FIELDWORK

Tones of Comfort / Additional booklet
regarding fieldwork observations & experiences

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CONTENT

Prologue
& INTRODUCTION

This booklet is an addition to the research plan 'Tones of Comfort,' detailing my fieldwork experiences. To support my research, I spent a week in dementia care facilities alongside two fellow students, Muriël and Amber. The booklet shows our additional observations, interviews, drawings, pictures, and thoughts. The conclusions and key findings or quotes drawn from these experiences are incorporated into the final research plan.

The first part of the week was spent at a small-scale dementia farm. Here, we closely followed daily life (from breakfast to dinner, activities both inside and outside the facility and farm life). We also created drawings, observed, and conducted interviews. The second part of the week was spent on a large-scale closed ward. We undertook this within a week to obtain a clear contrast between the two types of institutions. In the larger facility, we observed the daily lives of the residents and closely examined the use of the environment and activities. It was an interesting experience to first-hand experience a dementia facility to supplement my literary studies.

All our findings are documented in this extra booklet. All names of individuals involved have been changed to ensure anonymity. Individuals in the photographs have been made unrecognizable, either through image manipulation or the use of sketches. All photographs or drawings are self-made.

1

PLANS

A small scale care farm

The building is shaped in an L-form, connecting the different functions within the building. The building is surrounded by an anirmal farm and vegtable garden.

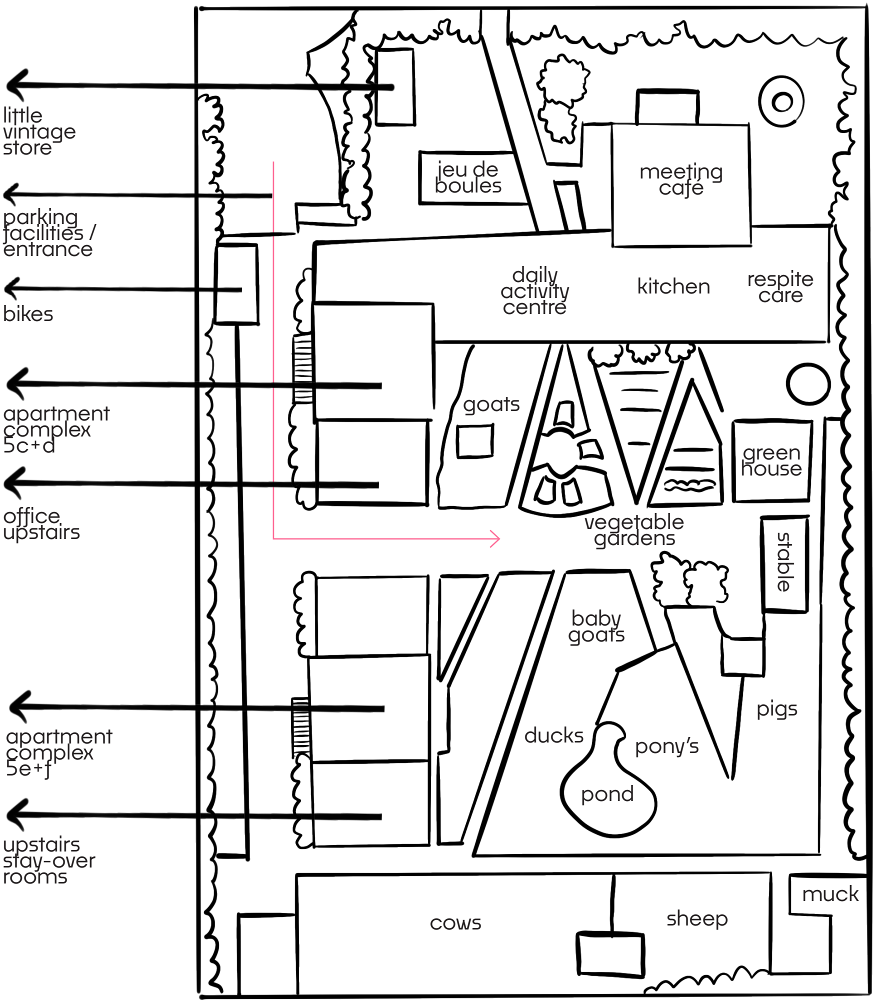

Image 1: Plan of 'small care farm'. Made by author (2023).

A large scale closed facility

The building consists of 12 floors: 4 somatic, 8 psychogeriatric. The departements are connected by a central elevator shaft.

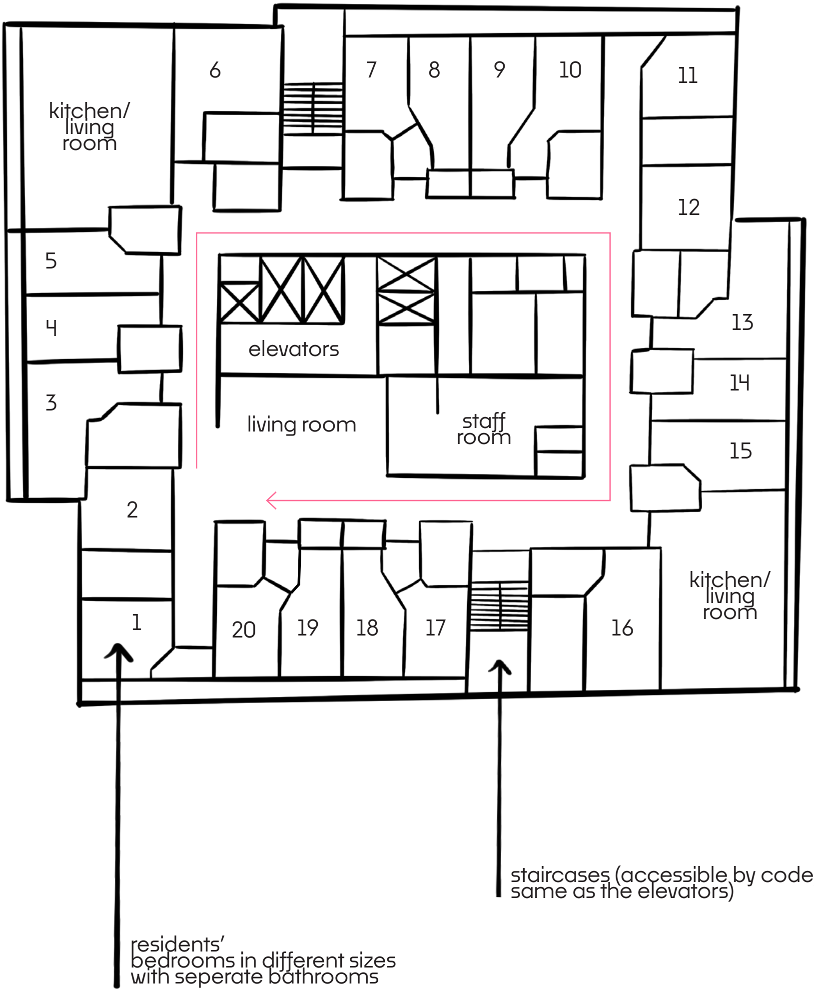

Image 2: Plan of 'large closed facility'. Made by author (2023).

