thus allow young people with dementia to live as much as normal life, where they can participate in society.
ARCHITECTURE HELPING TO BE **MEANINGFUL**

"I am now doing voluntary work for one day at a restaurant, where I help with preparing the food, which I enjoy doing and I have something to tell when I come home." (sufferer)

(Margreet – Jonge Mensen Met Dementie 2, 2022)

"There might be thousands like us who might be able to do something, but do not get the attention." (sufferer)

(Talpa Network, 2021 (S3E1))

"It is nice that she has a goal, she does a lot of the same at home. I can't make her that happy at home." (daughter)

(Talpa Network, 2022 (S2E6))

"Then you can do something again, you mean something again." (sufferer)

(Talpa Network, 2022 (S2E3))

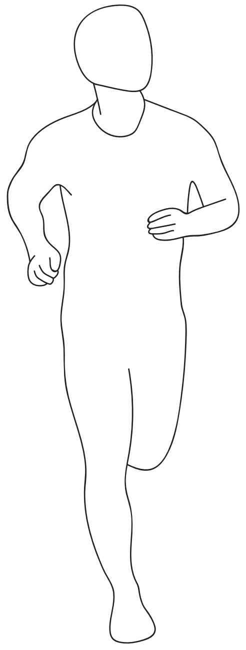


Figure 33 | Physical activity

Having physical activity

Young people are physically still fit and active. Having dementia can hamper their ability to move and cost much energy, as their coordination, visual perception and executing movements are impaired. As they cannot keep up with the pace of the sport or become scared, they stop (Baars, 2022, case 1). Although they still have a strong need to move and do physical challenging activities (fieldwork place 3; MAX, 2022).

The King Arhtur Groep has set up a sports program for young people with dementia and the supervisor stresses the importance of moving, physical, mental and social. “Moving helps them to rediscover that they can still do so many things” (King Arthur Groep & Baars, 2022). Besides having fun, it helps them to keep control over their body and to stay fit. Body functions are trained consciously, as their coördination and balance is stimulated, condition is maintained and the muscles are kept flexible and strong (Baars, 2022). After sporting, the participants are physically tired instead of being tired of doing nothing and being busy in their head (Baars, 2022).

Sporting also allows them to clear their mind and not have to think about their dementia for a while or to have deeper conversations about their disease with peers in contrast (King Arthur Groep & Baars, 2022; Baars, 2022). It is an outlet for them, they flourish and take initiative again, without they can be restless and apathetic (Baars, 2022).

A care home should thus enable young people with dementia to move and exercise, both together and independently.

ARCHITECTURE HELPING TO **MOVE**

"Not so long ago the participants were doing sports themselves, but their dementia made it more difficult after which they stopped at some point." (sport supervisor)

(Baars, 2022)

"I cycle 70 to 80 kilometres every day . I feel really fit and vital, it is just that things will not always go quite well in my head." (sufferer)

(Talpa Network, 2021 (S2E5))

The biggest difference with Late Onset Dementia is that younger people have a great urge to move, they are very active. (caregiver)

(fieldworkplace 3)

"A week before he moved to a care home, he was still mountain biking with a friend on a weekly basis." (partner)

(MAX, 2022)

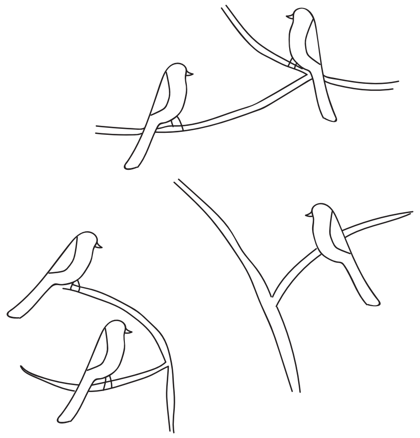


Figure 34 | Peers

Having social interaction with peers

Losing a job is often accompanied by the sudden loss of social interactions for young people with dementia. They end up alone at home and have a big chance to become socially isolated, because they are less capable of undertaking activities themselves and many people are at work during the day. This leads to a faster decline of their dementia and feeling lonely or anxious (Vught in Talpa Network, 2021 (S2E6); *Margreet - Jonge Mensen Met Dementie* 2, 2022). Seeing other people in combination with having something to do is therefore important for them.

Due to their dementia, they cannot keep up with the pace of the rest of the world, resulting in less self-confidence. When being surrounded by other peers with dementia, they do not have this pressure of their surroundings and are able to do everything at their pace. It will make them feel safe and give back their self-confidence (day supervisor for YOD in *Margreet - Jonge Mensen Met Dementie* 2, 2022). In combination with doing things together, it also results in being more able to fulfil tasks (Talpa Network, 2021 (S2E4, S2E6)).

Another positive effect of interaction with peers that is stressed by people with Young Onset Dementia, is that they feel understood, since they face the same difficulties and are cognitive on a same level (Talpa Network, 2021). This also forms a ground for friendships; even if your brain functions deteriorate, this will remain valuable in life (Vught in Talpa Network, 2022 (S3E4)).

A care home should thus bring young people with dementia together and enable social interaction.

ARCHITECTURE HELPING TO **INTERACT**

"It is like a fairy-tale. You step into a world where everyone has dementia. I do not have to be afraid to make mistakes, here I am allowed to. I would always live in a world where I do not have to walk on my toes." (sufferer) *(Talpa Network, 2021 (S2E4))*

I cannot cook anymore, do you?

No, I also cannot do that.

HaHaHa. (sufferers)

(Case 1)

"Before she came to the restaurant, she could not do this task, but now she does it smoothly. She is bursting with self-confidence, she has gained much more guts and is much more daring to do something." (doctor) *(Talpa Network, 2021, (S2E6))*

"Contact with fellow sufferers is everything to me, I feel that I am understood and that is so much, that alone makes me feel so comfortable." (sufferer) *(Talpa Network, 2021 (S2E3))*

"My 8-year-old son was angry because I had decided that dad had to leave home. "This is your worst idea ever," he said." (partner)

(Carola's Man (48) Heeft Dementie, 2022)

"Well, I very much look after myself. My sadness only begins once I have to bring him to a nursing home." (partner)

(Hoppe, 2022)

"Every day again when going to the nursing home, I am kind of excited to see him again. Then you are back together and think 'oh yes, it was like this' and when you go back home and you miss him again." (partner)

(MAX, 2022)

"Look after yourself', well, that is easy to think for others, because this is looking after ourselves. Taking care of him is important to me. I find it great to be able to do this for as long as possible." (child, 21)

(Hoppe, 2022)

4.2 NEEDS OF RELATIVES

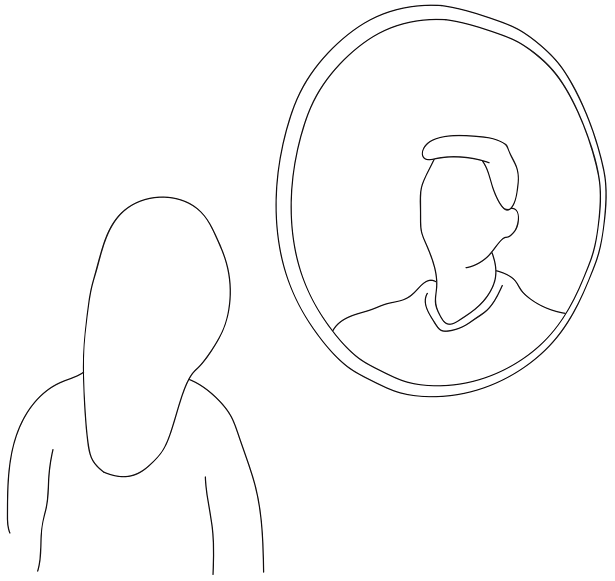


Figure 35 | Dividuality

Lens of dividuality

Dividuality is the opposite of individuality and means that persons are "constructed as plural in the relationship that produced them" (Strathern, 1988, p. 13 in Hoppe, 2022). People thus do not identify as 'I' but as 'we'.

This concept is strongly present in families with a relative with Young Onset Dementia. The needs and wishes of the sick family member are embodied in the other relatives. Choosing to take care of their relative is seen as choosing to take care of themselves and is thus not seen as a choice (Hoppe, 2022). This often comes with adapting life choices for children as for example taking up responsibilities in the household and caregiving or by not moving far away for studies or work (Hoppe, 2022). Caring for a loved one is thus part of their identity.

Although informal caregiving is a tough and demanding task, relatives report that the suffering only begins when they are no longer able to. It means a loss of their dividual elements, it is not simply not doing something anymore, but not being something (Hoppe, 2022). Being separated from a loved one is therefore even more painful. Vice versa, the relatives are also contained in the sick relative, they need to feel their presence to feel soothed and experience this **dividuality**. A care home should thus not only focus on the person with young onset dementia, but also on their relatives.

ARCHITECTURE HELPING TO REMAIN **ONE**

"I left written instructions at home, but after a while he called me in distress, even before I had left the street. Even though my work is my outlet , I did not dare to leave him alone at home anymore, so I quit my job." (partner)

(Carpentier, 2016)

"The stress at home meant that it took her two years longer to finish school than her peers." (child, 18)

(Hoppe, 2022)

"When he still lived at home, I took over quite a lot of care tasks, I felt like being a kind of parent to him. I thought, that is not what a twenty-year-old should have to deal with. I have my job on the side, I have school."

(child)

(Hoppe, 2022)

"You do not get the sleep you need, and as a consequence, you are dead tired. And then you end up in a circle you cannot escape, you are on your last legs. I took a few days off and that helped me a lot." (partner) *(Hoppe, 2022)*

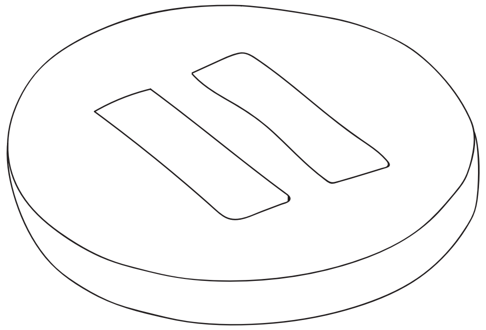


Figure 35 | Break

Having a break

Especially in Young Onset Dementia, the caregiver burden is even higher than in late onset dementia, due to the different life stage and the many roles and responsibilities they have to keep up with (Alzheimer Nederland, 2021; Armstrong, 2021). They have their jobs, their school, care tasks for the children, the household to run, their hobbies or sport and their own social life. Having a demanding caregiving task on top of that can be tough.

Their relative with Young Onset Dementia slightly get more dependent, they have to arrange everything for them, from personal care to managing their day, until the full care relies on them. Eventually, this means that they cannot be left home alone anymore, since it can cause dangerous or worrisome situations. They might forget the most basal things and everything in the house can form a risk. Since they do not have the presence of mind to ask for help, even when relatives are not in a direct care task, they experience constant worries.

Although caregivers are willing to do a lot for their relative through the lens of dividuality, there is a limit in what is feasible and what they can handle. They often mention the need for a break, so they can take some time to breathe without having those worries and care tasks for a moment and can recharge (Carpentier, 2016; *Margreet - Jonge Mensen Met Dementie* 2, 2022; Hoppe, 2022). A care home should therefore provide opportunities to take a break from caregiving.

"I had some sessions with a psychologist, but I did not achieve anything. Whereas at the partner meetings, you said a few words, but they already understood you. Without these conversations, I would not have made it." (partner)

(Hoppe, 2022)

"It is important for a child to know that you are not the only one with a parent with dementia, as it is also important for the partner to meet other families going through the same, this contact is valuable." (partner)

(MAX, 2022)

"Sometimes I think I will never get to know my mother as a grown-up. I just knew her as a child, teenager and adolescent. Actually, I never had a mother. Physically yes, but not someone who had cookies ready when I returned from school." (child)

(Hoppe, 2022)

"Sometimes I say it is easier to explain that my mother is dead; they understand that: "Oh you don't have a mother anymore." But if I say my mother has dementia, they think: "Oh yes, she forgets things, she is still there."

(child) *(Hoppe, 2022)*

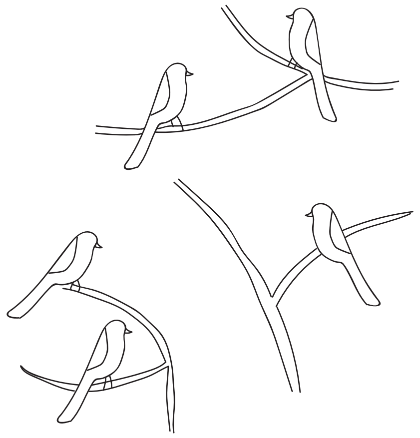


Figure 36 | Peers

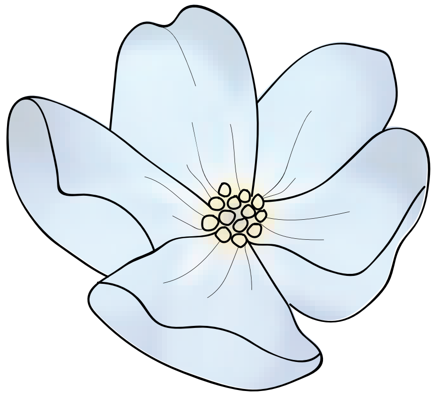
Feel understood by peers

Partners and children face difficulties with explaining their situation with a relative with young onset dementia (MAX, 2022; Hoppe, 2022). Outsiders do not seem to understand what it means and it is often not notable at a first sight that something is wrong, since they look fit and healthy. They only see that someone looks good, but do not know how a situation is at home and that the person got help by dressing up properly (Hoppe, 2022). Only if you are with them longer, it becomes clear how difficult the situation is.

Not many people have a picture in their head of what dementia is and often underestimate it. They think they do by referring to their grandparents who forget some things, but it is not only that, it is becoming a whole different person (Hoppe, 2022). The fact that people are there physically, but not mentally, making them no longer able to fulfil their role as a parent or partner, is a complex situation to explain. Sometimes it seems easier to tell someone is not alive anymore (MAX, 2022; Hoppe, 2022).

This lack of recognition and understanding of their struggles can be frustrating and can lead to an even tougher situation (Hoppe, 2022). Children can also be ashamed of their situation and do not want to talk about it with their friends, because they think it is strange (MAX, 2022).
It is therefore important for them to have the opportunity to come in contact with peers, since partners and children feel almost only understood by other relatives of persons with Young Onset Dementia. A care home should therefore enable relatives to interact with each other.

