Research Report

Towards a We-Reliant Health Care System

Minor More Healthy Years
University of Groningen
The Netherlands
Group 1 – Living with Dementia

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Foreword

This project has been established under the supervision of the *minor More Healthy Years* (2019-2020) of the University of Groningen, the Netherlands.

The IP generated by this project from the *minor More Healthy Years* belongs to the following students: Anna-Lena Hasselder, Dilay Günal, Julius Govers, Maria Sativa Baumann and Marije van Boven. If any company would like to make arrangements for the use of the IP, they can contact the clients for whom this was designed. The clients, Marijke Teeuw and Klaus Boonstra, can be contacted through the GGD Fryslân, the Netherlands.

There are two parts identified in order to give a broad perspective of the problem:

1. An analysis of Self-Reliance within (Early Stage) Dementia: A review of the Northern Netherlands.
2. The research report: Towards a We-Reliant Health Care System.

We would like to thank the people and organisations that have participated and helped us during this project, as well as the teachers and mentors from the minor. Lastly, we would like to thank our clients for the opportunity to work on this project and for their guidance.

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Abbreviation List

BPSW	Beroepsvereniging voor Professionals in Sociaal Werk
ESD	Early stage dementia
Dyad	Person with dementia and informal caretaker (*Mantelzorger)*
GGD	Gemeentelijke Gezondheidsdienst
GP	General Practitioner (*Huisarts*)
iPH	Institute for Positive Health
ICT	Informal caretaker (*Mantelzorger*)
PwD	Person/people with (early stage) dementia

Introduction

While every era has dealt with their own challenges, this one is undoubtedly faced with the prospect of an ever-ageing population. The World Health Organization (2018) estimated that between 2015 and 2050, the proportion of the population being older than 60 years, will almost double from 12% to 22%. Similarly, by 2020, the number of people above 60 will outnumber children younger than 5 years, indicating the immense strain this will have on our current health system and health spending. That being said, two main drivers are identified for population ageing: increasing life expectancy and falling fertility rates (WHO, 2015, p. 47-48). As an individual is ageing, numerous changes within the body occur, increasing the risk for chronic diseases (WHO, 2015). Although people's health can partially be explained by genetics, much is due to people's physical and social environments, the determinants of health, including their homes, neighbourhoods and communities as well as gender, ethnicity and socioeconomic status. Accordingly, external factors influence the ageing process early in our lives, therefore, it is important to take preventive measures, so people can spend later years in good health.

When looking at ageing populations, one can identify several risk factors associated with negative health such as: obesity, sedentary lifestyles, but also lack of social interactions and cognitive engagements. At higher age, there is also the risk of comorbidity, the experiencing of several chronic diseases at the same time. Especially with regard to lack of cognitive engagements, brain related diseases are rising. In fact, low mental activity, insufficient exercise, and depression are risk factors for one of the most widespread diseases in the world: dementia. In 2015, an estimated 47 million of the world's elderly population was affected by dementia, with predictions of 82 million people by 2030 (WHO, 2015). In fact, dementia can generally be classified as a loss of independence, encompassing several progressive diseases which affect memory, cognitive functions, and behavior. The most common types of dementia are Alzheimer's Dementia, Vascular Dementia, Frontotemporal Dementia and brain injury related Dementia e.g. from stroke (Alzheimer Nederland, z.d.-c). Since dementia is a cluster of symptoms and encompasses a variety of diseases, it is diverse in its progression and how it affects people's lives. Nevertheless, dementia can constitute a significant constraint to people's day-to-day lives, but also impacts human costs to countries, societies, communities and families. With regard to this, the personal, social and economic consequences of dementia are severe, as the disease will lead to increased long-term care costs (WHO, 2015). As a consequence of this, dementia has been recognized as one of the most considerable challenges for our societies in the next decades.

Taking the case of the Netherlands, one can see the repercussions of ageing on the population. Of the total population of 17 million, about 25% were older than 60 years (WHO, 2017). Moreover, the Public Health Foresight (National Institute for Public Health and the Environment Ministry of Health, Welfare and Sport, 2018) indicated that the life expectancy of the Dutch population will increase from 81 years to almost 86 years in 2040, leading age-related

diseases to increase. While dementia currently constitutes 12.5% of all deaths within the Netherlands, it is expected to become the leading cause of disease burden and the main cause of death in 2040. Furthermore, the costs associated with the disease amounts to 9.3 billion Euro, occupying almost 10% of all the healthcare cost. Moreover, costs related to dementia are estimated to increase by 2.7% per year (Alzheimer Nederland, 2019a). Since PwDs are frequently institutionalised, there is an ever-growing interest in increasing the span in which PwD can remain within their homes (Ministerie van Volksgezondheid, Welzijn en Sport, 2018). Conversely, being able to live at home is associated with positive health outcomes such as increased quality of life. With regard to this, the extent to which care at home can be perceived as positive, largely also depends on the situational care context, the caretaker and the surrounding structures. To make the care outcome as pleasant as possible, it is crucial to investigate the current situation at stake and to make recommendations for possible interventions that could enhance the quality of life for everyone involved.

With regard to this, it is necessary to state that there has been a restructuring of the Long Care System, which entered into force on the first of January 2015. Under the Long-Term Care Act, which replaces a part of the AWBZ, people who require permanent or 24-hour home care, find support (Ministerie van Volksgezondheid, Welzijn en Sport; 2016, p. 13). Under the 2015 reform, many long-term care responsibilities were transferred from AWBZ to the WMO and the Health Insurance Act (Dutch: Zorgverzekeringswet). This means that different responsibilities and competences which were previously organized at the national level, are now decentralized and transferred to the municipalities and health insurance companies (Jongen, 2017, p. 9). In this context, the municipalities are especially responsible for ensuring and facilitating social inclusion and independence for older citizens. Further, offering support for informal caregivers and arranging household care. In turn, the provision of nursing services, medical treatments and palliative care of older people receiving care at home, is the responsibility of health insurances (Jongen, 2017, p. 87).