2

Interviews

Interview

HANNEKE - FOUNDER 'SMALL CARE FARM'

What was the main reason behind founding the SF?
The beginning, of course, was my experience with my grandfather, who lived in a small-scale unit within a large, institutional nursing home. In that setting, I observed a significant lack of knowledge about dementia. For instance, when someone asked for a cup of coffee, the caregivers' response would be: 'Yes, I have already told you that.' For me, this indicated a lack of understanding. Education is crucial, covering knowledge about dementia and the physical environment. My grandfather always wanted to leave the unit. The absence of activities and stimuli for engagement throughout the day led to what I perceived as boredom for my grandfather, making things difficult, and resulting to so-called 'challenging behavior'. I realized that the approach of someone with dementia is crucial. So, initially, my ideas were centered around the importance of the approach and knowledge. Creating an environment where there is a variety of things to experience and do is essential.

I delved into dementia care, exploring various approaches. I started with validation theory and moved on to person-centered care, warm care, and small-scale living. Eventually, I came across a booklet on person-centered care by Kitwood, and that became my bible. It's a small booklet from 1997, but reading it deeply affected me. The essence of our vision and the most critical pillar is person-centered care. In simple terms, people with dementia are, first and foremost, individuals. They have dementia, yes, but fundamentally, they share the same basic needs as anyone else. However, due to dementia, they are less capable of fulfilling those needs independently. These needs include belonging, a meaningful daily routine, a sense of identity, security, attachment, and comfort. People with dementia have a kind of mist created by their condition, and we, as the other side of communication, need to go the extra mile to break through that mist. Kitwood talks about positive and negative interactions. In our interactions with residents or people with dementia in general, we can either empower or undermine them. Small things, often done unconsciously, can make a significant impact.

Employees in the care sector generally have good intentions, but sometimes, unintentionally, they do things that undermine people suffering from dementia. Training employees to be conscious of themselves as instruments is crucial.

With small-scale living, the aim is to create conditions that facilitate positive interactions. For example, cooking together with the residents, praising their involvement, and appreciating shared activities contribute to fostering a positive environment. The idea behind the care farm was to provide an environment that allows people to immerse themselves in the present moment. It offers a sense of purpose and freedom to talk about the here and now. The farm setting, with animals to care for, provides a meaningful context for engagement.
A fundamental principle is never to say no beforehand and to assess each situation individually. Everything is possible unless it proves otherwise in practice.

Yesterday, something occurred that I found very remarkable. Vera, of course, has been very creative in the past with sculpting figures. The caregiver shared that she once brought some clay to the SF, thinking that she could engage Vera in some clay modelling together. The personalized approach, where the staff comes up with these ideas themselves, thinking: 'I will bring this and try it out,' and then independently managing it, is something I find very special and delightful.

Yes, indeed, and that also requires a strong sense of security within the team, right? That experimentation is welcomed, and creativity is embraced. That is also the reason why we believe that small-scale living is so important. Working in small teams of 6 or 7 people per apartment unit allows the staff to truly get to know these individuals. They may not immediately recognize you, but over time, they often become accustomed to the caregivers. We also invest a lot of effort in gathering their life histories. Who were they?

So, either yesterday or the day before, I was sitting at the table at the stay-over house with Roos and Mark. We were chatting a bit, and Mark mentioned his previous job, but could not remember exactly what he did. Marleen, the caregiver, checked online for Mark's history that his family had sent, and said: 'Wim, you studied civil engineering at the TU Delft, right? You have a connection as graduates of TU Delft! Did you notice that similarity?' We previously had not noticed, but he was a professor at TU Delft! When Marleen asked him he responded: 'Yes, that's correct.'

Despite having not one house, but multiple blocks, you notice that everyone knows almost all the residents. When you want to talk about other residents with someone, they know who you are referring to. We were at the day centre, and it struck me that even all the staff members there know almost all the residents. I think it's beautiful that, when you have to help out someone you see walking on the premises, even if it's not someone directly under your care, you still know who they are, their names, and how to approach them when you encounter them outdoors. I believe that is a real strength: the scale and size of this project.

That there are only 27 residents allows us to truly know each and every one of them and provide that personal attention to everyone, which is crucial. Another important aspect is the choices we have made that may not be immediately apparent but make the implementation of this philosophy easier. For instance, we don't have temporary workers - never. In case of sickness, it's a disadvantage in one way because people must cover for each other, and sometimes fewer people are available, but when you work with flexible staff or temporary employees, they don't know the residents at all. When someone does not know anything about the individuals, it makes it very difficult to adhere to our philosophy. We don't have mandatory night shifts, which is different from many other organizations. Instead, at the SF, the people who work during the day also work night shifts. It is not a preferred shift, but everyone understands its importance because you need to know and understand what is happening, especially if you arrive for a night shift and there is chaos in the house. You need to think: 'Okay, something must have happened, or there must have been an activity recently, and that is okay.' We don't create two separate islands.

We also pay a lot of attention to our vision. We have vision days with staff twice a year to discuss our vision thoroughly. There are vision days for volunteers and family members, and we invest a great deal in open communication. Yesterday, there was a meeting day with a significant turnup, which I found quite enjoyable. Unfortunately, we will have to manage with less money next year. We organized a meeting to discuss with staff and family members how we are going to handle this. What ideas are the ideas concerning reducing staffing hours? It is great to see such a large turnup. Even though it is not a pleasant topic, it was a positive meeting because people felt heard. 'We have a say in it, and we're doing it together.' They appreciate the current setup with two staff members for 6 or 7 residents, sometimes with an additional volunteer. Their concerns are genuinely driven by the well-being of the residents. They want to ensure that the level of care and attention remains the same as it is now. It's not about their personal interests but, rather, about the importance of the residents. It emphasizes the focus on the residents' well-being, aiming to keep things as consistent as possible with minimal changes.

What changed since you started 10 years ago? Did the vision change? I can imagine there might be new insights gained through experiences or external ideas since you started.
Whenever new people join our team, I provide training on the vision. I always start by asking if the vision is mandatory. It is, but it's not rigid. If there are new insights about dementia, for example, we need to incorporate them. We should remain flexible, and if someone brings new ideas, we need to consider them. In 2018, we discussed the vision during a vision day, and we added a new pillar: 'Without freedom, there is no life.' Although it was already a core activity, it wasn't explicitly mentioned, so

we added it. Despite these discussions and additions, we still adhere to the core principles of the original vision. Working here sometimes feels like a mini village. We don't have ambitions to expand. There is a high demand, and we have a long waiting list, but we keep our current scale as we believe it is crucial to know everyone, both staff and residents. We currently have 65 employees, 36 more than when we started in 2013. Our goal is to maintain a tight community. Regarding the balance between freedom and safety, the open-door policy, and the ability for residents to roam freely, it is a concept I observed in various places during my time as a researcher. I learned from organizations practicing small-scale living. When we started, it took courage to maintain an open-door policy. We coached our staff extensively on how to handle the responsibility, especially when it comes to residents with specific risks. It was challenging, but gradually, as we built a team of staff who embraced this approach, it became easier for newcomers to adapt. This open-door philosophy is discussed during the training sessions for new staff, emphasizing the importance of maintaining it even when faced with challenges. Sometimes it's challenging, but we keep the door open and collectively think about how to resolve different situations. Initially, we used to lock the doors at night, and residents could not get out. However, last year, we replaced the doors with a twist cylinder from the inside, which had been our desire for a while. I believe that if residents want to go out, not being able to do so is more dreadful. Even though we use alarms that immediately notify us when someone exits, it can still mean a delay in finding them. For instance, there was a man with frontotemporal dementia who, at the beginning, frequently stood outside in his underwear during winter, by means of the emergency exit at the end of the hallway. The urgency is sometimes significant.