ARCHITECTURE HELPING TO **INTERACT**



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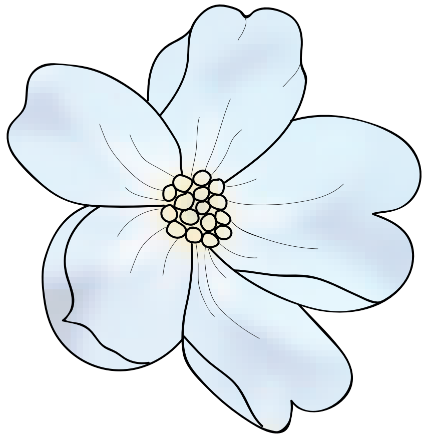
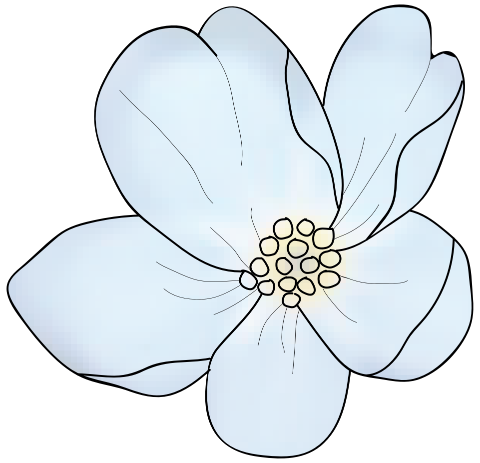




The reality

No place closeby Since facilities specific for people with Young Onset Dementia are scarce, there are often long waiting lists or they are further away, meaning having to travel long distances when visiting (*Op je 47e tussen de bejaarden, 2022*). One partner said that she takes the long car rides for granted, as it means her husband could live with other young people with dementia. Although it is not ideal: “you actually want a place for everyone near their own city, where people can pass by more easily” (*Op je 47e tussen de bejaarden, 2022*).

Living with your parents In most cases, young people are living in mainstream facilities, where their fellow residents are the same age as their parents (fieldwork place 1, *Op je 47e tussen de bejaarden, 2022*). They are from a different generation, having a different way of living and interests, as they listen for example to old music and watch old tv-programs. A young person did not like such music and chose often not to attend music activities (case 1).

Older people with dementia live more in the past and are not connected to reality, meaning they might think they are younger or make up their own reality. One woman kept mentioning that she did not live in the care home, but was there on holiday for a few days, which she does once in a while (fieldworkplace 2). This sense of reality stays intact by younger people instead (case 1, *Op je 47e tussen de bejaarden, 2022*).

No challenging physical activity Older people need less physical activity, since their body is less fit and their muscle strength and condition is impaired. Younger people instead are physically fit. Where older people are sitting in their chairs the whole day, younger people are seeking physical activity (MAX, 2022; case 1). For them ‘chair gymnastics’ is challenging enough as an activity, but not for the younger. They also do not want to participate in such activities (case 1, Armstrong, 2021).

Most of them also do not undertake outdoor activities anymore. When they go for a walk, it is only a small round at a low pace, while younger people want to do more. A young man played basketball with someone of his age at the daycare (case 1). In the care home, they did nordic walking or cycling at a home trainer every week with a small group, with him and some other fit people, which he enjoyed. His family took him every weekend on a longer walk in the forest, a friend came once a week to mountain bike with him and a family member played table tennis with him on a small table he brought himself. If there was time, a nurse would sometimes go for a ride with him on the duobike, play table tennis or attend when he was at the hometrainer. Since the other residents did not need such physical activities and there were only a few nurses, they often did not have this personal time.

No meaningful day Older people do not have the need to be busy or undertake many activities during the day. Most of them are satisfied with reading some newspapers, drinking some coffee and relaxing or taking a nap in the afternoon (fieldworkplace 1). A busy day scheme is not needed for them, while younger people want to do something instead. The man of case (1) was always looking for something to do. When he saw the garbage, he would bring it with a wheelbarrow to the bins and he was happy if he could help with feeding the chickens or getting bread. His partner tried to set up an active day schedule for him together with the nurses (partner, case 1). Another partner said that she did her utmost to arrange a good day care in the care home for him “With a good daily activity schedule he can live, instead of waiting until he is gone” (Keislair, 2022). They are doing physical activities, listening to music, watching a movie or cooking together. That seems to do him good, he is much calmer.

Young people with dementia have thus difficulties to integrate in facilities focused on elderly. Partners also mention that they rather see their relatives in an environment with other people with Young Onset Dementia, as it will fit their needs better and it would be much better for their children (*Op je 47e tussen de bejaarden, 2022*).

"My eldest two children do not dare to go with me to visit their dad anymore, because they find the nursing home and the old people scary. They ask me why people are sleeping at the table with daddy. (partner)

(MAX, 2022)

It is so important that young people feel worthy, but that is not the case now. (partner)

(Case 1)

"Many people in his ward are sitting in their chairs the whole day, while my partner is running around. " (partner)

(MAX, 2022)

I am not crazy

(YOD sufferer)

(Case 1)

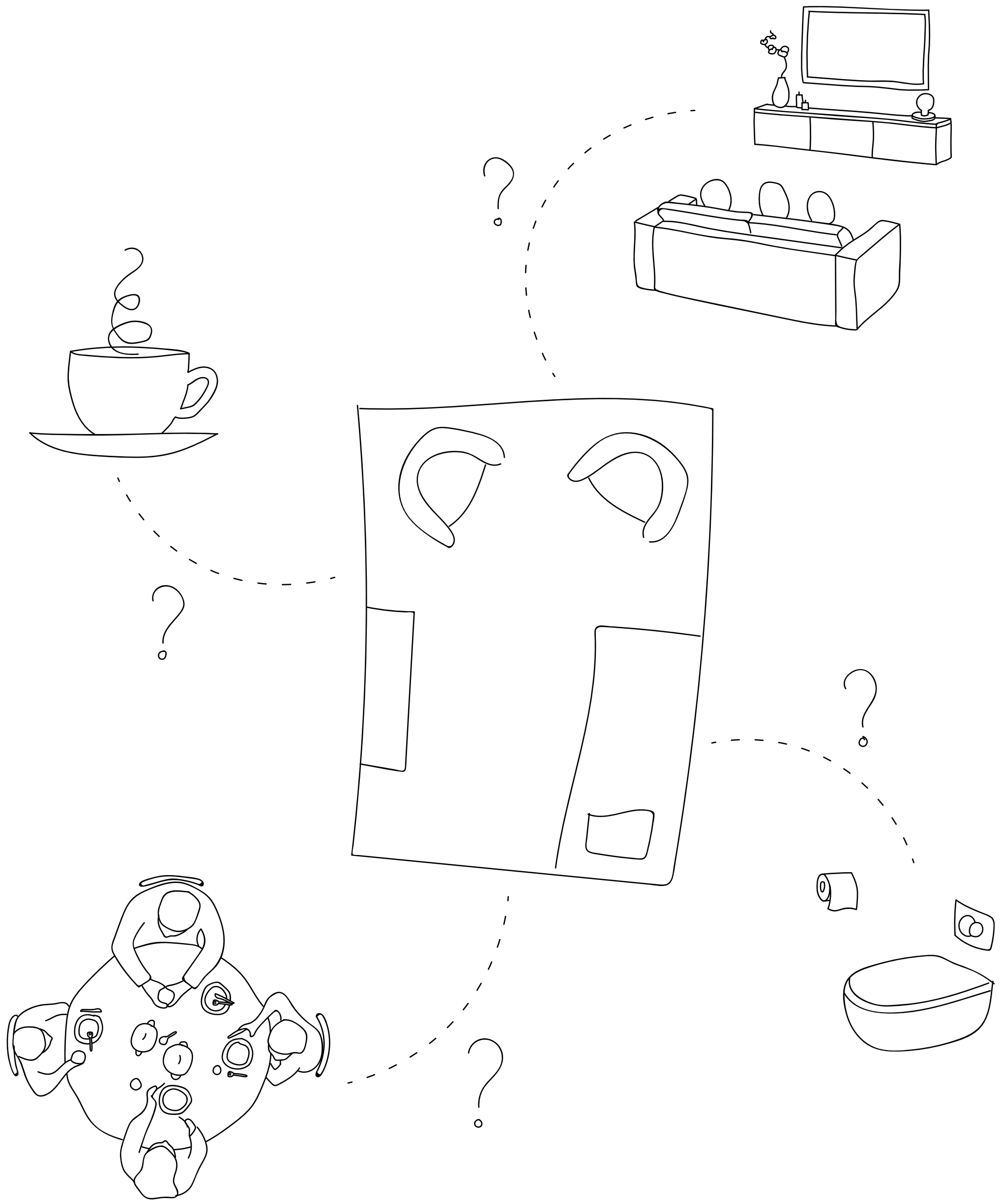


Figure 37 | Faced problems in care homes combined from fieldwork place 1, 2 and 3

Place for family

Relatives report to visit as often as possible (MAX, 2022; case 1). Although, there is only a bedroom as private space where they can be together. Where this might fulfil the needs of the elderly, as they do not have a family life anymore and have fewer visits a week, it does not for the younger. They are used to this family life where they are together every day. One ten year old girl said that she misses the normal daily things, such as eating at a table or watching tv on the couch (Alzheimer Nederland, 2016b). A partner once stayed over for lunch in her husband's room, but since there was no dining table, he was barely able to eat (case 1). Another family mentioned that almost the only thing they could do together was eating an ice cream (*Carola's Man (48) Heeft Dementie,* 2022). Other activities children undertook were baking together or roller skating through the halls (Bunniks Nieuws, 2015). There should thus be possibilities to be together and undertake activities in a daily way.

The rooms here are quite small, relatives can sit and drink some coffee, but there is no space to eat together. We have a few double sized rooms, relatives do have dinner together there. (caregiver) *(Fieldwork place 2)*

May I have three cups of coffee please?

(relative asking the caregiver)

(Fieldwork place 2)

When I have to go to the toilet, I have to ask the nurse for a key of the toilet of the ward on the other side or I have to go to the lounge on the opposite side of the building for the public toilets. (relative)

(Fieldowrk place 3)

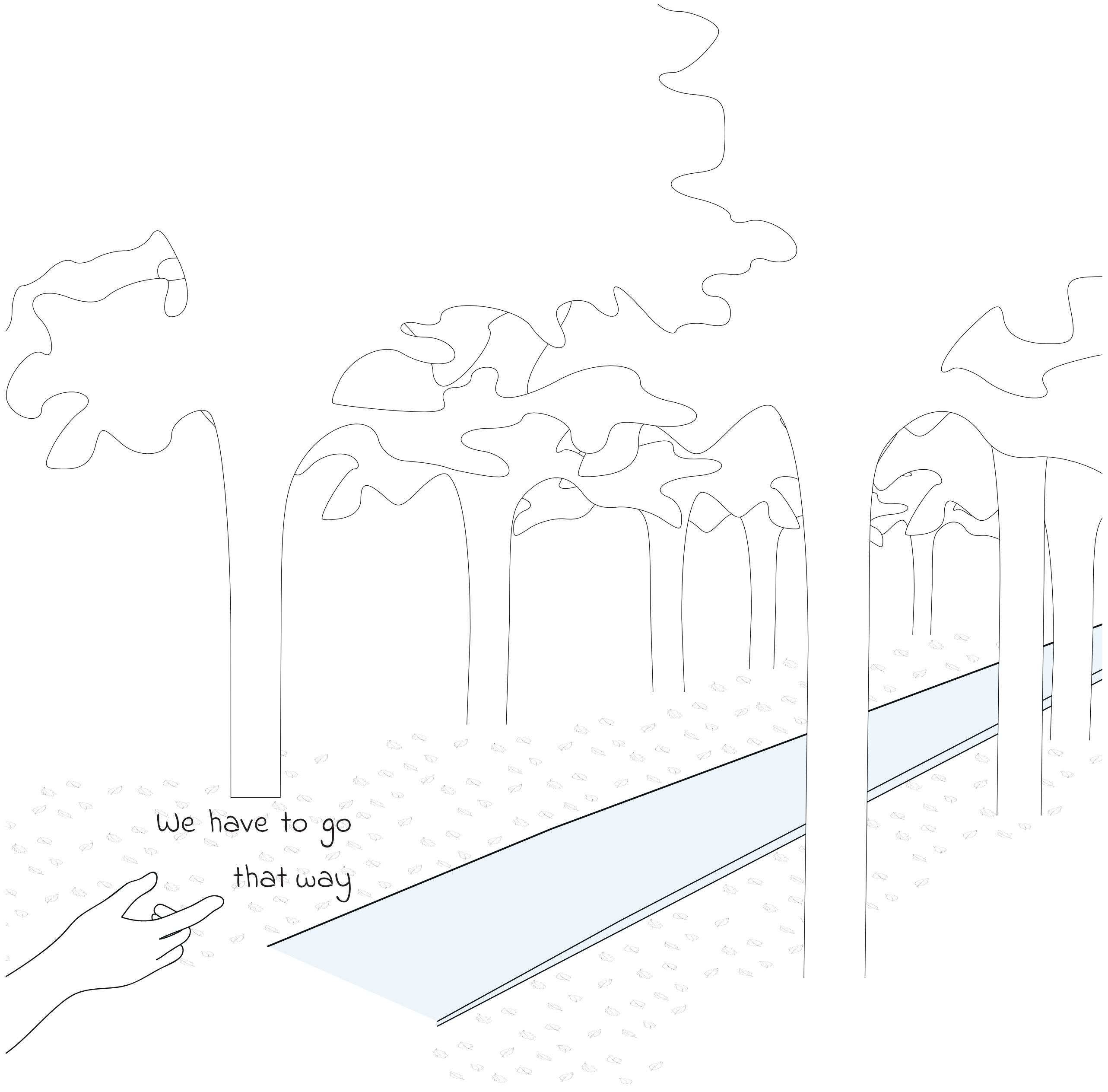
We used to watch a tv-program together on friday night when everyone was home. Now we sit in his bedroom on his bed, folding chair or wooden stool, since there is only room for two normal chairs. (relative)

(Fieldwork place 1)

Figure 38 | The path in the eyes of someone with dementia (fieldwork place 1)

Walking in the forest

Close to the site is a forest where we like to walk and come at least twice a week. There is a sand path between the trees ending at a paved path, leading back to the entrance of the forest. But at a certain moment, the sand path became too unclear, the only way he wanted to go was over the paved path. We always have to convince him that we know the way and that he could follow us on the sand path, which he did, but he was nervous the whole time. Once we saw the paved path he was reassured and could enjoy the walk back (relative, fieldwork place 1).



Specialised facilities for people with Young Onset Dementia are situated in mainstream built care homes and are not designed specifically for them. Many of them have an institutional character, which has a negative association.

Closed facility Care homes for dementia often have closed wards, choosing safety over the freedom of the residents (Alzheimer Nederland, 2016b; fieldwork place 2, 3). At fieldwork place 3, you could only enter the main building and then the ward with number codes. Residents could thus not independently leave their ward. One relative reported that there was an exercise garden with some fitness equipment, but since the wards were locked, residents could not just go there (case 1). One person with Young Onset Dementia did not want to live in such a specialised facility, due to the image and idea of nothing happening there (case 1). He wanted to live in a courtyard based designed care home in an outdoor and open environment (fieldwork place 1). Another partner mentioned that this should be more humane, she thinks it is not normal if residents are locked up (*Carola's Man (48) Heeft Dementie,* 2022).

Long corridors Something that was reported by a relative as unpleasant was the long corridor they had to pass when visiting her partner and dad (*Carola's Man (48) Heeft Dementie*, 2022). Mainly her children did not like that, since they saw many sick people, some of whom are particularly affected. Her eldest daughter immediately dives into her dads room and sits there in a corner the whole time. Two of the fieldwork places, 2 and 3, had such corridors. An older resident in fieldwork place 2, which has an L-shaped corridor with a loop, said that she sometimes finds it difficult to find her room, but the picture of herself at her front door helps her.