Because of this restructuring of responsibilities, and since ageing and dementia have been identified as important challenges within the Netherlands, the GGD (Gemeentelijke of Gemeenschappelijke Gezondheidsdienst) together with the municipality Friesland and other stakeholders in Vitale Regio aim to increase self-reliance within PwDs in their early stages. As many factors and stakeholders are involved in the care at home, the following research question will be answered within this report: *How might we create an environment in which people within early stages of dementia are enhanced/strengthened in their self-reliance?* When looking at this research question, three spheres of interest were identified as crucial to answer this question: early stage dementia, the concept of self-reliance, and the concept of living environment. Therefore, both desk and field research will be divided according to these themes. Moreover, the field research consists of a questionnaire and interviews of relevant stakeholders within the Northern Netherlands (Groningen, Friesland, Drenthe). By including many different perspectives,

stakeholders, and angles to the situation, we aim to bridge the gap between existing research and practice.

2. Discover Phase

2.1. Desk Research

Within the first weeks, we were mostly concerned with desk research to familiarize ourselves with existing data and to find insights with regard to our research question. For this, we identified three spheres of interest: Early Stage Dementia, Self-Reliance and Living Environment. Additionally, we were guided by perspective weeks focusing on different aspects of health. For instance, within the science week, we discovered the concept of positive health describing that health encompasses more than just physical health. Moreover, within the economics week, assistive and smart technologies which increase safety within the home, became a focal point of research.[1]

Through reviewing literature, we discovered the diversity and complexity of the disease. When it comes to dementia, the most typical symptoms are memory loss, and changes in mood or behaviour. While memory loss is normal within the elderly brain, there is a substantial difference between age-related changes in the brain and dementia induced ones. For instance, healthy elderly people might get confused with completing familiar tasks, but they will eventually figure it out. Conversely, PwD have trouble driving to a familiar location, organising a grocery list or remembering the rules of a favourite game. In this sense, the progression and complexity of the disease vary from patient to patient. Nevertheless, all dementia types result in the progressive loss of independence.

With regard to this, self-reliance is a crucial aspect as it means being able to rely on oneself and to remain independent. As such, the concept of self-management and self-efficacy become relevant. Whereas self-efficacy relates to one's belief in one's own ability to influence events, and is thus influenced by motivation, self-perception and well-being (Bandura, 1997), self-management should refer to both the PwD and their ICT as they are closely connected (Mountain, 2006). Due to the loss of independence, the PwD will progressively become more dependent on their caretaker, for which it is necessary to include their perspective as well. If left unattended, implications are excessive care burden and earlier institutionalisation.

Finally, self-reliance is particularly relevant with regard to Activities of Daily Living, such as cooking, house chores, grocery shopping, finances etc, as a PwD may encounter many different problems in this field. With regard to this, the living environment is an influential factor. It is important for their development, social networking, access to services, and mobility in general

[1] More can be found in *Part 1: An analysis of Self-Reliance within (Early Stage) Dementia: A review of the Northern Netherlands*

and can be divided into micro (home environment) and macro (neighbourhood, city, country). Within the case of PwDs, their living environment should be observed and analysed thoroughly to detect constraints and opportunities to self-reliance. While the micro environment needs to be safe, a place for reprise for the caretaker, and adapted to the needs, the macro environment requires input from the society and a good infrastructure (Mitchell, 2003).

With this in mind, we were able to discover perspectives initially not thought of, and to identify relevant stakeholders. In fact, one of the first crucial steps was the systemic view on stakeholders where we identified stakeholders relevant to our challenge.

2.2. Stakeholder Analysis

The following stakeholders were identified as relevant to our challenge in the discover phase:

1. The first stakeholder is the *person with dementia (PwD) who lives at home,* and it is of most importance to include this category to investigate their perspective on the situation to ensure their needs are fulfilled and their capabilities strengthened.
2. The second stakeholder, the *informal caretaker (ICT), dyad or mantelzorger* (in Dutch); is a crucial figure to include. As dementia progresses, people become more reliant on support from family members, and/ or care home agencies. With regard to this category, it is necessary to foreground that caretaker refers to *informal caretaker*, a person with no prior experience or connection to the care system. As this group is close with the PwD, it is pivotal to investigate their roles and needs to ensure a positive care situation.
3. The third stakeholder group are the *health and care professionals.* In contrast to the latter, this group is currently employed by a public or private health organisation providing support. Since this group of stakeholders is rather broad, it can include General Practitioners, Nurses, Psychologists, Physiotherapists and other people working within Dementia.
4. Another group crucial for gaining better insights are *experts*, who are people with current or recent experiences of undertaking dementia related research or involving aspects related to dementia.
5. The last group consists of policymakers and other actors who shape national, regional, or local dementia policies, including those who plan services.

During a workshop (systemic view on stakeholders) offered by the department of health psychology, we were able to gain insights into how an approach towards dementia should be structured. It was discovered that in order to increase self-reliance, a circular approach should be applied (see *annex I*). Therefore, every stakeholder mentioned above has to be included within

the situation while also being dependent on one another. Having concluded this, we were able to expand the scope of our research and plan the first interviews.