Yes, and there was an incident with the pond in the past 10 years. What happened?
That was the first and only time someone walked into it. It was noticed very quickly because the homes are arranged in

a way that everyone has a view of the central area. Such an incident must happen at least once, and then you see that it is not as severe as you thought in advance. The doors are open, and residents can see the pond, meaning they won't walk into it quickly. They will always come back because they find the SF a pleasant place and can go out, knowing they can also return. I am not sure where I heard that, but I find it beautiful that if you say no, you can't go outside, people will want to go out. However, if you say yes, okay, go ahead, they might just stand at the door, and think, okay, maybe I will just sit down or take a short walk, and they will come back on their own. Giving them a bit of control over their own lives, that is what I appreciate. We had someone who lived with us for a long time, a woman. Throughout her healthy life, she was known as a strict and not very cheerful person. It was a bit of a unique individual, and you often notice that the staff is fond of such personalities, more so than family members sometimes. She wanted to take a walk at night, so what did she do? She would go out through her garden door around 4 a.m. The night shift often got a scare when suddenly, she would be behind them, but it always went well. She took that stroll, and then she could go back to sleep. So, who are we to say: 'No, you can't do that', or: 'That's dangerous'? No, we don't interfere. It's their home.

We noticed that having two seating areas, two dining spots in a home, was really nice, and I spoke to someone yesterday who suggested maybe adding a curtain or some other partition to visually separate areas occasionally. This could help manage some unrest, she said. But at the same time, that long straight hallway, the straight corridor with the view, is beneficial. It provides a nice overview for the staff. So, how did you exactly plan the layout with an architect?
I invested a lot in the design of residential facilities, with two key principles in mind. It should resemble a sort of prosthesis, making it as easy as possible to align with what people are accustomed to while creating an overview. So, in almost every Dutch home, when you enter, there's the front door, a hallway where you hang your coat, a toilet. Then, you enter the living room. Some

living rooms can be complex, but here, you immediately see the kitchen and the rest. It's straightforward. If you want to go to your own apartment, you only need to go in one direction because it is somewhere in that hallway. This is because we wanted to embrace the terrain, making it more accessible.

They said a separation is sometimes nice for the residents because the restlessness in the living room is not felt when people wander in that hallway and come back. Perhaps it works well for that specific home, right?
Exactly, yes. This home was built by the housing association, so we had limited resources and no personal funds. It was great that we had a say in choosing the architect. We attended every construction team meeting to discuss the layout, the design, the materials, the colors. I delved into it deeply, ensuring no sharp contrasts were present in the design. However, sometimes things still went wrong, like a black threshold between the bathroom and the bedroom, which some people with dementia perceived as a hole in the ground. So, they found it challenging to step over it. We have since removed those thresholds to make it more accessible. We also considered the colors used for bathroom tiles, as research has shown the most soothing colors for dementia patients. The fact that, upon opening the bathroom door, you immediately see the toilet, is helpful. You know where to go if you need to use it quickly. When you head in the right direction, you are halfway there.

We looked at creating a list of criteria, which absolutely had to be in those floor plans. We had limited space, of course. You have a limited number of square meters and everything costs money. We chose to allocate a significant number of square meters to the common living room because most people, not everyone, but most often seek the safety of the staff. People with dementia are adept at finding the right staff member and seek the security of their presence. I also did my internship in a small-scale residential facility, and their living room was tiny. We sat together at the table all day, staring into each other's eyes. Well, nothing peaceful about that, especially if you don't sympathize with your roommate. We found it essential to create various seating areas. Indeed, for example, having two tables to eat.

What Erika always emphasized, and what we later noticed as well, is that on one side of each room, there is a door and on the other side there is a door to the garden. Some rooms, however, instead have a window to the road. Was this a deliberate choice? Because they all could be facing the beautiful farm pond, right?

I visited a center in England that focused extensively on designing for people with dementia. For instance, they used stickers on the wall to create the idea of a bookcase instead of a door and avoided the use of gravel in places where people should not be, like near the fence. That was inspiring, seeing how they used different colors for recognizability within the homes. My idea behind it was that I indeed did not want people to be on the roadside because that leads to the exit. So, I wanted to make that area as unattractive as possible. Of course, still beautiful, but not so much that you would be drawn to spend time there. Instead, you would be attracted to enjoy the farm garden and would not feel the need to go out in that direction. In practice, I think it might have been better to have doors there as well because you notice now that some people lean out of the window. I think the feeling of having your little garden is still valuable.

But I do understand what you are saying. You can clearly see that that embrace and focus on the beautiful garden here, so I really understand that concept and idea.

Yes, but it is funny how sometimes you have an idea, but in practice, it turns out differently.

We noticed that some people specifically asked to have the garden side when it was their turn to come here to live, but we don't allow that. First come, first served. Erika also mentioned that there is a difference in the view, as you can see here on

the first floor, where you only see the sky and some treetops. The quality of staying on the ground floor and being grounded is important. The thought of placing people with dementia on higher floors is common, hiding them away. Terrible. Being grounded is what people need most. Visual direction as well, because they might not consciously know it, but if they see it, they do.
I can get a bit upset about it, but there is a beautiful residential facility with 13 small-scale homes in Haarlem, with a lovely garden and all, but what you see is that the doors to those gardens are always closed. So, people don't go there because they are not stimulated or can't access it to enjoy it. They need someone to take them there. Here, if the weather is nice, the doors are always open. In the summer, it is like one big vacation park here; shops are open, people eat outside. It's one big outdoors experience. People often have a tan.

What struck us was that many employees pointed out almost no one walks with a wheelchair here. Everyone is quite fit. Waiting times might get a bit longer because people live here for a long time. People also exercise here. I find that something beautiful to see because it actually proves that the physical environment has so much influence on people with dementia. It's nice to walk, and I find the gravel path here quite amusing; you can hear it crackling a bit. It might be a bit more challenging with the flowerpots, but then they learn to navigate and engage their competitive brains. Even though it takes a bit longer, I really think it keeps them more vital.

Not everything is straightforward, indeed, certainly not. We sometimes hire a physiotherapist to train someone specifically, like recently when someone had a fracture. So, we do involve physiotherapists a few times a week, or, for example, Kor, who comes to walk with the nursing students, or Tim. It does not mean we don't use those professionals, but we don't have a gym or an exercise space. I genuinely think that because people walk so much here, they are much less likely to need a wheelchair. And, well, I have not conducted research; I can't provide proof.