Bare spaces A homely atmosphere is reported by residents, caregivers and relatives as important. A resident, who did not have dementia but lived at a community with care, mentioned that she could give us one tip while designing such an environment, is to make it homely (fieldwork place 2). Caregivers at fieldwork places 2 and 3 mentioned, although having an old and more institutional building, they try to make it cosy by placing a hearth with for example fake fire and wood, plants, decoration and wallpapers.

Although, the living spaces should be practical, since there is space needed for wheelchairs. Also furniture should be stable, and not have sharp edges, in order to function as a hold while falling and to prevent injuries when hitting, and should be easy to clean (caregiver, fieldwork place 2).

Big groups The visited care homes (fieldwork place 1, 2 and 3) had groups of 16, 14 and 18 residents respectively. Since this amount of people can cause too much stimuli, they have separate dining tables where smaller groups of four to six residents eat together, in two cases even in separate rooms (fieldwork place 1 and 2). They all had a separate quiet living room too, where residents could watch tv and not bother other people or could withdraw to get some rest. A caregiver of fieldwork place 2 mentioned it is preferable to have a good overview over all residents in the communal area.

Care space As residents in later stages of their dementia are more dependent and are in a wheelchair or in bed, they need more high care. This has implications for the space nurses need in the bed- or bathroom to dress or shower the residents and for the space taken up by care utensils, such as wheelchairs and hoists to transport residents. Fieldwork place 3 even had a bathroom with a special bath.

Also workspaces for staff and for family meetings are needed. In fieldwork place 1, these spaces for staff were situated on the floor of the communal house. In fieldwork place 2 was no separate room for an office on one ward, so the desk with computers was in the living room. This desk was in fieldwork place 3 situated in the hallway, where one younger resident liked to sit next to a nurse working there. The quiet living room was used as meeting spaces, as well as wardrobe and storage.

"The care home did not create opportunities to make people with dementia feel meaningful." (relative)

(Hoppe, 2022)

"If we do not take him outside, he is just sitting inside." (partner)

(MAX, 2022)

There should be a balance between a practical and a homelike environment. (Caregiver)

(Fieldwork place 2)

"And then you are in such a bare room. I tried to make sure his room was cosy after all. A piece of home, like a bookcase, that was recognisable for him." (partner)

(Keislair, 2022)

Figure 39 | Covered exit fieldworkplace 3

Trying to escape

The exit door of the ward first was a normal door, with two glass panels on the side. The residents were constantly opening this door trying to escape, since this is a human reaction when seeing a door: it can be opened and there is something behind. We covered it with a sticker of a bookshelf and now people do not see it as a door anymore, and are not trying to open it anymore, they do not feel locked anymore, which gives them rest (caregiver, fieldwork place 3).

So in case a locked exit door is inevitable, it should not look like a door.

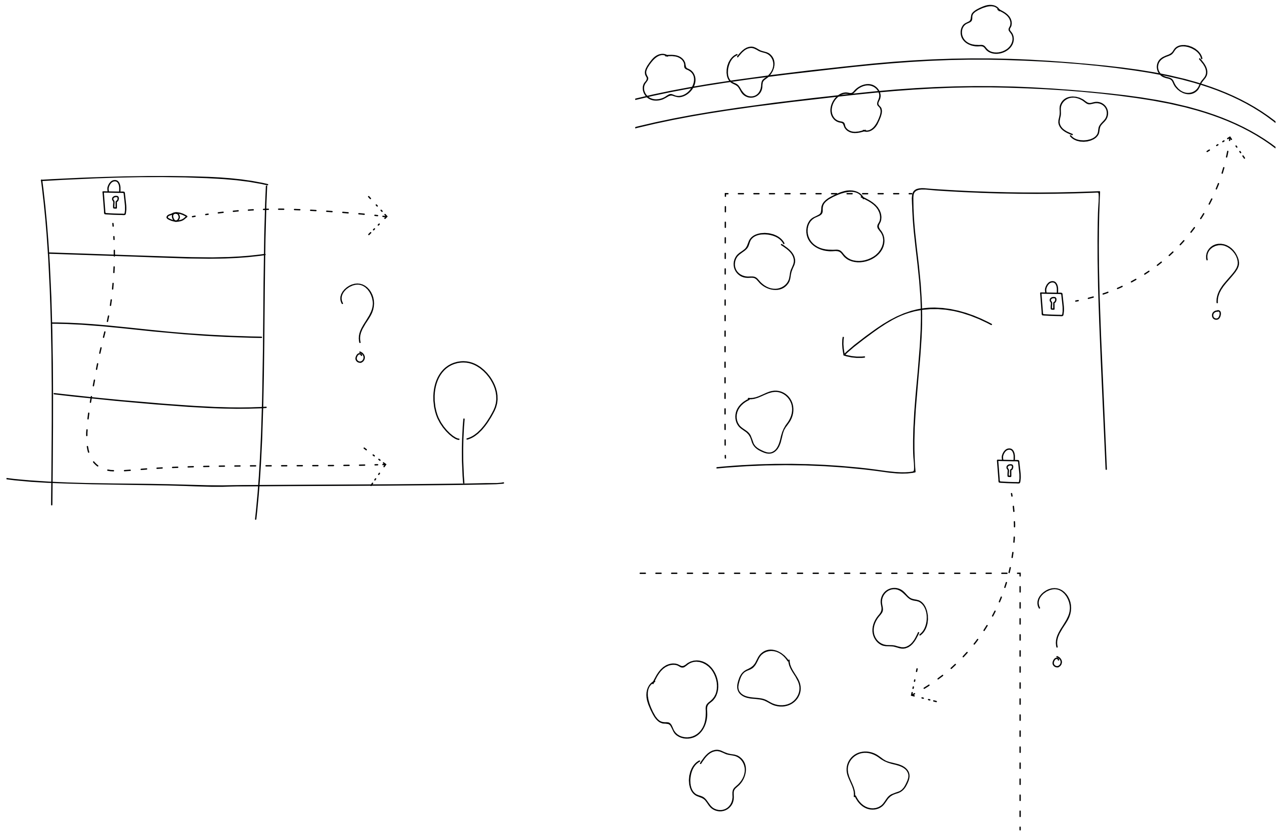


Figure 40 | Outdoor acces fieldwork place 2 (left) and 3 (right)

Outdoor access

Outdoor access is reported by caregivers and relatives to be important, since people have a big urge to go outside. However it is not always possible. In fieldwork place 2, the wards are on the floors and locked, meaning residents could only go outside with a relative. In fieldwork place 3, the ward has a private attached garden. A caregiver said this was not the case in her previous job and that they missed it there. However, the bigger shared garden in the middle of the complex could not be entered independently by most residents. Also the new walking path around the building was not accessible for them. In contrast, fieldwork place 1 was situated on a big site. The entrance gate was only locked during the evening and night. Residents could move around freely and visit the animals and the activity building too.

It is thus important to give residents independent outdoor access

Figure 41 | Corridor with apartments fieldwork place 3

The corridor

In fieldwork place 3, all the rooms are connected to a straight corridor. A caregiver told they got a budget for the ward and they decided to pimp the hallway with mural stickers, to make it look more like a street and with facades. The walls in the notches now have a brick look. The doors have all different wooden door covers, like you have in a normal street. In front of the doors is a printed foot mat and next to the doors are house numbers.

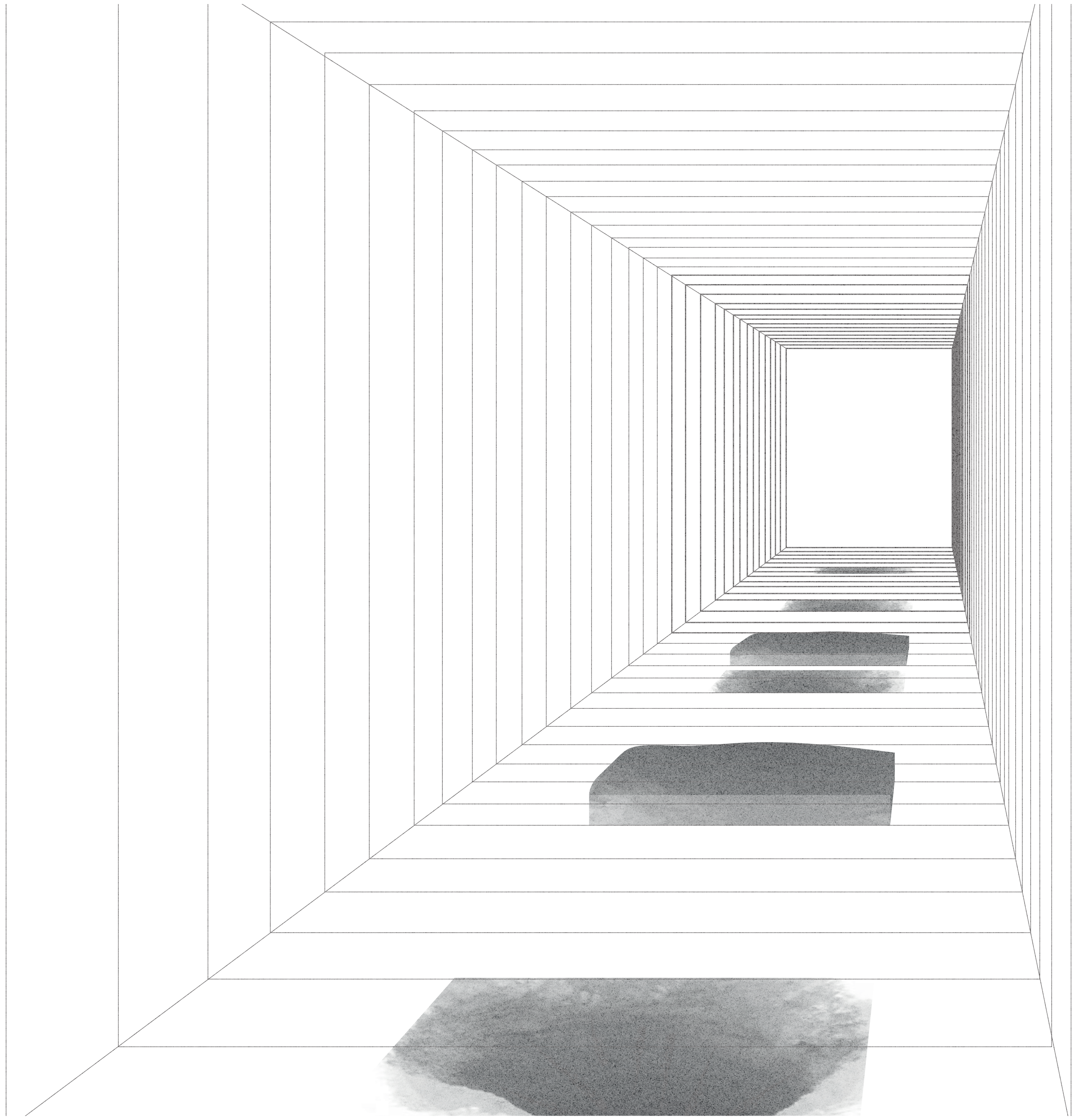


Figure 42 | The floor in the eyes of someone with demenita fieldwork place 3

The floors

The corridor in fieldwork place 3 have coloured surfaces on the floor. “On our side they are lighter, which makes some residents think they have to step on something. On the other side of this ward the colours are the other way around, and they see it as a whole they fall into” (caregiver, fieldwork place 3).

At fieldwork place 2, there was a flooring in the hallway with a blocked pattern in shades of green and yellow, which does not feel homely according to the caregiver.

Similar patterns on the floor should thus be prevented.

Figure 43 | Coloured doors in the couryard fieldwork place 1

Independent house

In contrast to fieldwork place 2 and 3, fieldwork place 1 does not have corridors connecting the bedrooms of the residents to the communal house. It is designed like a courtyard, where there are 5 houses with a front door, with three resident rooms inside. They thus have to go outside when going from their bedroom to the communal house and vice versa. To make it easier to find their room, they have different colours and the space under the overhanging roof can be personalised.

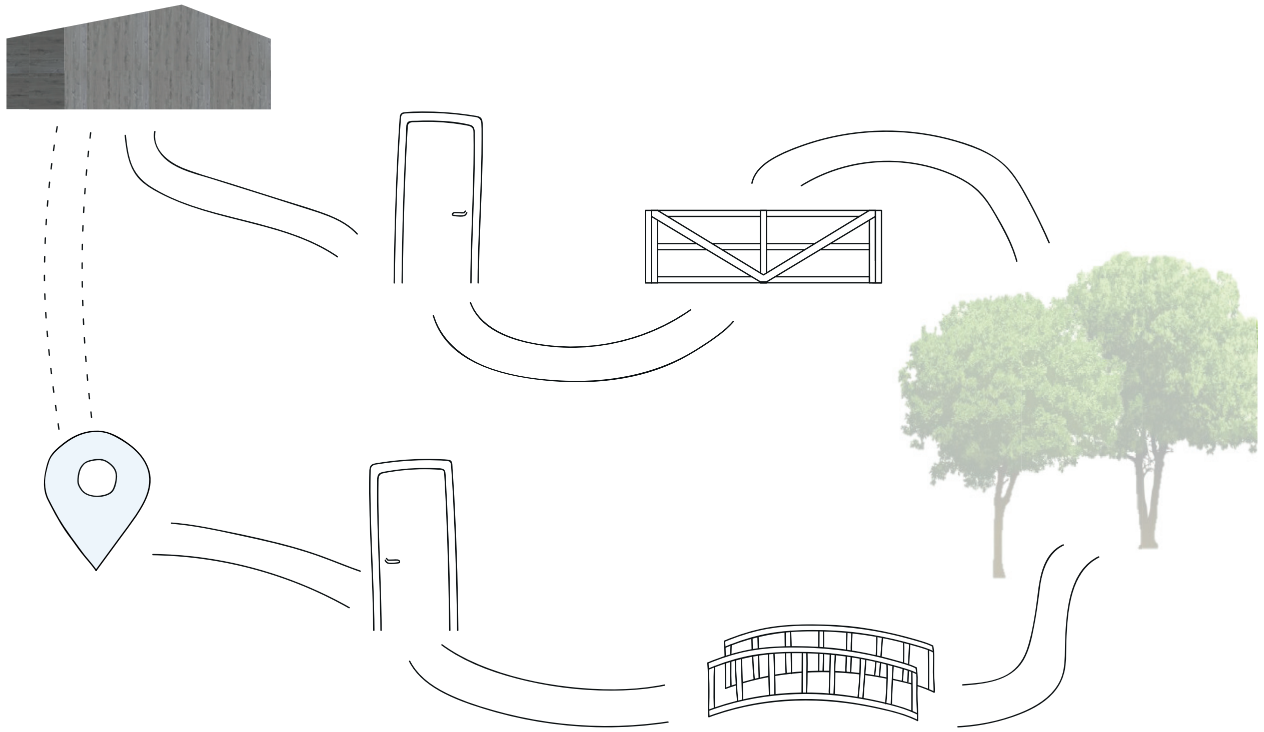


Figure 44 | Tresholds on route to activity room in the eyes of someone with demenita fieldwork place 1

Walking distance activity space

One of the residents did not dare anymore to go to the activity room at the other side of the site, although it is in plain sight and only a one minute walk. Everything behind the fence of the courtyard was too far (fieldwork place 1)

The activity room is in another part of the building. They have to go outside their own ward, to another floor with the lift, go through the door where you come into a big atrium and then follow the gallery almost to the end. Some of the residents do not want to go there, since they think it is too far and do not want to come with me (activity coach, fieldwork place 2).