2.3. Field Research

With regard to field research, the main focus was to learn about the practical lives of people involved within dementia care and personal accounts of people with early stage dementia, family members, caregivers, and experts. Therefore, we conducted 13 qualitative interviews with relevant stakeholders and a questionnaire completed by 37 participants from various fields. Through this, we gained insights into the attitudes, motivations, processes, barriers, etc that apply with regard to self-reliance within PwDs. From the field research, seven relevant factors were identified in relation to self-reliance and PwD. The results of these aspects can be found within the Research Report, but they generally amount to: *Activities of Daily Living (ADL), Awareness, Cognition and Illness Perception, Mobility, Social Aspects, Needs and Services,* and *Health Landscape.*

With regard to this, the aspect Cognition helped us to acquire a better perspective on the medical aspects related to dementia. In turn, Illness Perception and social aspects helped us to understand personal relationships and the role of society. It was generally remarked that stigma and acceptance play a great part within dementia. Moreover, to retain self-reliance ADL and Mobility were deemed as crucial. Although services are principally available, it is difficult for the PwD and their caretaker to navigate through the system. Finally, it should be foregrounded that there is no one-size-fits-all solution when it comes to dementia care and that a more personalized approach is necessary. Consequently, it can be said that the situation of the PwD needs to be viewed from all these aspects in order to find better solutions.

2.4 Conclusion

Within the Discover Phase, we responded to the question: *How might we create an environment in which people within early stages of dementia are enhanced/strengthened in their self-reliance?.* While the desk research, or more specifically the literature review, helped us to gain a general understanding of dementia, the field research offered valuable insights into the practical lives of people involved within dementia care, and personal accounts of people with early stage dementia, family members, caregivers and experts within the field. One could say the literature review helped us to acquire a bird's-eye perspective, whereas we gained a more worm’s eye perspective through the interviews we conducted. By combining the knowledge gained through both, we aimed to paint a more complete and realistic picture of people living with dementia, while also bridging the gap between the existing knowledge and the practical aspects of dementia.

The themes identified within the field research are important aspects within the life of a PwD and his or her caregiver. To visualize, it helps to map the aspects within a circular approach, in which the PwD and their informal caregiver are depicted within the center, surrounded by health professionals, family, friends, and volunteers within the living environment. Self-Reliance will be enhanced when the PwD and the informal caretaker are properly connected to the system to increase external support. Moreover, early disclosure of diagnosis, support with its consequences, focus upon the specific needs of the PwD, a more anticipatory system, and increasing awareness within society are crucial aspects to increase the self-reliance of a PwD, but also to increase their quality of life and well-being. Additionally, the role of the informal caretaker within the life and the care of a husband, wife, father, mother, or friend of a PwD has to be foregrounded. Their well-being should not be neglected in order to achieve a good situation for all people involved in the care. Furthermore, since there is not a-one-type-fits-all approach to dementia due to the diversity of disease and lifestyles, it is important to take the determinants of health into consideration by reducing risk factors early on. Ultimately, there are especially risks associated with people that feel lonely, live isolated or are generally little included within society so that further research in this field is encouraged.

3. Define Phase

During this phase, we were concerned with key results, selecting stakeholders and generating ideas based on the insights gained from the research. In order to make dementia more tangible in the community, we aimed to narrow down the scope of the problem. Therefore, we identified where themes intersected and where possible gaps could be addressed. To do so, it was necessary to make use of several tools, such as personas, a customer journey and more specific problem definition. Through this, we were able to approximate to a more person-specific perspective on dementia, enabling us to identify latent and future needs.

3.1. Personas

Firstly, we created personas who represent fictive people affected by the disease. This helped us to connect more easily with the end user and to better understand their needs and problems. We decided to create three personas: a care dyad, consisting of a man with dementia named Wytse, and his wife, Aaltje as the informal caretaker. However, since dementia also occurs within individuals living by themselves, we also included an elderly lady with dementia, Louise van Dycke, who did not have a spouse or close relative around her to assist. By including her, we aimed to account for a factor of social isolation and diminished access to possible interventions. Although our focus stays with the couple for several reasons that will become visible in the following phases, the single lady is also considered and can use the final product. The primary

reasons were for one, the additional workload of considering both journeys extensively and the more common situation of a care dyad, in which adult children and friends also are possible informal care takers.
However, in the following phases we used the care dyad Wytse and Aaltje. Underneath are found little introductions to the personas. The full stories and facts about the three personas can be found in *annex II*.

Wytse Venema

Wytse is a 67-year-old man who lives with his wife in Sneek, Fryslan, and retired four years ago as a construction worker. Nevertheless, he stays bodily active and is a member of the local football club and church, and is responsible for the household chores such as doing groceries. A few months ago, he was diagnosed with dementia, which also explains certain omissions, his disorientation and consequently reduced mobility. In his eyes, he does not have a problem and refuses to be categorized as demented because "everyone has memory problems". Names of objects and persons have been slipping from his mind for years. He is still worried about how people see him now, but stays generally positive as he is overall satisfied with his life and who he is. Moreover, he wishes to maintain his life that way; play and take care of his grandchild, go to the football club and most of all, keep a good and balanced relationship with his wife Aaltje.

Aaltje Venema-de Vries

Aaltje is 64 years old and has been married to Wytse for 42 years. They live together in Sneek, and also go regularly to church. Her hobbies are sewing and participating in her book club. Aaltje is still working as a secretary at a law firm. Anyhow, she is facing difficulties with continuing to manage her hobbies, work and supporting her husband with his daily life. This combination causes a lot of stress and feelings of being overwhelmed. These feelings are also reflected in her reaction whenever Wytse is showing 'dementia behaviour', which he is denying as this makes it even more difficult for her. Lastly, it is not easy for Aaltje to find professional support as she is not that familiar with the health care system, and does not have the time to navigate through the system.

Louise van Dycke

Louise is a 75-year old retired university professor and widow, who lives in Leeuwarden. She would be married 50 years now, but no children were born from the marriage. Therefore, she is isolated and only her neighbour comes by for a cup of tea once a week. Her other interactions are with the cleaning lady twice a week, but that is a mere working contract. Being the cultivated woman she is, she manages her own medical and financial life as she does like to have one or two glasses of wine in the evening. Lately, both of

those things seem to get a life on their own. Louis sometimes forgets she already had her drink, and doing her balances seems more like a challenge, rather than the easy walk, she was used to. This new situation is overwhelming and stressful for her, although she presents herself as the respected professor she remembers from not so long ago.