I don't know if that still exists in other residential facilities, but I used to do an internship in a small-scale living facility, where someone had been bedridden for two years. It was terrible because the woman was screaming all day that she didn't want to live anymore, but that never happens here. Even if someone is so limited, they can't sit well, you would put them in a moulded wheelchair or an office chair and take them to bed at appropriate times to ensure no constant pressure on their buttocks, but it really doesn't have to be like that.

Nowadays, people have to stay at home longer, right? And with long waiting times here, I wonder if people would have the opportunity to move here a bit earlier, and if this would be beneficial for their well-being. If the living environment would be better for people with dementia, could the early stage be more spread out? Do you see a difference between residents who arrive here later and those who come a bit earlier?

Of course, it would be great if someone can move here while they still understand a bit and can help set up their apartment, for example, when someone can still choose to live here. That has happened quite a bit, where people realize and know, 'I want to live here.' That is, of course, wonderful when that happens, and when someone gets used a bit and can move independently longer, they can better express what they want. That is, of course, very nice if it is possible. At the same time, we had someone last year who was very advanced in her dementia. She initially lived in another nursing home and then moved here anyway. You might almost say, well, is that still worthwhile? Very disrespectfully said, what does she get out of it? But there is much more to it than you think. You saw that the staff saw her as a person and started experimenting, finding out what made her happy. They started picking flowers for her, and you could see that she enjoyed those small things. Eventually, she passed away here. Her family is still so happy that she could live here in those last months because they felt she was seen here. The staff attended the funeral. It is remarkable that such a deeply demented woman actually gave so much to a caregiver; that someone can flourish like that again. At the beginning, you are kind of testing the waters, figuring out how people, for myself as well, react.

I used to be a researcher and at some point, employees had to fill out a questionnaire about the functioning of their patients on the scale of Cognitive Deterioration. I checked before sending it to the researchers, and what did they fill in? There was a lady who could not talk at all, except yes and no, and often it was even like, if she meant yes, she said no. She was very passive, really in an advanced stage of dementia and quite empty, very disrespectfully said. I was looking at the questionnaire, thinking, what has been filled in? For example: Mrs. can express herself well. Are we talking about the same person? I found it so beautiful the employees knew her so well, they understood what she meant, and in their view, could express herself well because they could interpret it very well.

That overnight stay house, or respite house, is relatively new. How did you come up with that? Why did you not make an extra apartment complex instead?
We found the overnight stay house to fulfil a very important societal function. The wish is, of course, that people live at home longer, but then the informal caregivers also must endure it longer. The biggest predictor of whether someone ends up in a residential facility is the burden on the caregiver, whether the caregiver can still handle it. It is not even about cognitive functioning or problem behaviour or anything like that. Yes, those are also predictors, but the most important predictor is the caregiver, whether he or she can still handle it in the environment where they live, I think. That is why it is so important to offer respite care, and you can do that in the form of day care, but that overnight stay house also offers a lot. For example, there was someone who used to come here every month, someone who still lives at home, to stay overnight, and he had a lot of problems with sleeping. But those were the only

two days of the month that his wife could sleep through the night. That way, we could prevent a crisis admission because, she could sit it out until there was a spot available at the SF.

I find it very nice to see that you can offer a kind of solution to people in a very high need, because that is the case with many people on the waiting list. Do you also see that many lodgers are on the waiting list?
Yes, but also people who are not on the list.

I walked in the day-care yesterday, and I think it was quite a young group. I was quite surprised by how young they all were, but I found it very nice to see that those people were so happy that they could go to the SF, having their goal for the day. I forgot his name, but he paints a lot here. You can see that he really comes alive here and at some point, he mentioned: 'Yes, I am tired of Alzheimer's sometimes, but I found painting, and I find it so beautiful to do that.' He felt like he is actually contributing something, and he has responsibility. He was also happy that he finally had people around him who understand him. Many of his friends no longer understand him, and now he has found a place where people have time for him, are patient, and he can do exactly what he wants. I found it so impressive. He also told us that he used to be very active as a volunteer and carpenter. He noticed that his identity was attached to that carpentry work and all the volunteering, but it became too much and too busy, also in social contacts, so he was really depressed before he came here. This has really given him a new zest for life. He said: 'Yes, I know I have this disease. Half of my brain no longer works, the other does. I can talk to one person, but not with several. I am not allowed to use the gas stove at home anymore, but here I can still bake an apple pie.'
They are actually making friends again, and because of that, they look forward to the whole week after, because they know that on that day, they are going to walk with their friend and bake an apple pie.

Do you think that there is a need for more of these facilities? In terms of day activities, especially for people who are still more integrated into society and who have been diagnosed with dementia at a much younger age? Do you notice there is a gap there?

Yes, we our day-care focusses specifically on younger people with dementia, and our facilities attract that as well. The challenge with early-onset dementia is that it is a relatively small target group that requires a certain expertise. But I do think there is a need for more activities and day-care of this kind, and fortunately, it is slowly coming. For example, Dementalent, where they really take on tasks independently. What sets us apart is that they are also moving away from traditional day-care where you come together all the time. It is not just group activities all the time. Someone works in the garden, someone is busy cooking, someone is in the creative studio, and someone else is going to the store to buy painting supplies. We ask much more, to focus on the individual, just like we do in the homes. I think that is slowly starting to change a bit more even in more traditional day activities, but there are still many places where you sit in a circle and do gymnastics and sit on chairs, just like in high school. I think that with this way of day care, the feeling of meaning, fullness, and responsibility is more appealing. It also goes wrong sometimes, for example, I just heard someone say there is too little weeding to do at the moment. So someone started weeding the flowers and plants.

Do you have any experience with couples moving to the SF?
There was a man that insisted on moving here with his wife because he could not let go of her. He only wanted her to move to a residential facility if he could come along, and he did that for 1.5 years; he was quite special. As dementia progresses, people often have a need for, for example, closeness, intimacy, and his wife and another woman could be very close to each other and give each other kisses. It was all very innocent in my opinion, but the spouse could not stand it. It was very difficult. Her partner really thought there was a lesbian relationship going on, so it was very interesting how to handle that well. I think it ultimately worked out well. I also think that the path he took is good.

Nowadays, you don’t really have apartments for couples, where you have people without and with an indication because there are still many logistical challenges. You want living space big enough for the two of you with your own space and your own room. Have you thought about what happens if one dies? And if one dies, what do you do then? We don't get any income if there is a healthy person living here and we are really focused on dementia. We get care package 5 or 7. That means we now get around € 300 per resident per day. We can pay our staff and rent with that, and if there is an empty apartment, or if it concerns a healthy person, then our model is no longer financially viable.