An activity room or building should thus be reachable without having to cross thresholds.

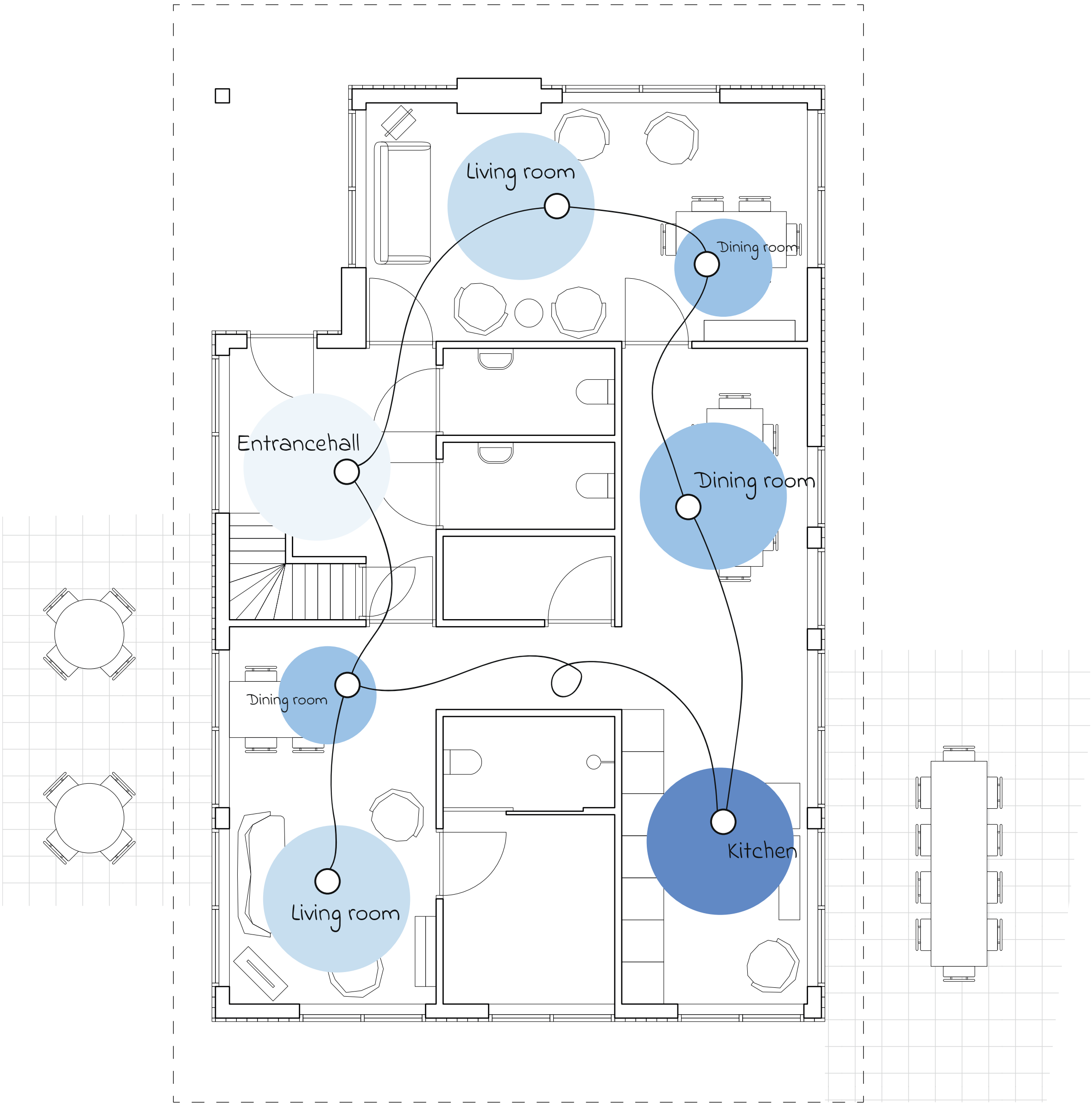


Figure 45 | Floorplan communal house fieldwork place 1

A normal home

The communal house of fieldwork place 1 is designed like a general house. You enter the hallway with stairs, a wardrobe and toilets. There are two doors giving access to two living rooms, a bigger and a smaller one. These two are connected by an open kitchen with dining room. The household is run together with the residents, the hostess cooks every evening in the communal house and the residents have the opportunity to help and many of them are willing to. The dining tables are set at all mealtimes and the residents eat together. With breakfast, the spreads are put on the tables and the residents can make their own bread and choose what they want to eat.

The big living room has a sloped roof with a heart to give it a homelike character. Although a relative questioned how cosy it is when it has a total height of three floors (case 1).

Figure 46 | Hearth fieldwork place 1

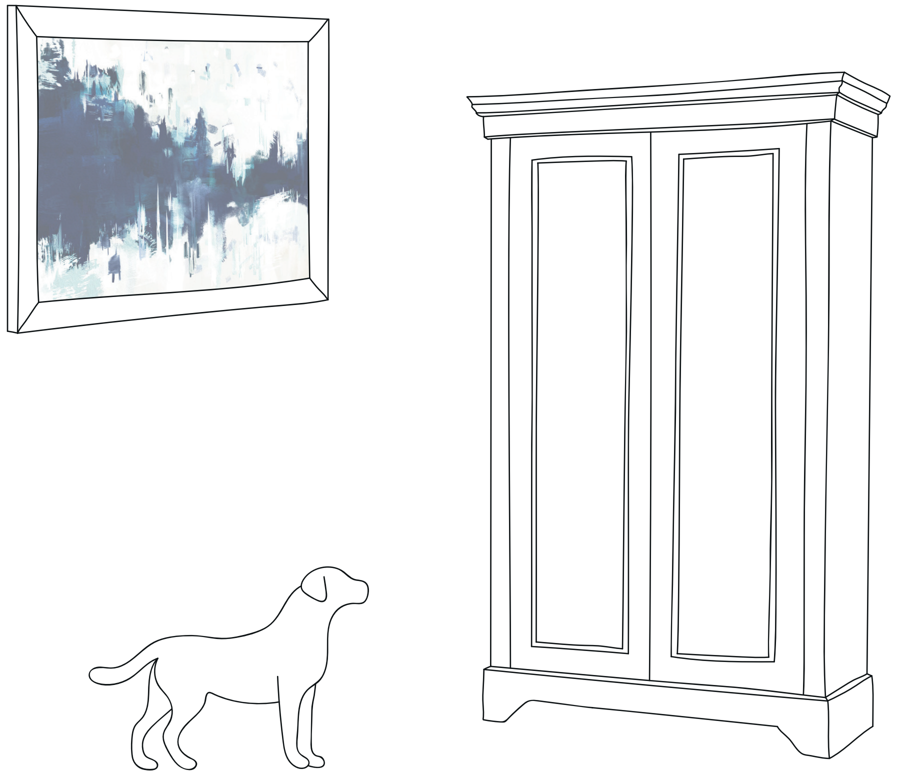


Figure 47 | Personal objects communal house fieldwork place 1

Personalisation

All the furniture in the communal house of fieldwork place 1 is similar to what the residents have at home. They also have the opportunity to bring their own furniture or decoration. We have for example this cupboard from one of the residents, someone brought a painting and another resident already had a little dog at home which she could bring here, we have a bench in our communal kitchen (caregiver, fieldwork place 1).

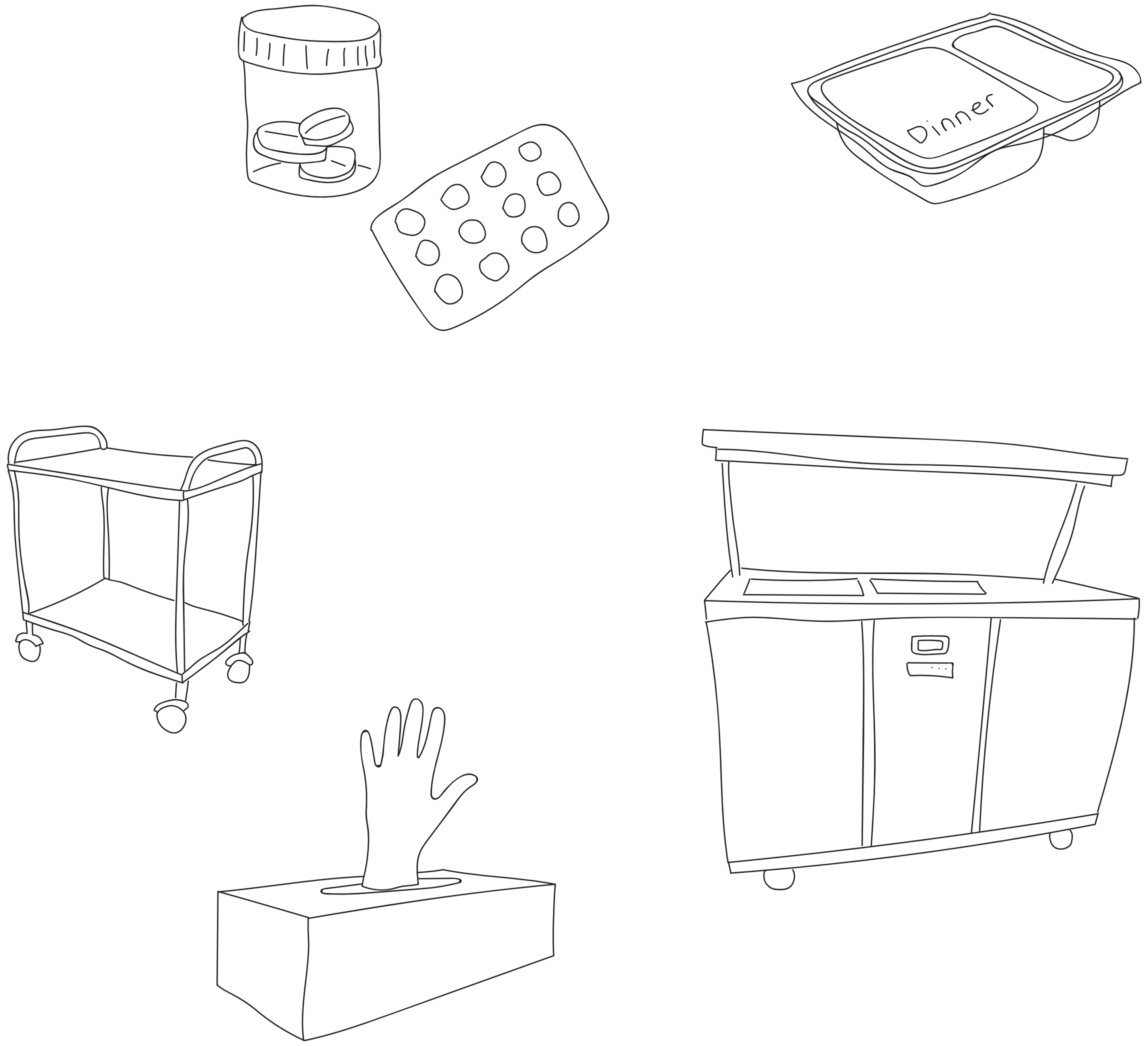


Figure 48 | Food and care utensils in care environments combined from fieldwork places 2 and 3

Traces of care

In contrast with fieldwork place 1, where dinner is made in the communal house by the hostess, it is served in fieldwork place 2 and 3. There are buffet trolleys (fieldwork place 2) or freshly made personal meals are sealed and brought in the morning and warmed up in the oven for dinner (fieldwork place 3).

Also other care traces as clinical products and even medicines are in sight. In fieldwork place 3, there is a medicine cupboard, which is covered, in front of the entrance of the communal living space. In fieldwork place 1, there was a separate built in storage where medicines are kept.

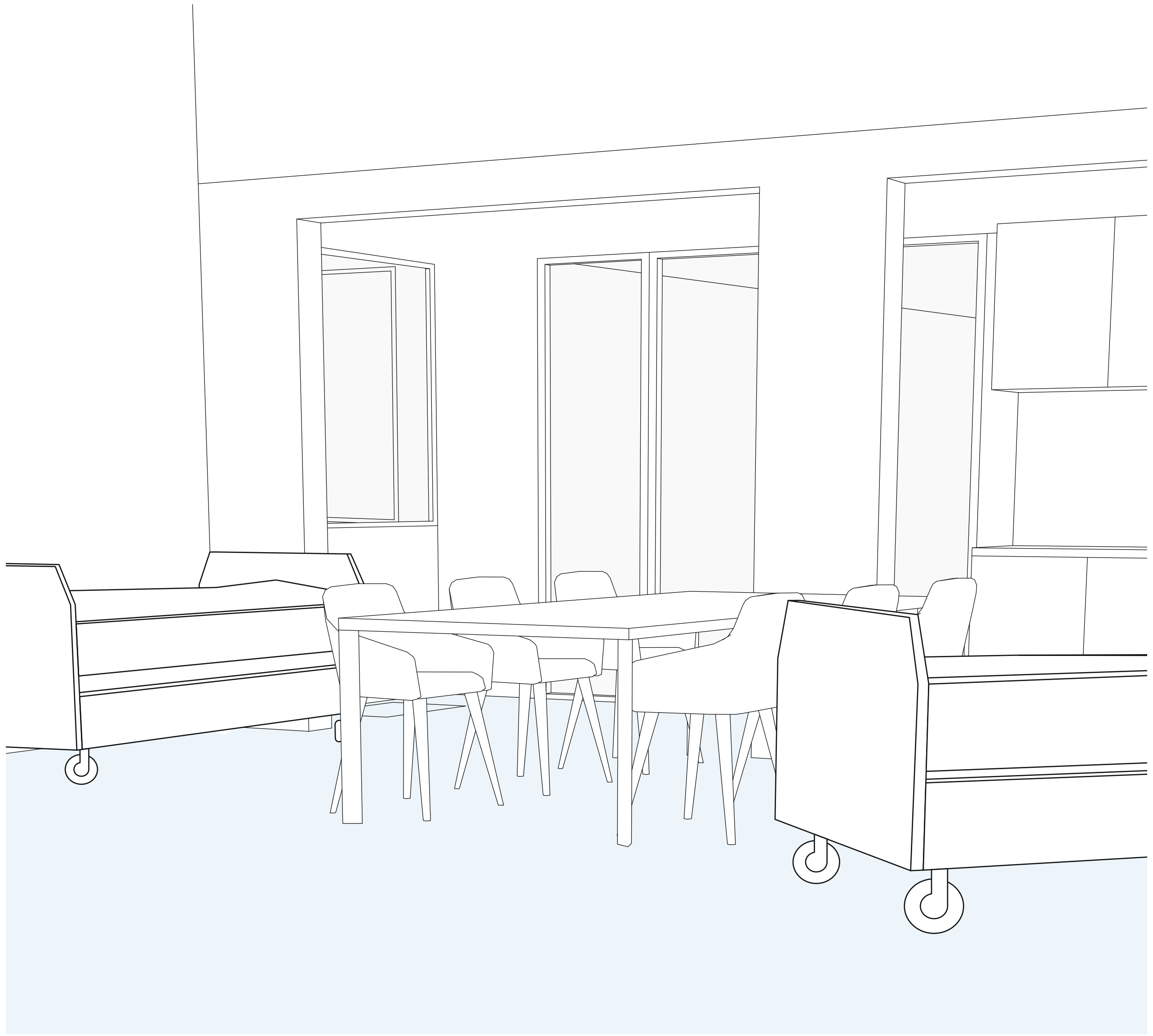


Figure 49 | Beds in the living room fieldwork place 3 (same situation in fieldwork place 2)

Beds in the living room

In a short amount of time residents can set a step back, which makes the image of the group differ a lot compared to half a year ago, when many people were still walking and active (caregiver, fieldwork place 3). Some residents are in a late stage and cannot get out of bed anymore. Caregivers want them to remain part of the group and be surrounded by other residents. Therefore they ride them in their beds to the living room. When doing the fieldwork, there were two beds in the living room. Other residents were also sitting in a wheelchair at the dining table or in a special beanbag in the living room.