Although Louise is less considered throughout the report, we have considered her status as an isolated ESD individual, since bringing the product developed to those will pose an obstacle.

3.2. Customer Journey

We made use of a customer journey which describes a process or moment in time from the point of view of the persona. By doing so, the customer journey helps to identify where obstacles might occur within the daily life of the persona and whether there are certain opportunities for improvements. In the customer journey, we experienced a few hours within the daily life of Wytse and Aaltje. It especially reflects on problems with complex tasks, lack of awareness in community, stigma and denial, and care burden. Most favorably, these problems should be turned into opportunities to enhance the environment of the care dyad.

3.2.1. Customer Journey Wytse at home

Usually Wytse is alone at home watching sports, while Aaltje is at work. Around noon, Wytse gets hungry and decides to make a baked egg sandwich for lunch. However, he encounters several obstacles on his way to success, such as forgetting the ingredients, having problems going to the supermarket, forgetting what he wanted to buy, and not having his wallet at the checkout. Furthermore, when he returns home with the ingredients and starts to cook, his daughter calls so that he forgets his eggs on the stove. Eventually, the smoke causes the fire alarm to go off and panic spreads. Luckily, his daughter on the phone notices the panic and assists him through this difficult situation. Simultaneously, Aaltje gets a phone call at work about the fire alarm going off and considers to return home immediately, but is assured by her daughter that everything is fine. Yet, Aaltje is still worried about whether she can leave Wytse alone at home at all. All those troubles and imaginations make her feel very overwhelmed and she wonders where she could find support.

3.2.2. Customer Journey Aaltje trying to find services

A second customer journey reflects on the care lag in the Netherlands, slowing down the responsive character of a smooth public health system. This is problematic considering the progressive character of the disease. As Aaltje already has problems communicating with Wytse about his disease, she decides to find day-care services. A friend recommends to her to go to the WMO-loket, however, the waiting time and the final benefits are not promising.

3.2.3. Insights Customer Journeys

Filtering out from the customer journeys, some opportunities for improval appear, such as writing grocery lists, modifying public infrastructure, including business into awareness campaigns or technological assistance. These led us to the conclusion to focus more on the connecting link between the medicalised and social world, the case manager. When observing the other opportunities, alleviating these could be happening if the social interaction towards the medicalised world persists.

Essentially, it is necessary to raise awareness about dementia in Wytse's surroundings. This might decrease the attached stigma to dementia and make him feel more comfortable to express his needs and may allow him to no longer be in denial. It might also make it easier for the care dyad, and particularly Wytse, to find coping strategies for memory loss, such as writing shopping lists and reminders. Ultimately, by providing a mentor/volunteer to assist him, it would be possible to reduce the care burden for Aaltje. Additionally, a case manager might be a good person to assist with administrative documents and finding services. Finally, while reflecting on Wytse and Aaltje's Customer Journey, we found the need and wish for a more responsive and adaptive healthcare system.

The full customer journey can be found in *annex III*.

3.3. Field Research

To further work towards a final definition, we conducted some interviews in the Define Phase. First of all, we interviewed a GP. The main goal of this interview was to research what exactly her role is in diagnosing someone with dementia. Since she is working in Friesland, we could ask her specifically how the system works in Friesland and explore the role of the community.

The GP becomes involved when there are signs of the disease, when the disease is more progressed or when the mantelzorger is overburdened. The GP explained the system and that the people are often referred to the hospital for a diagnosis. She also mentioned that the organisation TinZ was playing a crucial role in Friesland after the diagnosis. She explained that the conception of dementia is terrible and needs to be changed and we should have a more positive disease perception. Also, acceptance of the diagnosis is important and the network seems to take a crucial role, because without a stable network, the earlier institutionalisation is inevitable. Moreover, a real obstacle is finding the right services and the right activities for someone.

Afterwards, we went to an elderly care-organisation in Friesland that is working towards an inclusive dementia friendly society, with the main goal to adapt to the future needs. This involves cooperation and a better connection between people, groups, functions and facilities as the society plays an important role as do stigma and acceptance of diseases. Within their project they have indicated that there are currently problems with the availability of the staff and with

financial resources. When trying to anticipate the future, earlier institutionalisation is also indicated as a problem. Factors for this are amongst others: the care burden of the informal care-taker and the network around the PwD. As they explain, in order to overcome earlier institutionalisation, the other factors than the PwD, need to be ameliorated. In fig. 1 can be found an impression of how inclusion is compared to integration in a society (Sweco, 2019).

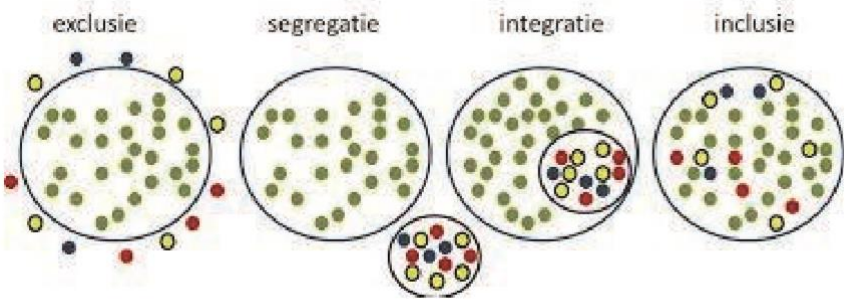

Figure 1: Representing different types of inclusiveness in society (Sweco, 2019)

Lastly, we went to the municipality of Súdwest-Fryslân in order to see to what extent they are involved in dementia care. They are linked to the project Vitale Regio to look at how PwD in the little villages will be able to live longer at home. Within Sneek, the focus is currently on the inclusiveness of society. Most of the time the municipality is not much involved in projects, however, other organisations are. An important improvement would be to strengthen the connection from the current projects and organisations with the municipality.