Last year, I used a report called 'Homely and Trusted,' and it contains a lot of knowledge about sightlines and contrasts. It's quite old, like from 2006 or so. Coming back to your question: I do think that it is beautiful for some people to have that option. It is just financially complicated. You should inquire, for example, at that mill district, how they do that financially, but they can do that more easily because they are larger organizations. Look, if you are an organization with, I don't know, 6000 residents in total with all your houses and home care and whatever you offer, then you can implement such a concept a little. For us, it's very pure, right? We can't. If you come up with the solution, I will think about it.

Interview

ROB (FROM VERA) AND JULIA (FROM TIM) - FAMILY

The partners talk about how tough it is to see their loved ones go through dementia. It is heart-breaking and feels dehumanizing when their partners don't recognize them anymore. The person with dementia is just not the same as the one they married. They both feel that the signs of dementia were there for years before it got diagnosed. It's a slow and painful process of watching their partners change. It's a tough journey filled with uncertainty and a gradual decline in their loved ones' abilities.

Julia noticed something was off in Tim. A friend of them had also recently been diagnosed with dementia and showed similar changes; that's when the journey of the diagnosis started.

Both partners express their gratitude towards the SF. They visit quite often and are grateful for the level of participation that is asked from the family members and volunteers. During monthly meetings they can voice their thoughts about changes or new ideas. Rob expresses: 'Dementia is a hell, but then the SF is undoubtedly the best option to make the most of it.'

Interview

JANICE (FROM ANITA) - FAMILY

Anita has been a resident at 5e for approximately two years now. In a recent conversation, they delved into Anita's current capabilities and observed changes in her behavior since her transition from independent living to the SF. While Anita had become retiring and grumpy at the independent living facility, she now sits smiling at the table and her shoulders are not hanging down anymore. When someone enters the living room she lifts and appears to be 'awake'.

The discussion also touched upon Anita's stress levels and how they have been managed in the new environment. It became evident that Anita recognizes mainly footsteps and faces, but interestingly, her own voice is no longer familiar to her. This quirk in perception adds an extra layer of complexity to her experiences. Exploring Anita's preferences and needs became a crucial part of the conversation. Understanding what brings her comfort and joy has been instrumental in providing personalized care. The atmosphere at the SF has played a significant role in positively impacting Anita. The contrast with a previous, more sterile environment highlights the importance of creating a setting that promotes well-being for individuals like Anita, navigating the challenges of dementia.

A story is shared about Anita's loved one: a man who is still alive, now living in a care home because he is over 90 and can no longer hear well, but mentally is still super sharp. The two hardly ever see each other anymore because the only possibility is for Anita's children to bring them together and they live more than an hour drive apart. In the beginning, Anita often asked about the man. When she was in the early stages of dementia and still living together, Anita often thought that a strange, young, blonde woman entered her husband's place. She hallucinated and then locked herself in her room for days, crying. Even though the images are not real, the emotions are, and they hurt just as much.

Interview
ERIKA - CAREGIVER 'SMALL CARE FARM'

At 11:00 hours, we had a conversation with Erika, a caregiver at the SF. She shared insights into the distinction between large care institutions and the intimate, small-scale living environment provided by the SF. With 27 years of experience in a large institution, Erika transitioned to the SF six years ago. Erika highlighted the individual-focused care at the SF, emphasizing the flexibility it allows in daily routines. She discussed efforts to facilitate connections among residents, promoting shared activities that contribute to a sense of community.

At her previous workplace, she had various criticisms: fixed bedtime, coffee breaks, and cleaning times. All residents ate together simultaneously, while the care management had a separate time. Everyone was awakened at fixed times, forced by opening their curtains, and lifted into a wheelchair. Almost everyone sat in a wheelchair. People were placed in front of the TV with a mandatory cup of coffee. This routine continued throughout the days. If people exhibited inappropriate behaviour, they were given sedatives. She found it to be an intense environment, and even after 27 years of service, a challenging and emotional situation she experienced was not acknowledged by the management.

According to Erika, the SF feels like a family, fostering an environment where challenging situations are openly acknowledged - a departure from her previous workplace. She also offered suggestions for improvements, focusing on room size, corridor width, and optimizing shared spaces to enhance resident comfort.

Interview

PETER - HAS DEMENTIA & AUDREY - EXPERT ON DEMENTIA

Can you share a bit about your journey with dementia?
I had a stable job at KPN, but issues arose, and things at home became challenging. Initially, I thought it was a burnout, but after seeking medical advice, I found out it was dementia: a progressive disease. I even applied for different work at KPN, but my old boss noticed the changes.

How was the diagnostic process for you?
It was quite a journey. I initially tested negative for Alzheimer's, and the process involved an MRI. I was diagnosed with PCA dementia, which affects the visual aspect. Partners sometimes feel excluded, but my case manager's support was crucial.

How do you cope with the challenges of living with dementia?
I focus on living day by day and what can be done. Staying active with sports, spending time with grandchildren, and handling household tasks help. Of course, I have had to let go of things like driving. Feeling safe and secure is crucial, and routine plays a significant role. Initially I was skeptical about the SF, but I now see its effectiveness. I would suggest exploring smaller-scale settings within larger institutions.

Audrey, can you elaborate on your perspective regarding dementia?
Certainly. I question the term 'behavioral problems' as it is a result of the disease. It is essential to see people beyond their illness. A diagnosis doesn't immediately mean dementia; it could be minor symptoms. Inclusion in society is crucial, and there is a need for personalized activities for young dementia patients. Partners often realize years later that symptoms were present earlier. Young dementia patients exhibit different symptoms, including character changes. The Kopgroep is a valuable resource for discussions among people in similar situations.

How do you think the environment impacts dementia patients?
The environment is significant. The loss of a partner is challenging, and there is a need for equal treatment. A new daily routine is essential, considering the diversity in preferences. Dementia symptoms can be similar to burnout or depression.

3

LOGBOOKS

A small scale care farm

Monday, November 14th
10:30: Arrival
We arrived and put our belongings in the two rooms we would be sleeping in. We slept upstairs in rooms meant for family stayovers. There were 2 rooms available. The rooms were, however, almost never used. The rooms consisted of single beds with a shared, large bathroom.

We began the day with a tour around the entire SF led by Kim. The terrain consists of an L-shaped building housing four apartment complexes (5c, 5d, 5e, 5f), a cafe, gym (under construction), day care, and a guest house, all located on the ground floor. These functions are connected by a garden and a farm. Here, residents can engage in gardening and walking, and there were various animals such as cows, chickens, goats, sheep, ponies, and pigs present. Access to the premises is always open for all the inhabitants, with only the outer perimeter enclosed by a fence.