There should thus be room in the living room for wheelchairs and beds and an internal connection to transport them.

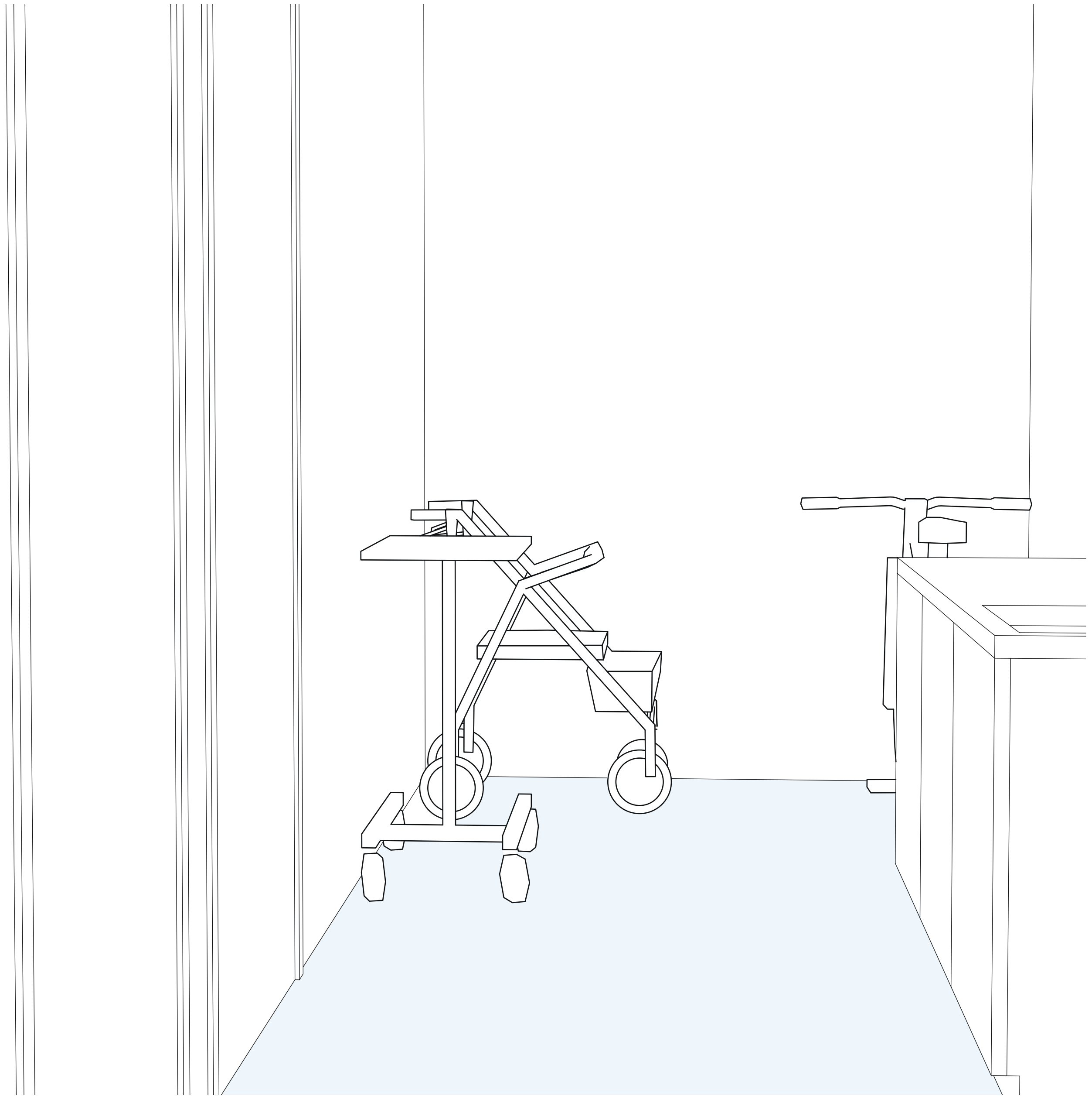


Figure 50 | Storage in entryhal of the cluster fieldwork place 1

Storage

In fieldwork place 1, the bike and table tennis table of the resident could be stored in the nook of the entry hall of the cluster (case 1). Sometimes, also old wheelchairs and walkers were stored there. When a hoist was needed, it also stood there and his room was taken up by other care utensils too.

There should thus be storage space for personal belongings as well as for care utensils.

The courtyard

Figure 51 | Courtyard in fieldwork place 1 (Beweging 3.0, 2022)