3.4. Final Definition

Having gained more practical insights into the situation by means of personas and a customer journey, we were able to further define our problem. Therefore, the following problem statement for self-reliance in PwDs can be found underneath.

Given the fact that dementia is a progressive disease, the self-reliance of a person changes over time. This means that as self-reliance decreases, the external support has to increase. To facilitate this, an interactive network around the PwD is pivotal, which should consist of the ICT and the community. If only the ICTs would devote themselves to the needs of the PwD, an excessive care burden will be the consequence, resulting in possible early institutionalisation and decreasing health in the carer. Therefore, the involvement of the community is necessary to accompany both the needs of the caretaker and of the PwD. The optimal situation thus requires a certain level of interaction between the PwD, the ICTs and the community.

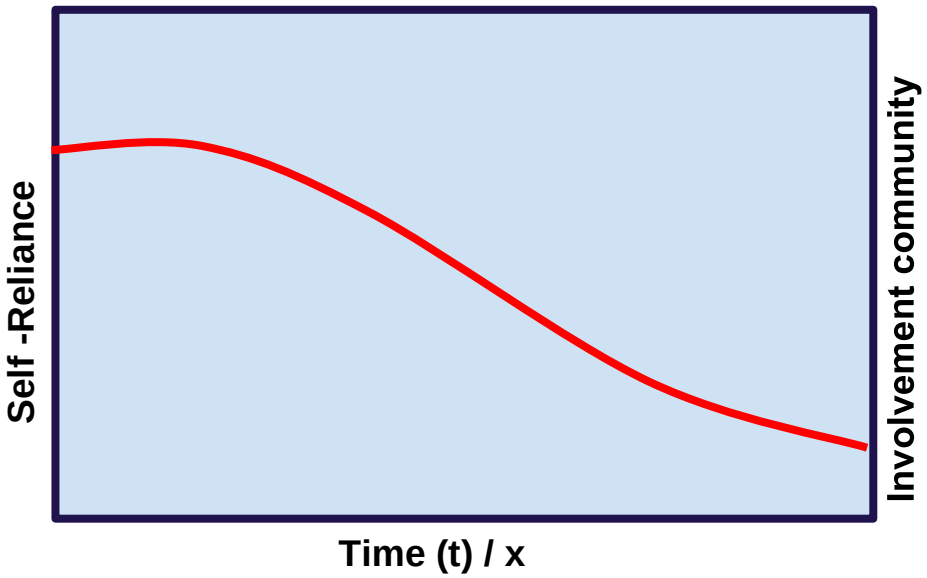

Figure 2: Self-Reliance Graph - As self-reliance decreases, involvement of the community has to increase

Figure 2 functions as a visualisation of how the external support in terms of the involvement of the community has to increase when the self-reliance of the PwD decreases over time. The more the self-reliance of a PwD decreases, the more external support is necessary for them to function properly.

As identified in the Discover Phase research, self-reliance needs to be enabled by a responsive, future-oriented public health structure that can facilitate interaction by maintaining a social network, providing assistance, and strengthening mobility. By doing so, cognition can be sustained as long as possible and needs resulting from the loss of self-reliance can be met. Due to the broad nature of the term community, the actors for this sector should be further elaborated upon. The most important role within this sphere for this challenge is played by the health professionals, the municipality, experts and civil society. It should be said that other actors might also play a crucial role such as, but not limited to, NGOs, health insurances, businesses and cultural centers. Depending on the family situation, ICTs might constitute the spouse, children, or other family members, but also friends, volunteers or the civil society. As stated above, the ICT is often faced with a high care burden. To minimize this burden, the community should function as a safety net for the ICT to get information and support. While the community provides information about the next steps to take and emotional support, the ICT can give insights and takes over a role in the public health structure.

Figure 3 illustrates the interconnection between the PwD, their network and the community. The numbers indicate an interconnection and key words between two of the circles.

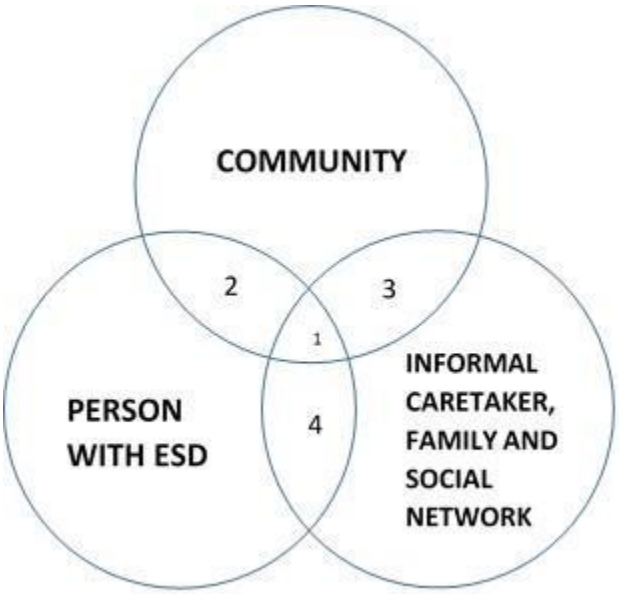

Figure 3:

1. **The main intersection:** interaction of the three dimensions and aim of what should be targeted.
2. **A branch intersection:** obstacles - for example isolation of the PwD from community. Keywords: stigma, one-size-fits-all and awareness
3. **A branch intersection**: obstacles - for example overburdening of the caretaker. Keywords: information and support
4. **A branch intersection:** obstacles - for example the described care lag. Keywords: care burden, belittling, perception and ADL

When it comes to the interaction between the PwD and the community, the perception of illness and stigma are relevant topics. Stigmatisation of dementia is a factor that worsens the situation for the PwD. For instance, stigmatisation can result in denial of symptoms by the PwD as they might not want to be perceived as less or is afraid others might view them differently. This is problematic as the PwD might refrain from asking for support, which in turn isolates the PwD from the rest of community making services less accessible decreasing self-reliance. Accordingly, stigmatisation needs to be tackled by creating positive awareness of dementia within communities through a more open dialogue. Through this, a one-size-fits-all approach should be discarded for more individualized services closer to the perspective of the PwD. Currently, it could be said that the community is rather passive in supporting the care dyad in their self-reliance as interactions are still not fully achieved.