11:00: Coffee
Amber and I continued our day with coffee at apartment 5f. We divided our morning visit between the three apartments because having three people present at the same time would be too overwhelming for the residents. One apartment accommodates seven residents and is assisted by two caregivers. Not everyone was awake yet, but we quickly observed the dynamics. Cobie emerged as the lively one, giving both Amber and me a warm hug upon arrival. She then jumped onto the lap of Joris, one of the caregivers. Cobie struggled with one of her fellow residents who suffered from both Parkinson's and dementia. He slouched in his chair because sitting upright posed a challenge for him. However, he could still walk independently. 'Why is he sitting like that? Sit up straight,' Cobie remarked. Joris responded calmly: 'Maybe he finds it comfortable this way.' 'No, you know what that is? Seeking attention.' People with dementia often lose a filter when it comes to expressing their thoughts. Another man, Rudy, was staring at Cobie from across the table with a

glazed look (common in dementia). She commented: 'That one over there is looking at me again, disgusting.' The same man, Rudy, sat next to me, eating from the sugar pot with a spoon. I didn't notice, but Bea on the opposite side of the table did, 'Dis-gus-ting,' she remarked. Joris responded calmly: 'Oh, what's happening here? I will take this away; would you like another cookie instead?' Bea found Joris to be 'a creep.' It's noteworthy that often people with dementia get an unpleasant feeling about certain caregivers without clear reasons.

Cobie was delighted that we were present and enjoyed showing us her room. She brought her own bed from home instead of a hospital bed, as she didn't need one. The room was fully personalized with photos and belongings. At the SF, residents are encouraged to bring and arrange their own furniture, creating a homely and personalized interior. Cobie has a window overlooking the garden, where she often climbs out of to sit outside by the birdhouse. All corridors and rooms have a cosy appearance. Items were on the floor, and not everything was neatly arranged. According to the SF's philosophy, it's essential for people to realize they must navigate around obstacles, keeping their brains active. Adequate lighting is also crucial, not just for preventing falls or injuries but also for the residents' peace of mind during darker days. All apartments were similar, but sometimes mirrored. The shared living and dining rooms were (mostly) arranged with residents' furniture for familiarity and a sense of being at home. The rooms are connected in a straight line by a long corridor, always with a window or view at the end. Only in house 5c it was different; there, the corridor turned a corner. Perhaps that's why younger residents with dementia live there, as they tend to be more restless. Due to the bend in the corridor, the tumult from the dining- and living room is less hearable or visible when people enter and exit their bedrooms.

The SF also has a small second-hand clothing store on the street side, an initiative by a volunteer and there are plans to expand it with a coffee/tea and bakery for the local community to visit. There is also a shared cafe inside, where people can have lunch together.

12:30: Lunch
Amber and I had lunch together at apartment 5e while Muriël visited apartment 5d.

In 5d, there was a (younger) man who took a long time to respond, if you got any response at all. The man was often mentioned as the resident who was the youngest and struggled the most with his quick decline in health. For a long time, he found peace in painting, but even this had become frustrating. He had just returned from a swimming activity and seemed overwhelmed, making communication even more challenging. After eating, the overstimulated man wished to return to his room immediately. Most residents focused on eating their toast without actively engaging in conversation. The staff member, having transitioned from a closed ward to the SF two years ago, expressed: 'Compared to the closed ward where I used to work, this is a paradise.' It's remarkable that many residents no longer have partners; some receive frequent family visits, but most rarely do.

In 5e, our lunch comprised cooked eggs, and we sat down with some residents. Attempts were made to bring Vera to the table, but she continued to restlessly wander on her own. Perhaps our visit was overwhelming for her. Eventually, a small table was brought to her. Residents have the autonomy to choose where, when, and how much they want to eat. Greet spent the entire time with a doll, engaging in conversation with Anita about how sweet the doll was and how it kept laughing. Anita and Greet were in good spirits, considered 'one of the better ones'. Kor took a brief walk before eating, which was acceptable; he could freely roam the premises and he returned quickly, knowing exactly where he lived. Kor also insisted on fetching forks/knives himself but would later forget which drawer to use. He had been suffering from dementia since 2009. It's noteworthy that people with dementia often say, 'Oh, I don't remember that, but that was such a long time ago,' as a way of 'covering' the disease. Anita suddenly started clapping at the table. Vera, from the other side, remarked: 'And now it's over, god damn.' Anita answered: 'She should shut up. She is not even sitting at the table.' They also frequently pointed fingers at their foreheads, indicating that the other person is crazy.

15:00: Tour in Heemskerk
17:00: Pancake dinner at the guest house
For dinner, we were invited to join the stay-over house (also called respite care), where we had pancakes. The respite house is a relatively new initiative at the SF. It serves as a place where individuals with dementia can stay for 1 night to 3 weeks, based on reservations, to temporarily relieve their caregivers at home. The facility is designed for 3 guests, but the aim is to expand the facility to accommodate 5 houseguests, due to high demand. During our visit, only Mark and Roos were present, but they were fully booked for the rest of the year. One caregiver, Marleen, was present.

Marleen, who had been with the SF since its founding, highlighted the beauty of the SF's vision: 'We are here as visitors in the residents' homes, helping them; they are not in our home.' Marleen values the fact that the environment is intentionally not entirely safe, aligning with the 'real world'. The paths inside and outside may be uneven, but that is considered beneficial for the residents. Marleen also emphasized that the SF's staff is expected to show more initiative. While this may not be suitable for everyone, this involvement is crucial for maintaining the quality of care at the SF. She shared a story about a couple living in one of the apartments: a small room of about 12 square metres. The man was healthy and did not have a care indication but insisted on living with his wife. Eventually, he wanted to be involved in household matters, leading to irritations from both sides. Additionally, they had a German Shepherd, which did not go well with other residents. However, Marleen mentioned that if a future resident would arrive with a dog again, they would be open to trying again. The philosophy is to never say no in advance and to try everything.

The SF has a waiting list of almost 4 to 5 years without specific selection criteria; anyone diagnosed with dementia can register (in any stage). Marleen mentioned that she and her partner would immediately join the list if one of them was diagnosed. Marleen observed that few people use wheelchairs on the premises, and there are few deaths (only 1 in the past year). She attributes this to the specific living environment with greenery, normal conditions (risk of falling), and the residents' active engagement in daily activities like caring for animals.

During our pancake dinner, a resident enters the living room through the back door because she could not find her room. Marleen explained this happens quite often, but then people can simply join and have a cup of coffee, or they are guided back to their own homes. Mark, who studied civil engineering at the TU Delft, travelled extensively for work, including being a professor, although he did not remember it himself. He mentioned always traveling to assess what went well or wrong at different locations and we thought he was making it up. Family is requested to hand in a form with extra information regarding the houseguest before there stay-over. Having conversations with Mark and remembering him about his past made him seem calm. He enjoyed speaking about his past and recognized us as fellow TU Delft students. Roos frequently shared stories about her cat, which used to bump into the glass door and then cuddle in her neck every evening. Mark did not mention Roos told the same story for 10 times and we came up with a unique answer each time. We actually had a lot of nice conversations and got to know Roos and Mark pretty well.

Tuesday, November 15th
09:00: Breakfast

At 9 am at 5e, no one was at the breakfast table yet. Residents can decide when to come to the kitchen. Some eat first and then go back to bed; there is no restricted eating or wake-up time. The table was not set due to hygiene reasons. Eva was already dressed and ate chips that she apparently had put in her walker the night before. At 5f, only Bea was at breakfast in her bathrobe. Joris helped her with her food. Cobie entered and mentioned someone without clothes in the corridor. Bea almost fell asleep at the table and went back to bed but returned because she did not remember what she wanted to do.