Figure 52 | Site plan 1:1000

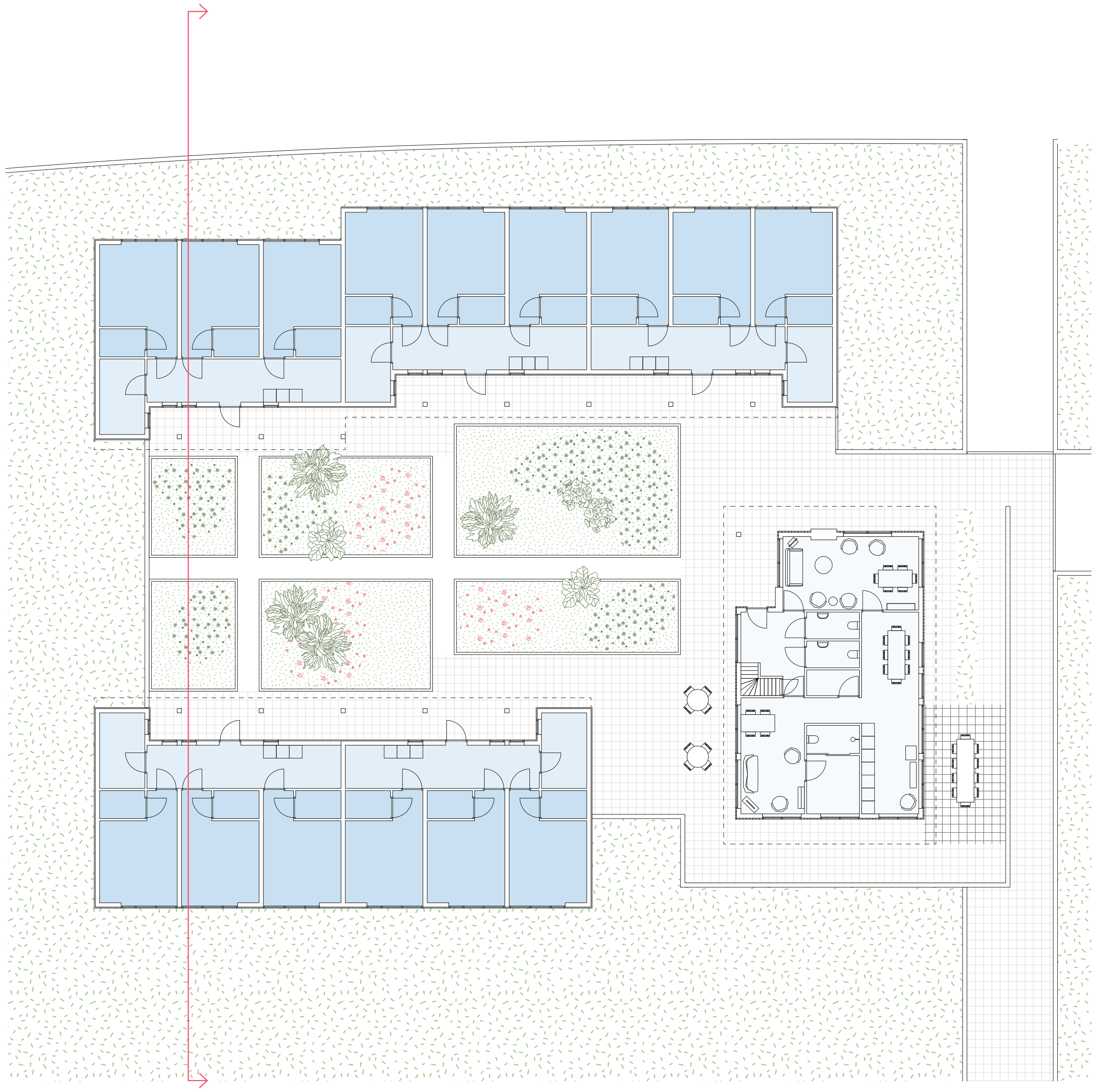


Figure 54 | Courtyard plan 1:300

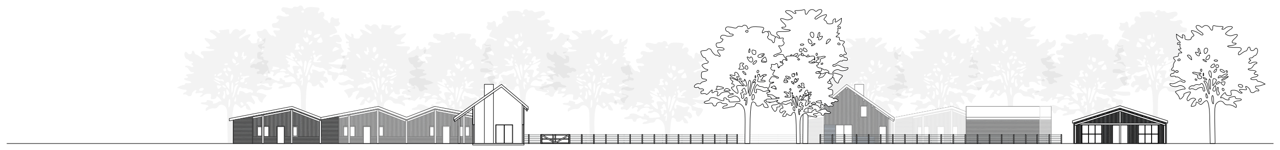


Figure 53 | Site section 1:1000

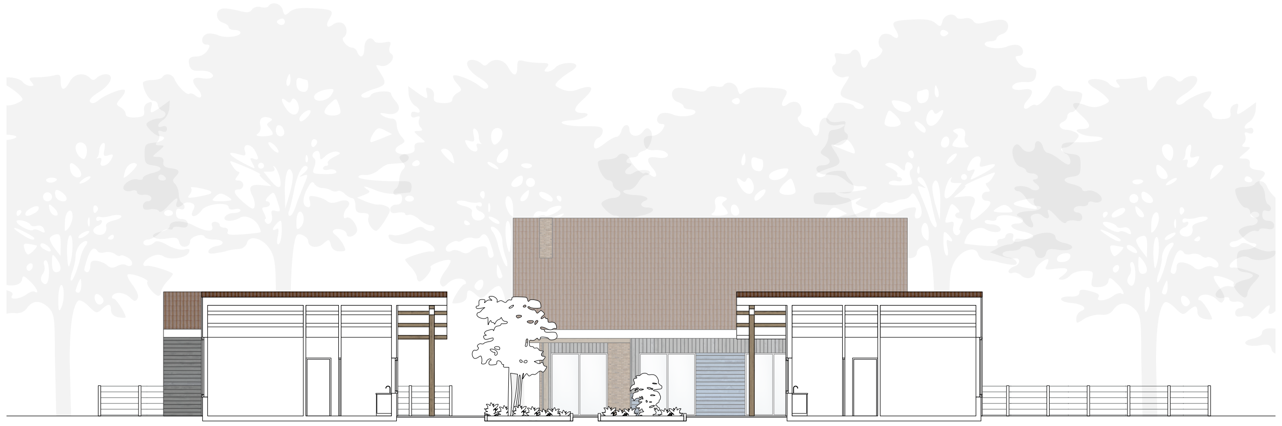


Figure 55 | Courtyard section 1:300

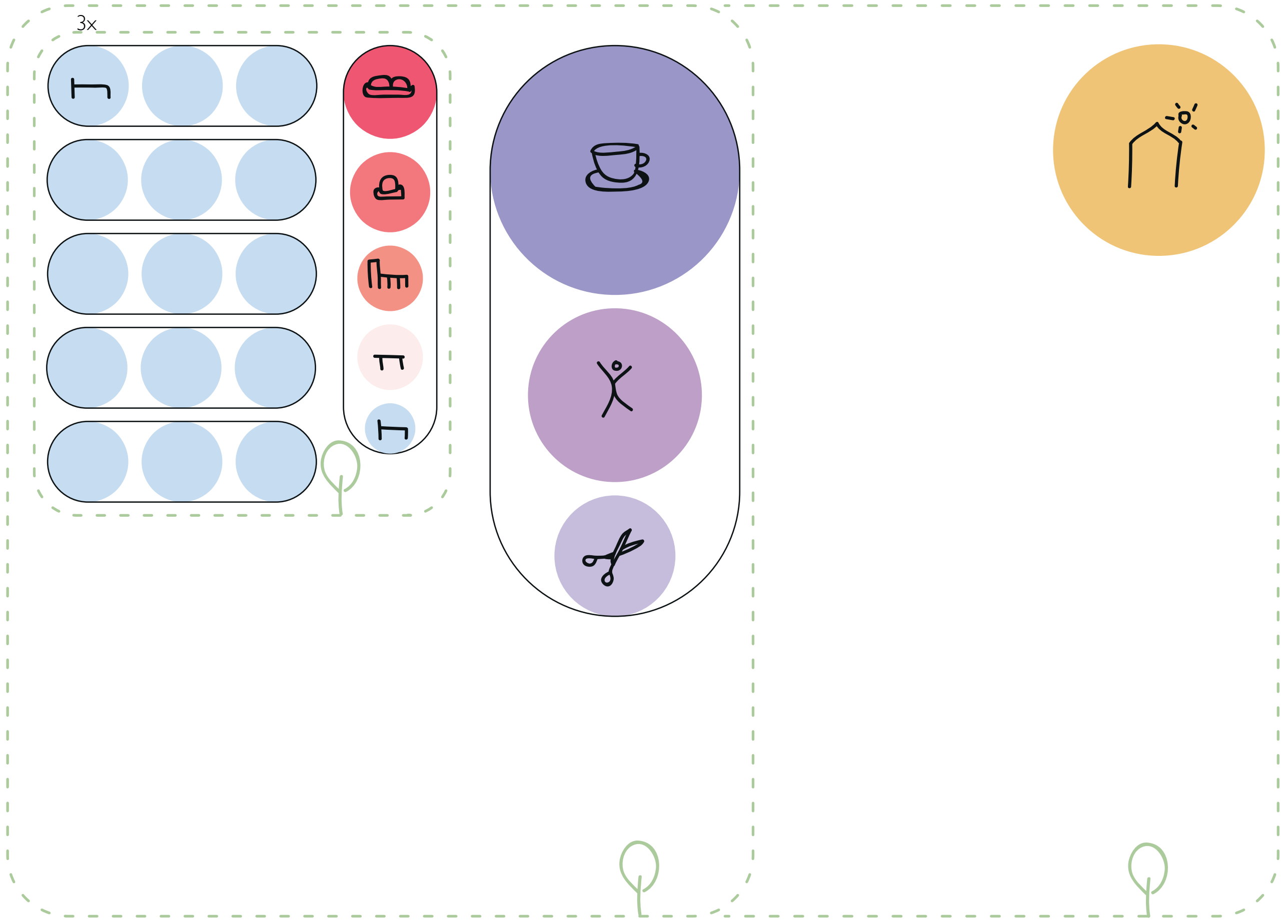


Figure 56 | Program of the courtyard

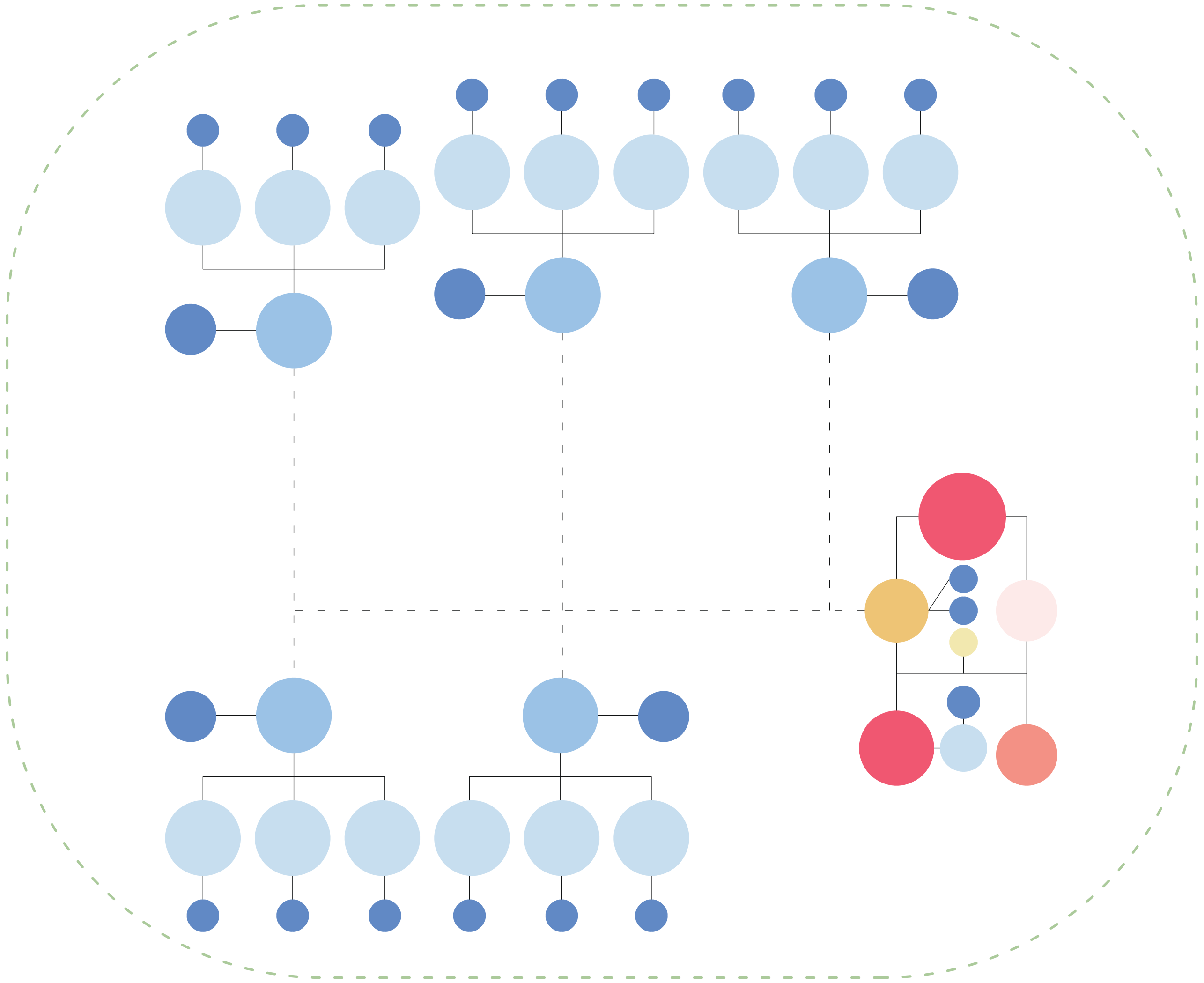


Figure 57 | Spatial organisation of the courtyard

Program

This care home is located on a big site in the countryside near a forest. There are three courtyards for 15 residents scattered over the site. Each courtyard has five clusters with private bedrooms for the residents and a communal house with a living room, smaller living room, dining room, kitchen and a guest bedroom. In the middle of the courtyard is a shared garden, surrounded by a fence with sheep walking behind.

Residents are free to enter the rest of the site outside the courtyards. There is an activity building, with a hairdresser, a public cafe, where residents sometimes go for lunch together, and a multi-functional space, and there are small animal shelters with pastures in front, with some rabbits, chickens, pigs, horses and cows. At the northeast of the site, there is a daycare attached.

Spatial organisation

Three residents share a cluster together, which has one front door. Inside, there is a shared hallway with a little kitchen block, with a water cooker and coffee machine, and a big bathroom. From the entry hall there are three doors leading to the private bedrooms, which all have a private toilet.

To go to the communal house, residents have to go outside through the garden.

The ward

Figure 58 | Bird eye overview fieldwork place 3 (Beweging 3.0, 2023)

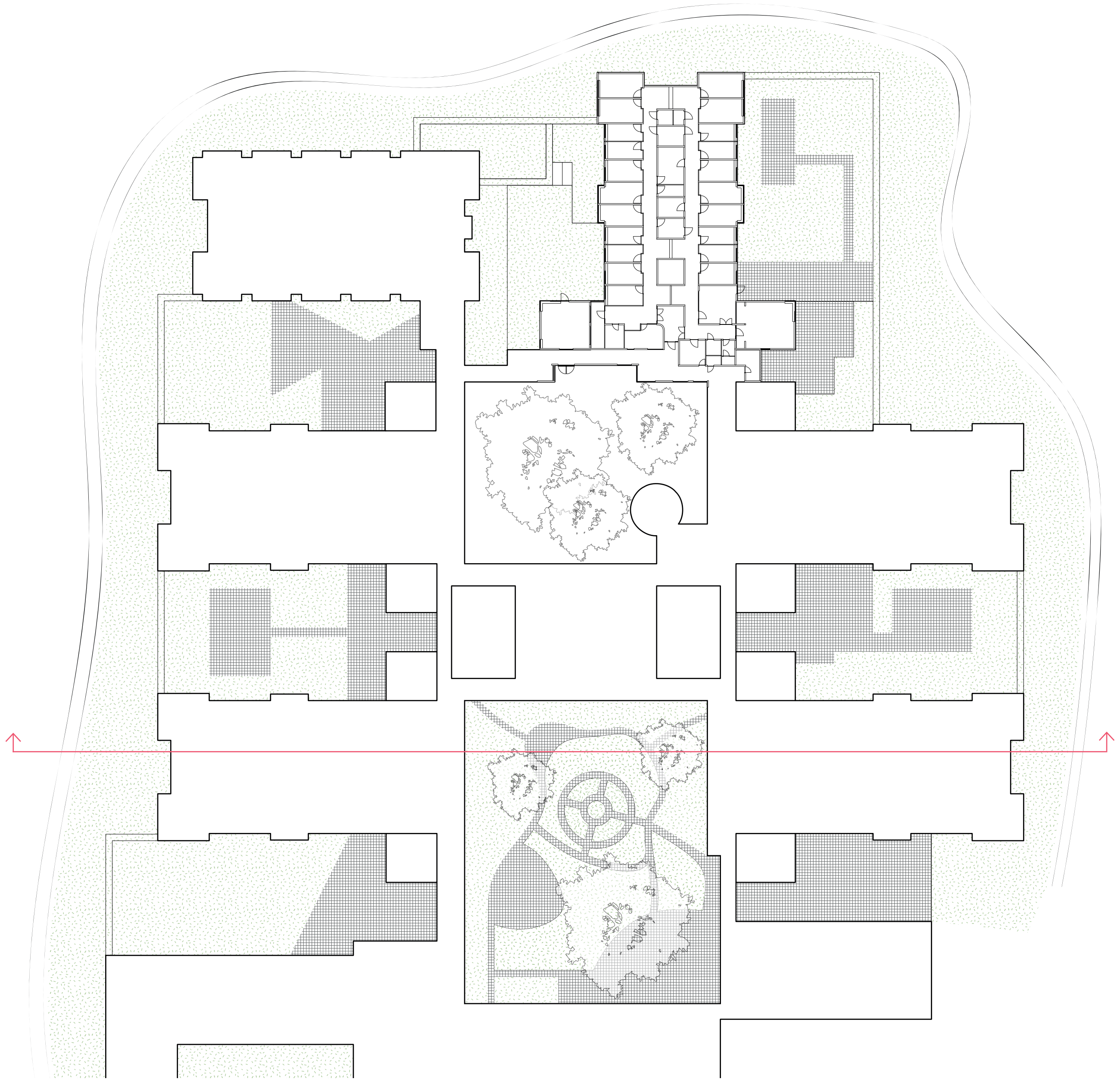


Figure 59 | Site plan 1:1000

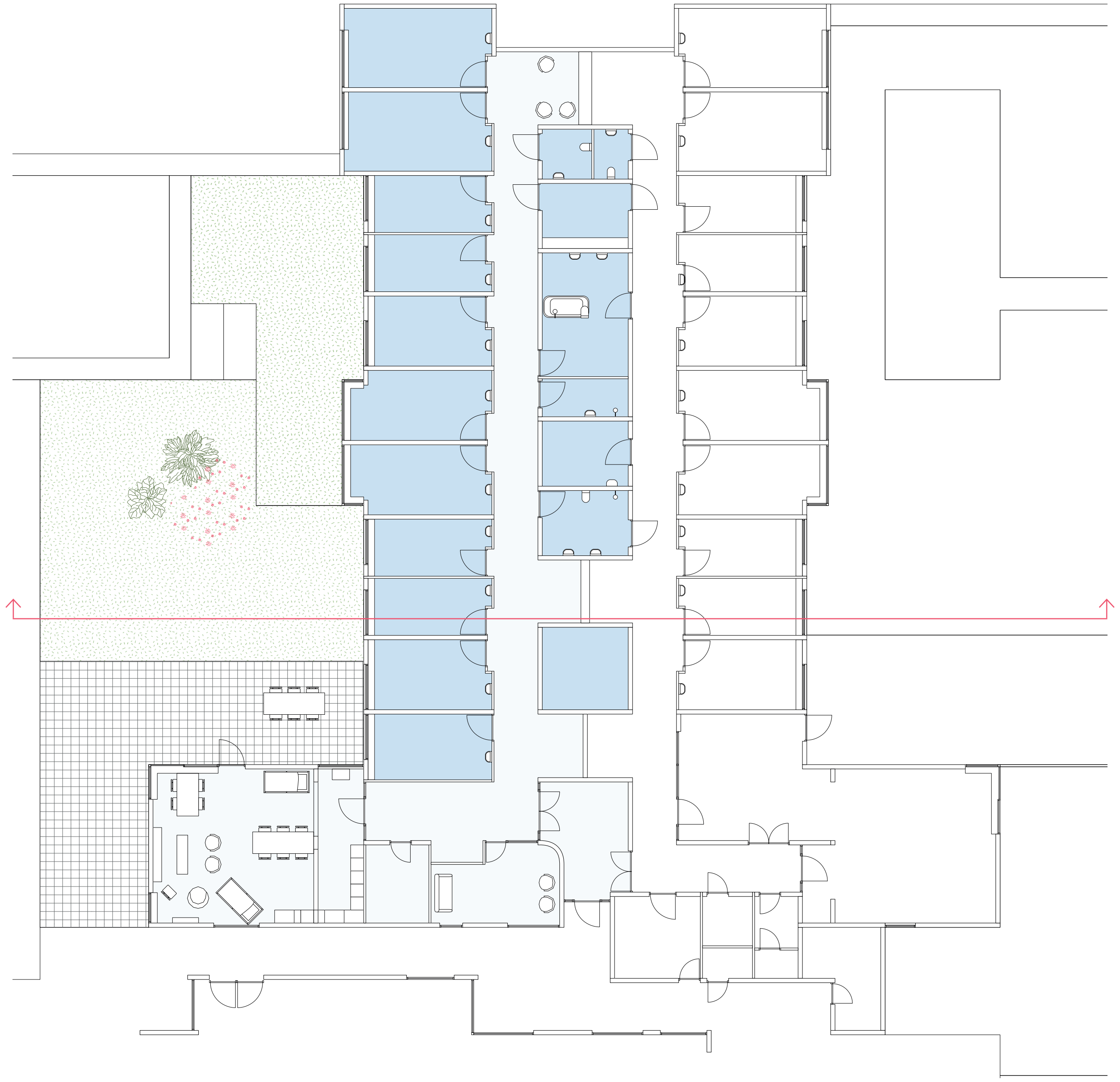


Figure 61 | Ward section 1:300

Figure 60 | Site section 1:1000

Figure 62 | Ward section 1:300

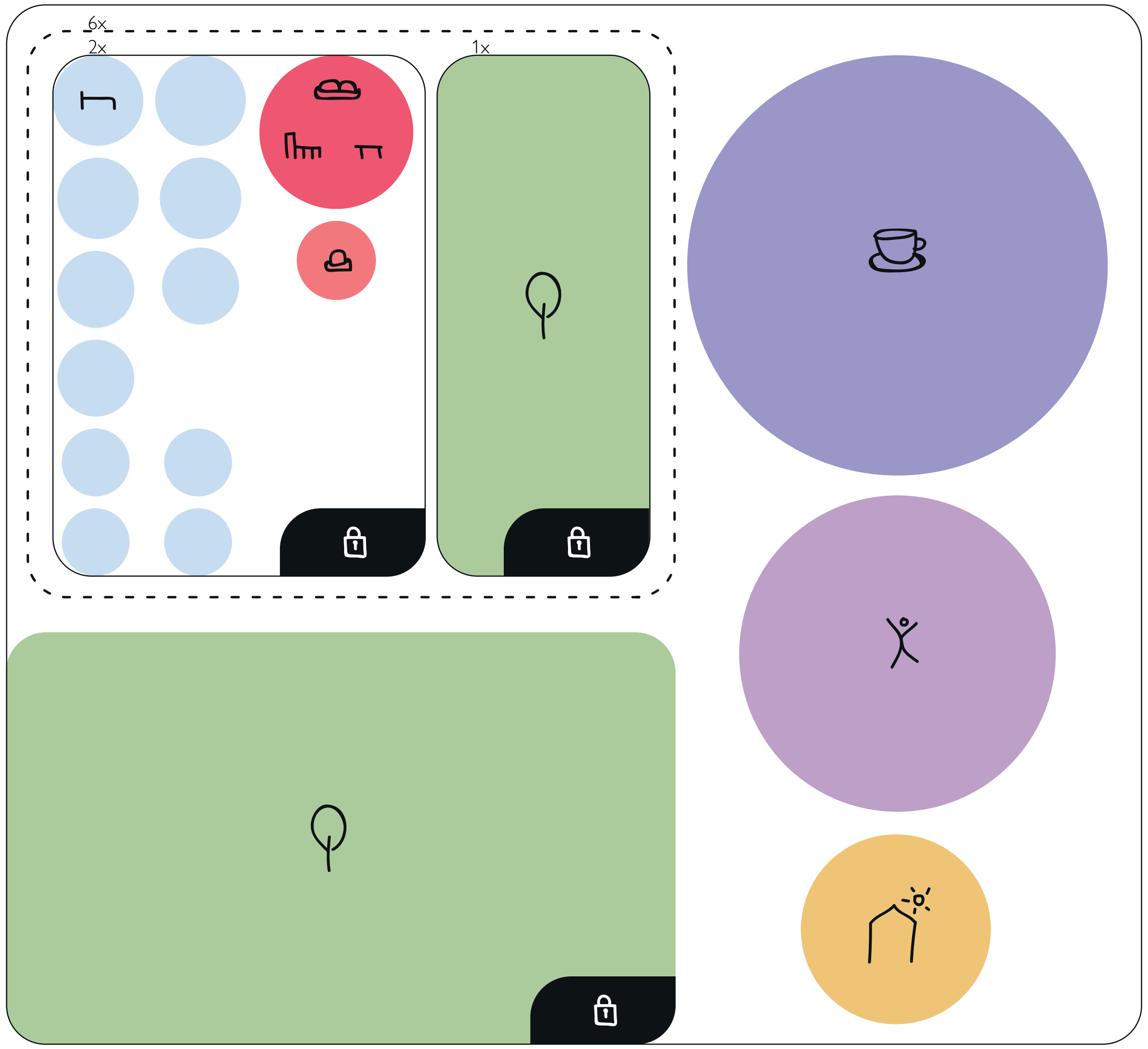


Figure 63 | Program of the ward

Program

This care home is located on the border of a village. It is one complex consisting of 12 wards, each for 11 residents. Within the ward is a communal area, with a living room, dining room, kitchen and a guest bedroom. Separate from this communal area is a small quiet living room. Attached to the ward is an enclosed garden, which is shared with another ward. The residents can move freely through their ward, but the entrance door is locked.