At the end of the Define Phase, we had to create a problem definition and a how-might-we question. This enabled us to focus on one specific part of our challenge we wanted to find a solution for. The goal of the *how-might-we question* was to open up space for brainstorming. The problem was defined as follows; "*As dementia progresses over time, the self-reliance of Wytse simultaneously decreases, increasing the need for external support.* Based on this, we selected the following *how-might-we-questions* to guide our next research phase:

"*How might we remove/diminish the community barriers to help/support Wytse to remain self-reliant and Aaltje to have a bearable care burden?"*

This problem statement and the *how-might-we-question*, will guide us within the next phase to have a clearer focus on the situation of the Personas, their problems, concerns and needs, to establish a suitable solution.

4. Ideate Phase

4.1. Ideate Session

Having defined the problem further, the next phase was concerned with developing ideas that could solve, or improve the problem. To do so, we used the themes identified in the research: stigma, acceptance, social connection, care lag, lack and acquisition of services. Within the ideating face, we generated over a hundred different ideas that are either related to the problem, or offer possible solutions for it. After generating all these different ideas, we narrowed them down further and eventually picked a top five that seemed most applicable and feasible to us. With these five ideas in mind, we went through a series of sketching, designing, prototyping, and feedback rounds in order to make the ideas as good as possible. Having gone through this process, we were left with five low-fidelity prototypes, which are briefly explained below.

4.2. Initial Set of Prototypes

Having gone through this process, we were left with five low-fidelity prototypes which are briefly explained below:

Care Cloud: The idea of the care cloud was to create a team consisting of all stakeholders involved within the care of a PwD and their caretaker. This would result in a care cloud that could anticipate more on the person's needs and the needs of the caretaker as they get to know them over time. We also identified the need for a connecting person in the system that can guide the care dyad through the system and who receives information from the health professionals.

Supermarket Assistance: The idea of the supermarket buddy was created based on the customer scenario for Wytze. In this system, the PwD could go to the supermarket with their grocery list. At the supermarket, someone would be waiting for them to help them to get the groceries they need, and to assist them when going through checkout. The grocery list could be either on paper or sent to the supermarket digitally.

Buddy System: The buddy system would provide each PwD with one or more buddies. These buddies could provide them with assistance while doing activities of daily living, but also accompany them while going out for the day or joining them with hobbies. In

Wytse's case it might for example be someone from the local soccer club who would take Wytse out to play a soccer game. In Louise's case, this buddy would also have a social role.

Smart home: The smart home was an idea that would provide the PwD and the caretaker with a modular home that could anticipate on future needs. As dementia progresses, the relationship between the PwD and the caretaker also changes. The caretaker may desire a separate room where they can retreat and have their own time. The smart modular home would make this a possibility, as the technology is able to look out for the PwD, it can for example detect when someone is wandering and falls. Another option for the smart home is putting in appliances that ensure the safety of the PwD, such as a stove that turns itself off or a TV that tells them to take their medicine.

Tinder/Marketplace app*:* DementiaTinder is an app that connects PwD or the caretaker to a volunteer or activity that suits their preferences. Individuals and organisations can offer their services on the platform and the PwD or the caretaker can choose which they would like to receive or work with.

4.3. Feedback on Prototypes

After developing these low-fidelity prototypes for the different solutions, we went through another round of feedback from possible end-users and other stakeholders. These end-users include one project leader of creating an inclusive society, one manager from an elderly care-organisation in Friesland and one professional working on dementia friendly societies. The most important feedback we got from all the end-users is that every person is unique. This supported our earlier conclusion that there is no one-size-fits-all solution to any problem PwD face. With regard to this, they suggested and emphasized to us to create something flexible, and adaptive to every person's needs. Conversely, we received a warning from one of the end-users to watch out with making something too childish as this could unwillingly be stigmatizing for them or their caretakers. A third point of feedback from the end-users is that the bases of these ideas have already been carried out, but never got a foothold, thus we would have to come up with something to renew them and make them stick.

Having carefully considered the feedback, we decided to move forward with the idea of the care cloud. This was due to three reasons: first, because the final solution should be both impactful and original, but also feasible and a good value fit. Second, we estimated the care cloud to be a great possibility to get to a flexible solution that could be customized according to the person's wishes and needs. And lastly, we chose the care cloud because it might be a way to reduce stigma and raise more awareness in society. This could not only help PwD feel more

valued and taken seriously, but also brings society closer to the person and ameliorate the connection.

During these days we created several graphs and visualisations for a better understanding of our problems and where we would like to have the aim of our solution. However, these graphs are condition-dependent and person-dependent.