13:00-15:00: Taking care of the guest house
There was a meeting held with volunteers, employees, owners, and family members to discuss the future of the SF. Salary increases for employees might lead to budget cuts, but they are committed to maintaining the current care approach and the number of care workers. However, there is a possibility of reducing the caregiver count from 2 to 1 per house, causing concern among family members. Because of the meeting, over a short period of time there was a shortage of caretakers, and we were asked to keep an eye on Roos and Mark for a few hours, since we knew the pair already.

We had a nice chat and tea with Roos and Mark. It was enjoyable talking about things from the past, like church weddings, or making them laugh with old sayings such as 'looie pijp.' Mark mentioned having a twin brother but could not recall his name, remembering only that he was a troublemaker in the past. On the contrary, he vividly remembered his wife's name. He often thought he saw her walking outside. Surprisingly, Mark expressed a desire to go for a walk when the volunteer and intern went out to take a stroll. This was special because initiative is uncommon in people with (advanced) dementia. However, he struggled to sense when he needed to use the restroom. Distraction and laughter seem to reduce restlessness. When Mark was alone with the younger and unexperienced intern, he repeatedly asked when he could go home. He fell asleep on the couch in front of the TV but happily engaged in conversation at the table. The respite house had accessible rooms where Roos could retreat by herself when she was tired. The doors however were sometimes too small for a walker to get through. Roos enjoyed sitting at the table and chatting and listening to our conversations, despite her hearing impairment.

13:00-15:00: Amber with day care
Day-care is for people with dementia who still live at home but want to come by just once or twice a week. The group that day was sharp and relatively young. The day-care lasts from 10 am to 4 pm. At 10 am there is coffee and at 10.30-11.30 they go outdoors. Then at 12.30 it's time for lunch and some rest. From 2 pm, there is an activity such as painting, carpentry, watching movies, or working in the garden. Then around 3 pm, they wrap up with some whipped cream or a glass of wine. There is also a group of six men that visits weekly to engage in activities together. They receive a to-do list every week, but the number of tasks that must be completed varies by day, and not all tasks need to be checked off.

We joined the day-care group during a walk, where the group engaged in meaningful one-on-one conversations, contrasting with their less participative lunchtime discussions. Some enjoyed puzzles, conversation, billiards, or gardening. Each day of the weak has a separate goal, like:

- A Thursday afternoon 'advanced group' discusses how they feel in society with the disease, sharing experiences about work, communication with colleagues, or coping with stimuli in a supermarket.
- Thursday mornings feature an active group doing boot camp in the dunes (ages 50-65). The day-care provides a space for those still sharp enough to converse with like-minded individuals, as their regular friends and colleagues may struggle to understand them.

A man (possibly with a wife and children) who was a skilled carpenter expressed regret about his inability to make furniture due to half of his brain not functioning. He enjoys baking apple pies but is restricted at home due to safety concerns. At the day-care he bakes every week. They joke about being paid without working, share their unique stories and advise each other positively on how to always keep smiling.

18:00: Dinner
For dinner, I had pasta with salmon, prepared within the weekly budget provided for each house. With the weekly budget, the care staff creates a different menu every week based on the residents' (discussed) preferences. The staff mentioned that in closed units, residents typically receive food from a communal kitchen, while the aroma of food can contribute to a calming environment.

Vera used to be an excellent sculptor. Because my research focuses on art, the care staff quickly fetched some sculptures from Vera's room to show me. Unfortunately, Vera showed no signs of recognition when I expressed admiration for her artwork. The staff informed me that art is frequently incorporated in the daily life of the residents, and everyone receives individualized and unique care. They once spontaneously brought clay from home to encourage Vera to sculpt again, but it did not go well as some residents attempted to eat the clay. Vera prefers to restlessly wander around. Her husband gave her an iPod so she could listen to music while walking to calm down. After dinner, we all began to sing. Even residents in advanced stages spontaneously sang along to songs from the past and brightened up. Kor and David, the young intern, dined in the conservatory, as separate dining for some residents proves to be calming. David, an 18-year-old boy, resonates well with the male residents. Generally, young people are highly appreciated by older individuals with dementia, especially young children.

At 5f the daily menu consisted of pasta pesto. Residents can help cooking or even switch between the different apartment blocks for meals if they prefer a different dish or company. One of the visitors assisted with folding laundry, initially with suspicion from Cobie, who later appreciated the help. Some people were playing games, and others were engaged in various activities. Bea and Cobie ate separately due to potential negative interactions during meals. They are considering adding a curtain or screen between the conservatory and the kitchen to visually separate the eating areas.

Wednesday, November 16th
09:00: Breakfast
At 5e, I enjoyed breakfast with Kor and Anita. Vera joined later, appearing to have a relatively clear morning. The caregiver I met that morning brought a small white dog with her, lifting everyone's spirits. It's noteworthy that the residents give the dog the name they remember from their own past pets. The caregiver shared that she used to work at Gamma, and her experience there proved beneficial in the SF environment. KOR independently went to fetch the newspaper, just as he used to do in the past. Spending multiple days with the same group of residents' benefits understanding their individual preferences. At 5f, Bea and Sandra were present. Groceries from Albert Heijn had just arrived. Bea had a small bowl of pills that she needed to take. She wanted to know the purpose of each pill individually. When they told her they were for her heart, she joked about bidding farewell to her heart if she did not take them. Sandra enjoyed her breakfast and later went out independently to the village.

12:00: Heading home

A large scale closed facility

10:00: Arrival
We started the day with a brief intake interview with Diana. The LCF was not adequately prepared for our visit due to Diana's three-week vacation. However, they were immediately welcoming and delighted that we had come. Diana provided insights into the sheltered housing, consisting of 8 psychogeriatric departments and 4 somatic departments in the building. Upon entering, we found a cosy large hall, retro in its design, where many people were enjoying coffee. Stands with hand-knit clothing and homemade Christmas cards were also present for purchase. As young women, we stood out, and while waiting for Diana, we were approached by two men; their wives lived in a psychogeriatric department, and one of the gentlemen mentioned living across from this complex. Originally, he and his wife lived together, but caring for his wife, who had dementia, became overwhelming for him. They decided she had to move into this complex, and now he visits her every afternoon while having his own mornings, peaceful nights, and poker evenings with friends.

10:30-11:00: Visiting the departments
We were introduced to department 4 (psychogeriatric). An immediate noticeable difference with the SF was that each department (or floor) had a square layout with a corridor around the elevator shaft. Residents could essentially only walk in circles. Due to the similar corridors, we, too, initially lost our orientation. Some corridors had windows at the end with a view, while others did not, leading to a somewhat darker end of the hallway.