Outside of the wards, in the middle of the complex is a big shared enclosed garden for all residents, where there is a walk path, some seating areas and some chickens. When entering the complex, there is a brasserie where residents, family and staff can meet. Attached is an activity space, where different activities, for example performances as a circus take place once in a while. In one of the wings of the complex is a separate daycare.

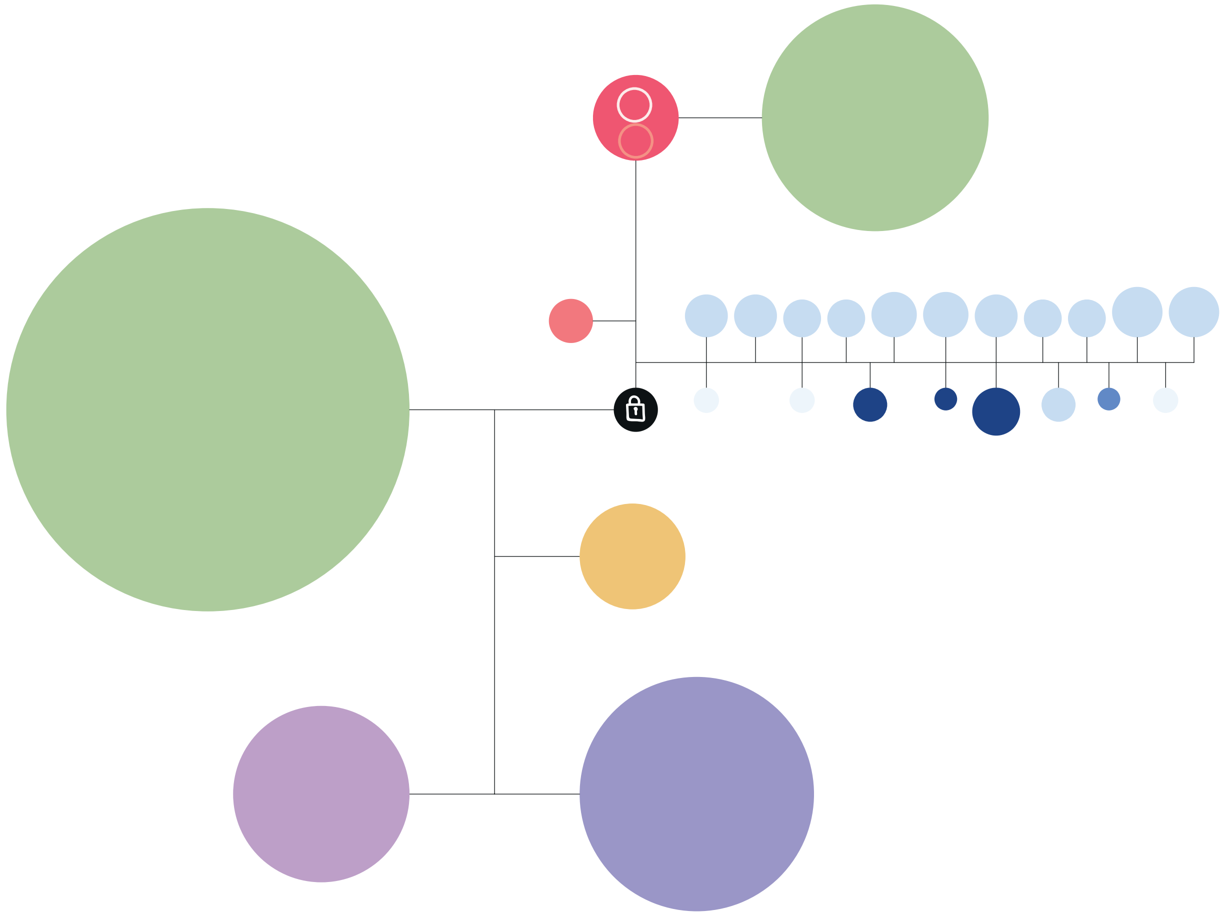
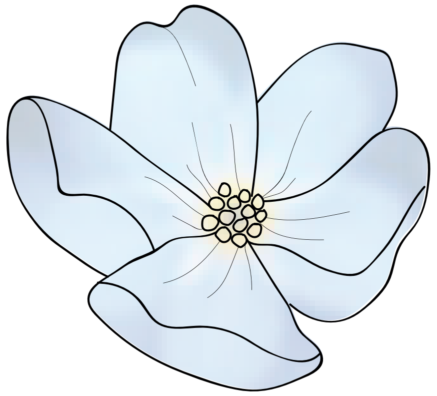


Figure 64 | Spatial organisation of the ward

Spatial organisation

The private bedrooms of the residents are situated along one side of a long corridor with a dead end. At the other side are some toilets, bathrooms, as they do not have private ones, and storage spaces, which are shared with the ward on the other side. At the end of the corridor is the entrance to the communal area and the quiet living room. Outside of the ward is another corridor around the shared enclosed garden, leading to the entrance with the brasserie, meeting space and daycare.



CHAPTER

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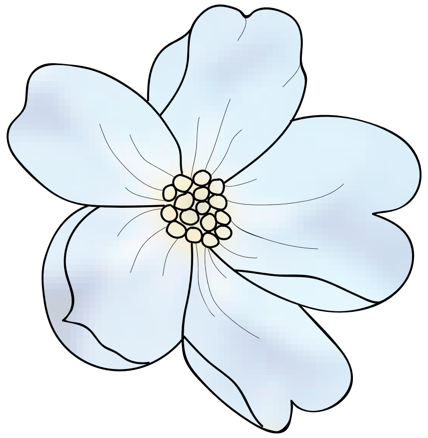
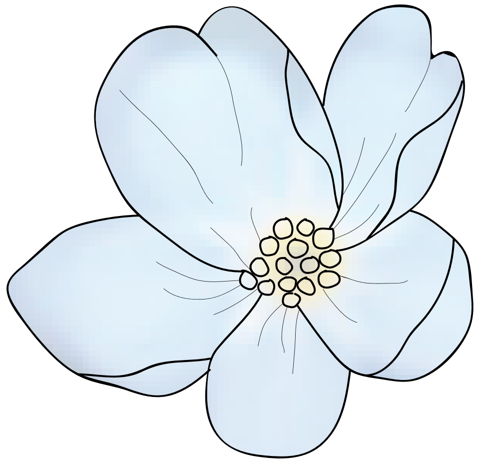




The conclusion

Dementia causes impaired cognitive functions, which has implications for how someone understands an environment. There are already architectural principles for designing a dementia friendly environment.

An impaired short-term, and eventually long-term memory makes it difficult to learn a new environment. In addition, an impaired visual spatial ability and sense of time makes it difficult to recognise places and to orientate themselves. An environment should therefore be easy to understand and rely on fixed patterns. Important architectural principles are creating familiarity by using archetypes and a homelike setting, readability by defining space, supporting wayfinding by providing clear routes and cues, creating a small scale, by using a compact design and providing structure by allowing daylight and outdoor access.

An impaired coordination and ability to execute daily tasks can make someone apractical. In addition, the brain has an impaired ability to filter stimuli or to stimulate itself, which causes over- and understimulation. An environment should therefore stimulate people, help them to remember and keep them secure from harm. Important architectural principles are creating familiarity, by creating a homelike setting, providing a small scale by less residents, balance stimuli, by minimising unhelpful stimuli and optimising helpful stimuli, create privacy by single bedrooms and provide safety by reducing risks.

People with Young Onset Dementia have specific spatial needs for a care environment, based on their different life stage compared to older people with dementia.

They used to be an active part in society, but lost many of their roles due to dementia, resulting in not having a purpose anymore. Almost all of them stress to want normality in their life and to focus on what they can do. In the period before moving to a care home, many of them are participating in society by volunteering.

Young people are also still fit and active, but at a certain moment they cannot keep up with their sport anymore as it becomes too complex or they become scared. Although it remains important for them to keep moving, as it maintains their body control, clears their mind and is an outlet.

By losing their daily life as a job or sport and are more at home, they lose social interactions. Many young people with dementia like to be with peers, as they feel safe and understood by them. It gives back their self-confidence and forms a ground for friendships.

From a residents perspective, a care home should therefore bring young people with dementia together and facilitate a normal way of living, where they remain a part of society and are able to move and exercise.

Relatives of people with Young Onset Dementia have specific spatial needs for a care environment too.

Dividuality is strongly present in those families. They identify as ‘we’ instead of ‘I’ and taking care is part of their identity. Being separated is therefore painful for them.

At the same time, they have a high caregiver burden as they have other responsibilities coming with their life stage too. They stress the importance of having some rest from constant caregiving. However, having less time together when the relative lives in a care home, the moments together have more quality, since they do not have to care.

Relatives also stress the importance of having contact with peers in the same situation. It is helpful for both partners and children to deal with their situation as they face difficulties with explaining it and getting recognition from their surroundings.

From a relatives perspective, a care home should therefore focus on the family too, by creating opportunities for relatives of people with Young Onset Dementia to interact, being together as a family in a normal daily way and providing them to have a break and enjoy the time together.

In the current care homes, these spatial needs are not met. Young people with dementia often live with older residents. Since they have different needs and interests and are sometimes disconnected from reality, young people have difficulties with integrating in such a care group. Older people do not need a busy day scheme, while younger people are searching for something to do. Also partners stress the importance of a meaningful day. Older people also do not need much physical activity, chair yoga or a small walk is enough, while younger people need more challenging physical activities, such as cycling, walking and doing ball sports or fitness.

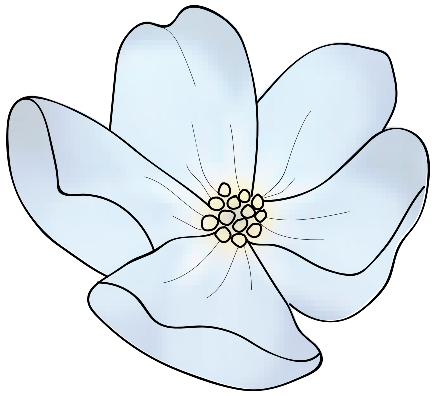
For being together with family are little opportunities. There is only a bedroom as private space annex living space and no real daily living spaces as a dining or living room. There are also little opportunities to undertake activities together. There is therefore a big shift from living together to living separate, the dividual elements can thus not be expressed. When it comes to the institutional architecture of a care environment, relatives report they would like to see that differently. They prefer an open facility where their relative can move freely and can go outside independently. The long corridors are seen as unpleasant and they rather see a more homely and normal atmosphere instead of bare rooms.

In addition, there are some important care needs and unmet care needs in care homes reported by caregivers. Within the big group, there should be an overview and smaller settings for dinner and a quiet living room. Also space is needed for beds and wheelchairs in the common areas, for personal care in the rooms and for storage of (care) utensils. Activity spaces should be close to their living area and workspaces for staff and for family meetings are needed.

The main question of this thesis was: how can a care home for people with Young Onset Dementia be designed in such a way that it facilitates them, and their relatives, in maintaining their quality of life? To conclude, there are two main themes for designing a care home for people with Young Onset Dementia: **dignity** and **active.**

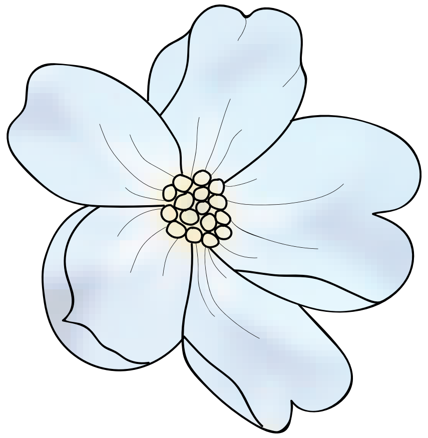
Both the person with Young Onset Dementia and their relatives want to live a more dignified life. The focus should thus not only be on the residents, but also on their relatives. A care home should therefore allow them to keep an as normal way of living, by creating opportunities and spaces to spend valuable time together as a family, locating it in a neighbourhood and by designing it as such that it is like a normal home where they are not locked up. When it comes to the social aspect of a care home, it should bring young people with dementia and their relatives together and provide opportunities to interact.

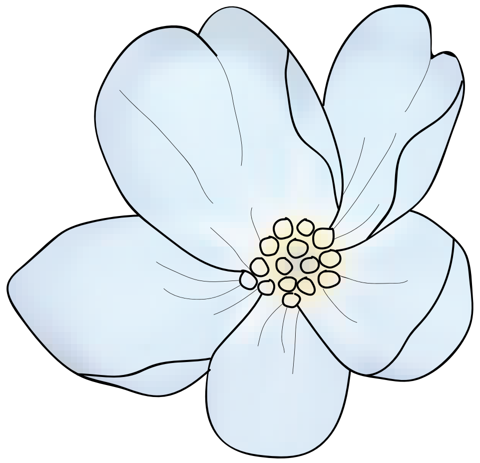
For the person with Young Onset Dementia, it is important to continue to live an active life. A care home should therefore allow them to remain part of society and provide possibilities to do something, by facilitating meaningful day activities and challenging physical activities.