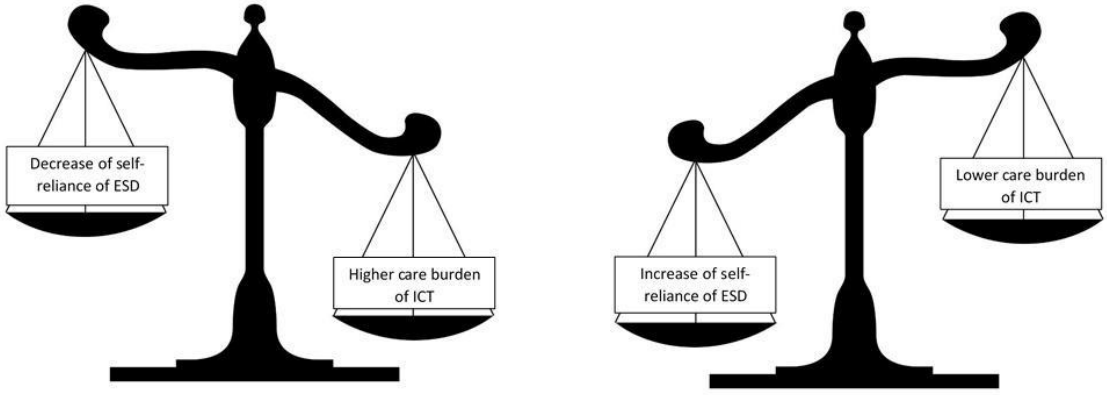

Figure 4 A&B representing a balance of scales between self-reliance and care burden

1. **The scales of self-reliance and care burden:** it is important to find the right balance between these two aspects. Self-reliance of the PwD is interconnected with the care burden of the ICT. Under the condition that there is no external support, we can conclude the following:

   If Wytse's self-reliance decreases, he will no longer be able to do everything by himself. Consequently, Aaltje might need to do more for him and will thus have a higher care burden, which is visualised in Fig. 4A

   If Wytse's self-reliance increases, he will be able to do more and his scale will go down. Consequently, the care burden of Aaltje will automatically be lighter, which is visualised in Fig. 4B

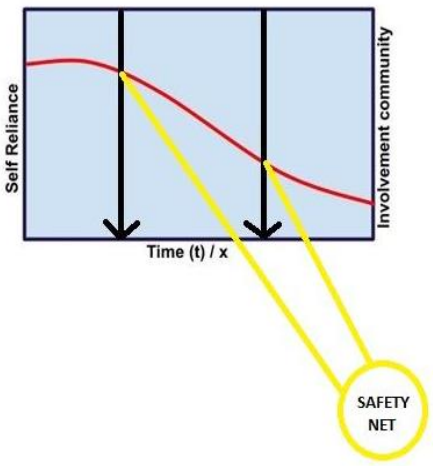

Figure 5: Safety Net catching the down slope of self-reliance

2. **The self-reliance graph with safety net:** we identified the different needs of the PwD at different times in his disease. The needs are equivalent to the situation. As we identified earlier, Wytse's self-reliance decreases as dementia progresses. Since he is going through a stage of denial, he is not likely to accept the right support when needed. In this case, his self-reliance will decline faster and he might miss out on opportunities. Once Wytse has accepted his disease, at a later point in his disease progression, he might regret not having organized things earlier. In order to overcome the gap in accepting the need for help, the aim is to create a system that will function as a safety net for Wytse. This safety net should have the function to catch the dementia-induced fall in self-reliance by spanning a web between the medical services and people necessary that already take or will take care of him. Simultaneously, also to alleviate the care burden of Aaltje by amplifying Wytse's social contacts.

5. Prototype Phase

5.1.Service Scenario

To contextualize our idea, we used a service scenario to map out our previously established prototype: **Care Cloud.** A service scenario functions as a visualization of the end-user experiencing the product or the service we designed. So, we are able to identify steps that are necessary to be taken, possible obstacles and opportunities, as well as benefits of the product. Within our service scenario, we painted the picture of what might happen when Wytse and Aaltje go through the initiation of the prototype. This helped us to visualize the aims of the prototype such as to provide information about the disease, the process and next steps to take, increasing

awareness of services, offering emotional support for Wytse and Aaltje, and hopefully reducing the care burden.

Accordingly, our service scenario begins when the PwD receives their diagnosis. As this diagnosis might be confronting to some and difficult to take in, every person receiving a diagnosis in our scenario will be assigned to a social worker that guides them through a series of steps in order to set up the beginning of the care cloud.

Service Scenario Steps:

1. After the diagnosis, Wytse and Aaltje get assigned a social worker. The social worker will sit down with them and explain the disease, what the possibilities are, and what the next steps could be.
2. After the first meeting, a break of a few days up to two weeks will take place so that Wytse and Aaltje have time to digest everything that has happened and decide whether they wish to continue working with the assigned social worker.
3. Wytse and Aaltje will schedule a second meeting with their social worker. In this meeting, they will be going over the immediate needs and discuss activities that are going well and those that are difficult.
4. Wytse and Aaltje will think about possible future needs they may have, while also focusing on the possibilities and activities they would like to continue doing.
5. The social worker will advise Wytse and Aaltje on how to apply for the long term care act (WLZ) or the social support act (WMO).
6. After the second meeting, another break will take place. This will help the dyad to process information and to integrate the knowledge into their daily lives
7. Wytse and Aaltje will schedule a third meeting with the social worker. In this meeting, it will be discussed which healthcare professionals and other important people might be part of the care cloud. During this process it is important to look at the people themselves, such as their wishes and worries.
8. The social worker will go ahead and mobilize the carecloud team. The social worker will also identify the interests and capabilities of Wytse and Aaltje and suggest activities that might fit well with them and/or suggest that Wytse gets a buddy.
9. Wytse is still in denial, but Aaltje convinces him to get the buddy.
    a. Wytse goes to ‘Meet your buddy event’, organized by an NGO related to dementia, and meets a buddy who also likes soccer.
    b. Wytse, Aaltje and the buddy have a meeting to discuss wishes and expectations and how often they would like to meet, etc.
10. (After Wytse has progressed into accepting his disease, the buddy may suggest engaging within an event organised by the NGO to raise more awareness for dementia).