On each floor, there were 2 living rooms/kitchens where the 'host' made coffee and prepared lunch for his 'clients' (explicitly not 'residents'). Patrick, the host, was a kind man with good intentions, but the difference from the SF could not be more significant. Almost all residents sat in wheelchairs at the table. The staff drank from separate cups and ate from separate plates. Patrick spoke about the residents in their presence. We asked

Tom, one of the residents, if he enjoyed where he now lived, and he replied: 'There is no other option.'
Tom was a member of the Delft Student Bond and had a great student time. When my phone lit up with a message, he asked: 'Are those all your boyfriends?' I replied: 'Yes, they stand in line! Did you have many girlfriends during your time in Delft?' He replied: 'Yes, several, after going out, that's how it was back then.' Tom still appeared fit and quite sharp, but Patrick claimed he was severely demented (in Tom's presence), which was far from the truth. Tom seemed grumpy/dejected. However, we had pleasant conversations with other ladies at the table, much like at the SF. One lady told us she had lived in Uganda and swam in the Nile. They almost all originally came from Rotterdam, making it easy for me to connect.

Patrick had worked in healthcare for 30 years, but his true passion was music. However, he never made music with the residents because reggae 'would not be to their taste.' I, however, think they would enjoy any music.

11:00-12:30: Painting day activity
The day activity at the LCF is very enjoyable. Various activities are organized downstairs during the week, and residents can participate voluntarily. However, the care staff decides who is 'fit' enough to go downstairs and join these activities. This is a significant difference from the SF, where both care and well-being are handled by the same staff. In our perception, this creates a better connection with the residents, allowing for a more accurate assessment of what is best for each individual. At the LCF, different staff members handle care and well-being, and while they also have the residents' best interests at heart, they may not know and assess them as well as the SF staff.

Thursday was painting morning. People from different departments and the assisted living homes joined. Amber spent about 1.5 hours helping Sylvia unravel a ball of wool. Sylvia, a woman with dementia who still lived independently, wanted to show us her home. What we noticed most was that she lacked a lot of attention skills and emphasized several times when Simone and Amber looked at her room how sweet it was that we took the time to come and see her room. Attention and love are crucial for people. At the LCF, assisted living homes are connected to the communal hallway where activities take place during the day. This way, inhabitants can easily leave their home and remain in a safe and protected place.

Muriël and Simone painted with another woman. Muriël had a real connection with her because they both knitted their own sweater. The woman was mentally very well but used a wheelchair. She had been living at the LCF (somatic department) for years, and I asked if she had made friends there, to which she replied (a bit surprised): 'No, actually not, I have always been alone.' She moved within the LCF from the assisted living department to the somatic departments. She sat alone at the head of the table (perhaps due to her enormous wheelchair), but she also sat next to some elderly people with dementia. Communicating with them was a bit more challenging. There were several elderly individuals who were 'mentally fit', but they were spread across the different tables.

12:30: Lunch
For lunch, the three of us sat in the large lobby. Many people were drinking coffee or eating something with their families. There was a menu, and you could order anything: from croquettes to salmon salads, to ice cream for the kids, to a simple coffee. Residents of the closed departments had lunch in one of the two dining rooms on their own floor. There today's menu featured macaroni with a salad on the side, which the host prepares on his own.

14:00: Music
The 'Van Wanrooy sisters' came to sing and play the accordion. It was quite old-fashioned, but I don't think it mattered to the residents what kind of music it was. The sisters played

familiar tunes from the past. Even residents who were quite advanced in their dementia seemed to come to life with the music and 'moved along'. Residents from the psychogeriatric departments 'were rolled' downstairs in large numbers. Only those considered 'calm' enough were taken downstairs, while the rest had to stay upstairs. We were immediately put to work helping with the wheelchairs. It was striking that almost 80% of the LCF residents were in wheelchairs, while hardly anyone at the SF used a wheelchair and even rarely needed assistance from a walker. Bringing everyone downstairs was a significant undertaking. There were 4 elevators, so there was a long wait before you could go downstairs. We also noticed that this entire 'migration' caused confusion among several residents because they had no idea where they were going, as the elevator brought you to an entirely different environment. At the SF, everything was on the same level, so when the inhabitants went to see the animals, they already had a visual image of where they were going, creating a sense of calm, and understanding of the situation.

During the music activity, we spoke with Henk, the swimmer. He repeatedly said about the building: 'Beautiful building, but they could have done so much more with it.' I found it remarkable that when, at one point, I invented my 5th different answer to his repeated comment and said: 'But those lamps are beautiful,' Henk replied: 'Yes... but again, too small.' Henk was intrigued by the busy lobby where a lot was happening and much to see. He enjoyed sitting in his wheelchair, looking around. He swayed with the music and wanted to dance together, holding hands. We also spoke with another woman who was still quite sharp. I asked her if she liked living here, and she responded very enthusiastically, yes, but she missed being able to go into the city. Another woman also liked the LCF because the shared activities on the ground floor provided enough company during the day, and she did not feel so alone. The caretakers took away half of the residents halfway through the performance because otherwise, there would be a 'traffic jam at the elevator,' and it would take even longer. Music was the only activity and escape from the closed department most residents had during their day.

When we assisted the care staff in bringing the residents back upstairs, we experienced a somewhat challenging and tragic moment. A man was crying and clearly in panic, walking in circles down the hallway on his own department. We took him by the hand and tried to calm him by walking, which worked to some extent. He was evidently panicking due to the significant contrast differences in the hallway caused by the light and shadows from the light shaft and felt lost. At that moment, the care staff was preparing dinner and were present with about 4/5 different caregivers. Four of them were on their phones and did not pay any attention to the man. Our day was ending, and we struggled with leaving the man behind. We asked a young caregiver if we could leave him with her, and she indifferently responded with a yes.

16:30: Closing conversation with Diana
We had a brief concluding conversation with Diana, whom we had not seen for the rest of the day. She showed us the gym where residents receive physiotherapy (but only if necessary). Residents who don't need physiotherapy but want to exercise, must do so on their own floor, which was supposed to be organized by the well-being staff per department. I, however, have not seen any room fit for activities like this on the departments upstairs. To be honest, I wonder how much exercise these residents actually get.

4

OBSERVATIONS

Vision

OF THE SMALL CARE FARM ABOUT LIVING & CARE

1

Person-Centered Care

Residents' well-being takes priority, respecting their preferences and needs. Collaboration with family is crucial.

2

Psychosocial Needs

Good care fulfills psychosocial needs such as love, warmth, engagement, and attachment. The environment should contribute to this, considering individual pace and preferences.

3

Sense of Home

A recognizable and normal environment provides residents with a sense of security. They have individual apartments that they decorate to their liking, with active involvement from family.

4

Flexibility

Everything is possible unless practically unfeasible. Pets, family dinners, and individual preferences are actively supported.

5

Freedom

Residents have the freedom to walk around and, if necessary, go outside the premises. No coercive measures are used, and freedom means accepting risks.

6

Meaningful Daily Activities

Activities are offered to keep residents engaged. Involving residents in activities is a core task, and, together with family, efforts are made to create a pleasant daily routine.

7

Community Integration

Residents are part of society, with accessibility for family, volunteers, and the community. Collaborations and events encourage interaction with people from outside.

5

PICTURES & DRAWINGS

A small scale care farm


STAL EN DIEREN
KAS EN MOESTUIN


APPEL
en

A large scale closed facility


Brasserie INTERMETZO


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