CHAPTER

07

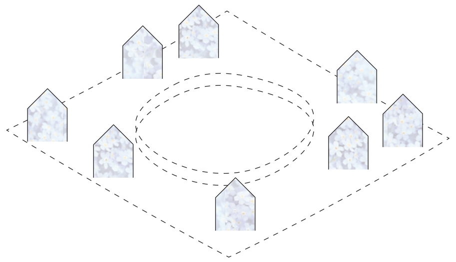




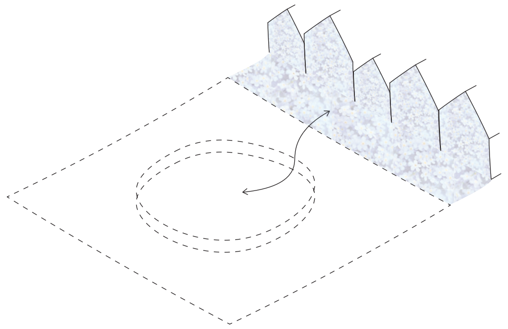
The guidelines

Dignity

Neighbourhood

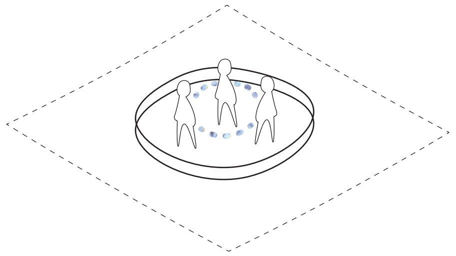


Connect with the neighbourhood

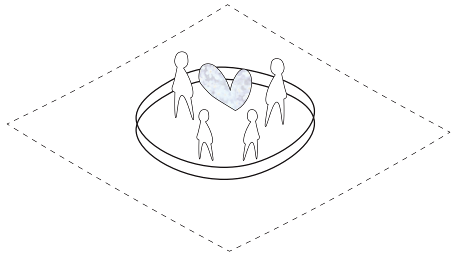


Connect to a centre

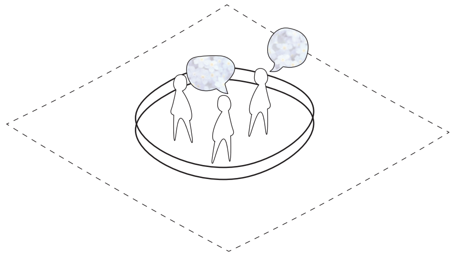
Care home



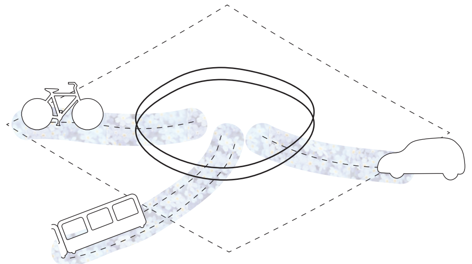
Place for young people



Place for family

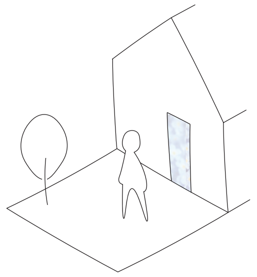


Place for meeting each other

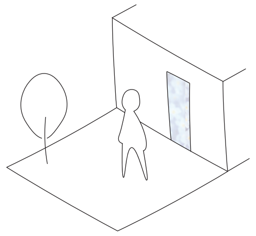


Place close by family

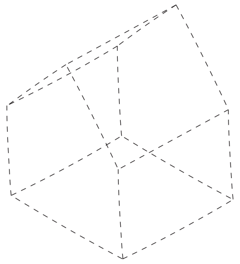
Care home



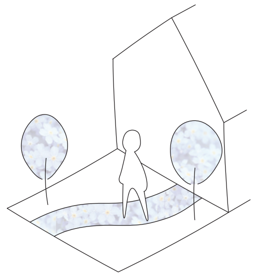
Own frontdoor to communal house



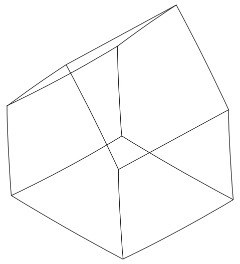
Own external frontdoor to room



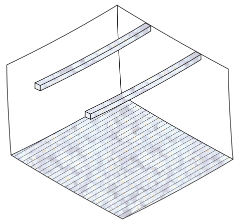
Open facility



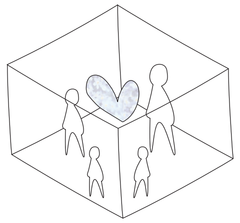
Direct outdoor acces



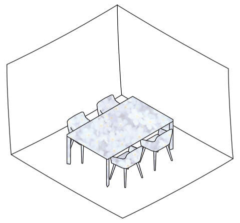
Normal idea of a dwelling



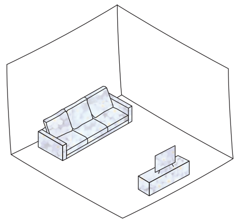
Homelike basic room



Family space in own room



Enable eating together in room



Enable sitting together in room

Figure 65 | Guidelines dignity

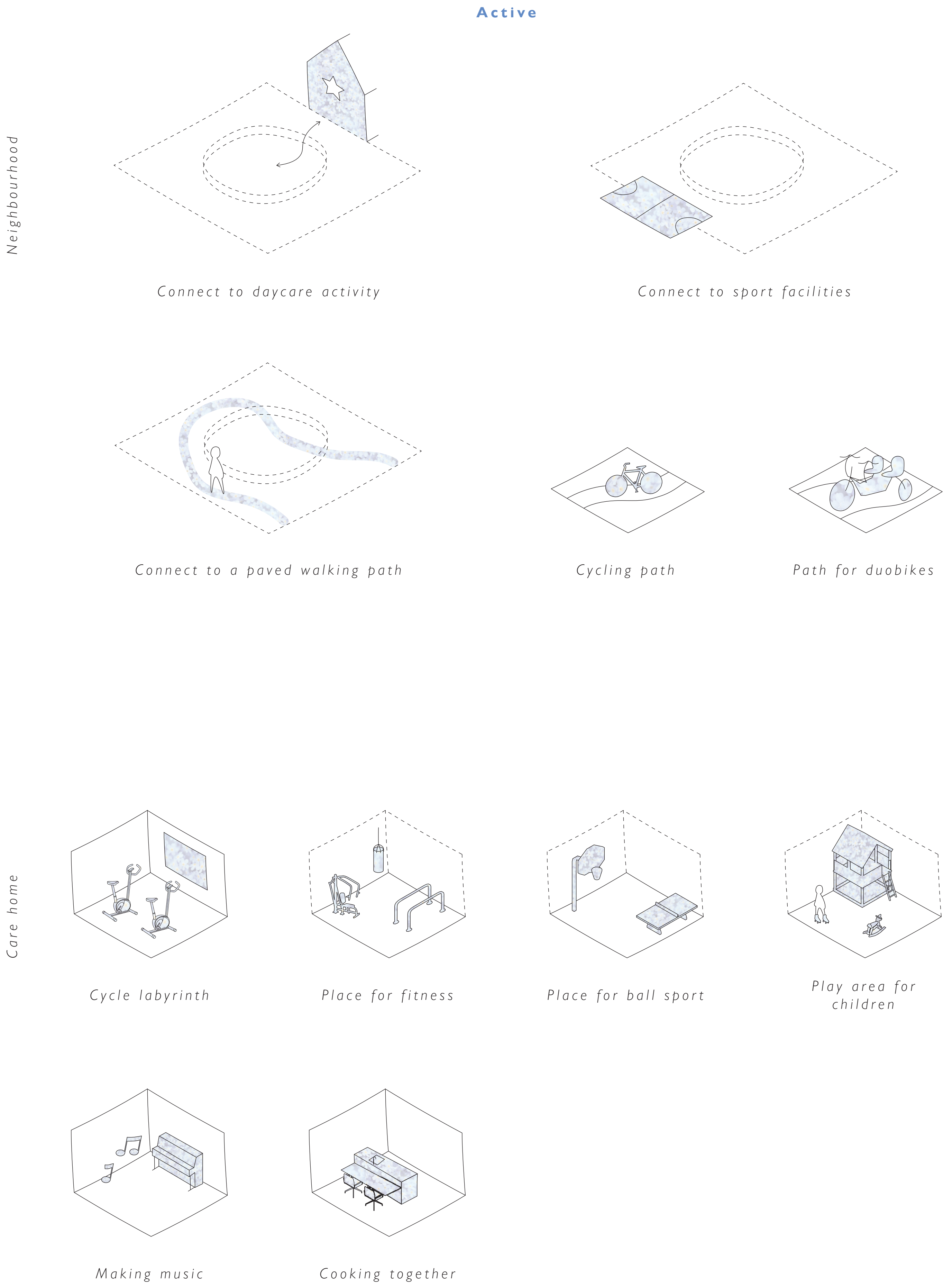


Figure 66 | Guidelines active

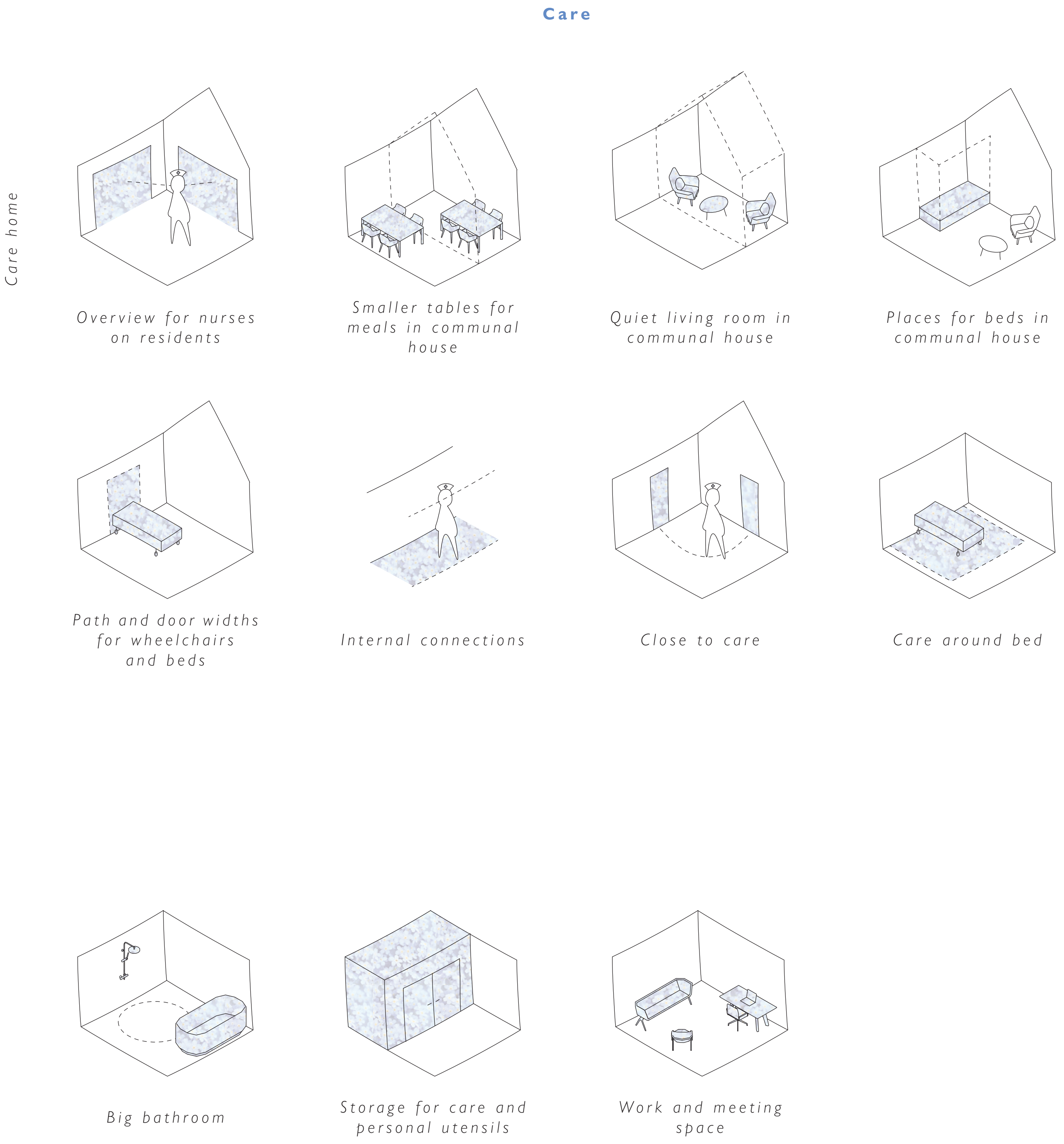


Figure 67 | Guidelines care

My graduation project is a design for a long-term care home for people with Young Onset Dementia, and their relatives, with the goal to provide an environment that is working in their health favour, to maintain their quality of life. This is directly connected to the two main topics of the MSc3 graduation studio, designing for health and care in an inclusive living environment. Within the bigger picture of the master programme Architecture, my graduation project achieves this better quality of life by developing architectural guidelines for a built living environment, with the focus on spatial qualities of the care home.

My research led to these guidelines. Out of my literature review came already existing design principles for an environment for people with dementia in general, which was validated by my fieldwork in care homes for people with dementia. This set the basis for the spatial lay-out of my design. While designing, new questions arose as a result of implementing the guidelines in a new design, which led to new practical and programmatic analysis in the case studies, to be able to make the right design choices. Out of my ethnographic research came two main topics with guidelines specifically for designing an environment for young people with dementia: a dignified and an active life. These formed the fundamentals and influenced my design by transforming mainstream care environments in a non-institutional place, a family place and a meaningful place. By using this ethnographic research as main argumentation for design choices, my graduation project is human based, which I value as important as my target group is in a vulnerable position in life.

There is no architectural research done yet into how to design a living environment for people with Young Onset Dementia in the future and the current facilities are not designed specifically on an architectural level. My graduation project thus gives insight and awareness about the importance of a specific care home for people with Young Onset Dementia and their relatives and what they need based on their life phase and on how current care homes are built and function. This provides good basic guidelines for a care home specifically for them in order to provide them a better life through a suitable living environment for the later stages of their dementia. However, knowledge about how relatives see the future of giving care and how it could be integrated differently in their lives, out of the grid of the current care situation and way of living in the Dutch context is now mainly a developed vision, based on their current situation and life.

Since the provided guidelines focus on both the care home and the neighbourhood, they are applicable on other locations too. The main element of the new designed care home is the cluster of two combined residents rooms with a specific lay-out of the family and care side, both with another entrance and degree of privacy. This patient room is therefore a general element that is transferable and could result in a different care home at another location with the same principles. My graduation plan is a way or could be seen as an example of how to translate those guidelines in design solutions. In addition, the addition of this family part of the room and family related guidelines could be extended to other long-term care facilities where younger families are involved, since their dividual elements are the same.

Most of my design time has been put in this cluster of two residents rooms. Other parts of the building have gotten less attention. The upper floor with the different rooms where relatives could stay and the communal house for the family function, but could have been more diverse, providing better space for different sleeping options. The communal house on the ground level for the residents is not an important quality of my design, since this is about the already existing design principles for a living environment for people with dementia. This is therefore designed on a basic level, but does contain the found additional guidelines from my fieldwork.

My biggest trap during my graduation was my perfectionism and wanting to think everything through in detail, despite knowing this about myself. This has cost me a lot of time and resulted in postponing decisions. I might have wanted too much and too difficult at the same time. This detailed thinking and maybe difficult thinking often has no physical result but does in the end result in losing attention to the bigger picture and choices that might not be thought logically and are less detailed instead in the end.

Reflection

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