After the creation of the service scenario, we presented it in a coach roast in order to acquire feedback on the problem and critical questions. At the roast, two mentors and a design thinking expert were present. While the coaches liked the general idea and aims of the product, they still had a lot of questions on the service scenario, most of which ended up in the test plan. They posed questions such as:

- What would be the channel of communication?
- Is the system easy to follow?
- Who exactly is your end-user?
- How would you give the care-dyad grip on the situation?
- Do you think it is feasible to implement?

The coaches also suggested looking into the costs of the plan, since it might be hard to make the carecloud cost effective. Overall, all three of the coaches did appreciate the patient centered approach and the flexible approach to make it valuable for everyone.

5.2. Test Plan

After creating the initial prototype and service scenario, there were a lot of remaining questions. Therefore, we created a test plan to test the fundamentals of our service scenario and our prototype. As testing the exact service scenario or even parts of it would be too difficult to achieve, due to privacy and emotional constraints, as well as problems of communicating with someone with dementia, we decided to test our ideas via feedback gained from interviews conducted with experts involved with dementia care. This meant not only interviewing social workers and case managers, but also doctors, nurses, health psychologists, and other experts.

While different guidelines for the interviewees were composed depending on their field of expertise, we aimed to enquire about specific parts of our prototype by testing assumptions and filling research gaps. Guiding questions in each interview were structured as follows:

1. Questions about the person interviewed and their position within the field
2. Questions about the concept, the logic, relevance and feasibility of our prototype:
    a. Who connects the different types of care ?
    b. Are there already existing structures for this?
    c. Is there an existing overview of services?
    d. What do you think of the positive approach to health? Are you working with this approach?
    e. Would you add or change an aspect of the prototype?

f. Do you think it adds value to the system?

3. Questions about research gaps we aimed to cover:
    a. Who should be the connective person?
    b. The diagnosis and the aftermath.
    c. The role of the municipality.
    d. Positive health.

5.2.2. Results Test Plan

During the testing phase, we conducted six interviews with end-users, who are several people working within dementia care. This led us to crucial insights that helped us to create the final concept. As stated above, through the acquisition of feedback, we were able to test assumptions about our product while adapting our concept accordingly. In the following paragraphs, we will discuss the most important insights from these interviews and desk research that led us to the final concept.

Health Psychologist GGZ

We interviewed a health psychologist from the GGZ who specifically works with dementia cases that are difficult to diagnose and to provide care for. We questioned if our service scenario with an assigned social worker would be realistic. We also asked questions about the course of events and which methods the GGZ was familiar with to see if they were interested in something like positive health.

The health psychologist explained that independence sounds like a nice goal for PwD, but that it should not be the final one. Someone may go through a lot of pain and trouble to stay 'independent' and thereby misses out on other valuable activities. Therefore, we should guard quality of life, rather than independence.

Moreover, not all people diagnosed with dementia receive a social worker, but all have the right to a case manager. For her, the case manager could use an upgrade, especially with regard to positive health. She agrees that positive health could help the client to achieve a higher quality of life. With regard to this, the case manager often builds a relationship with a client, so they are able to motivate them and to help the ICT not to fall into isolation. Since there is a limited number of case managers, giving them a lower caseload and more time to spend with clients would be one of the challenges in this idea.

Nursing consultant

The geriatrics department at the hospital has started working with aftercare consultation. We specifically had questions with regard to the process of diagnosis and what kind of assessment the hospital normally uses. We also wanted to know whether she, or the hospital, were already using methods of positive health and finally, how a case manager would be assigned.

The consultations are done by the nurse (and some colleagues) for the care dyad to ask questions after the diagnosis. Her main tasks during these consultations is to provide information, to listen, to give people time to express their feelings, and to look for possibilities of current and future care needs. These tasks are very similar to what a case manager does, however, the majority of case managers lack a psychosocial component, for which positive health could account for. The nursing consultant had a great interest in the positive health approach and corresponding form of the Institute for Positive Health.

At the first appointment, the nurse will refer the care dyad to a case manager. However, sometimes it is difficult to find the most suitable case manager for a certain client since there may be issues such as a waiting list, unfamiliar care organisations or a long distance. Finally, she informed us that no real overview of the possibilities of care for PwD and their caretakers were available for her.

Social Worker #1

The BPSW is the Professional Association for Social Workers. The first social worker interviewed has collaborated with them to create the Expertise profile for case managers. We specifically had questions about the current numbers of case management (e.g. shortages and backgrounds) and their view on the current bottlenecks in the case management system.

Currently, about 80% of the case managers have a nursing background. There is a lot of medical support for PwD, but very little psychosocial care. According to the BPSW there should be more investment in the social aspect of PwD. This is why the BPSW is aiming to have more case managers with a social work background, who can provide psychosocial focussed care. Since there is a shortage of nurses, and most case managers have a nursing background, it comes as no surprise that there is also a shortage of case managers for PwD.

Furthermore, some municipalities and health insurances have less clarity about the financing of the case managers. There is little consensus about by whom this responsibility lies. This is however different for every municipality. Finally, many care organisations are not aware that it is possible for a social worker to become a case manager, which is why they still only install nurses on the position. If more care organisations and health insurances become aware of the possibility to have social workers as case managers, this might be more accepted.

Social worker #2

The second social worker we interviewed is also a '*verzorgende'* for a care organisation. We were specifically interested in the tasks of the social worker and '*verzorgende'* in order to understand our connective person better. We were also interested in the position of the case manager from the view of a social worker, and whether a social worker would become a case manager. Finally, we wanted to know if she and her organisation knew about the existence of positive health.

PwD appreciate having structure in their lives. The 'verzorgende' is part of the client's network and provides them with as much assistance and structure as possible. When people get a case manager, the GP and/or the hospital will be less involved or even not at all. The case manager is directly involved with the '*verzorgenden'* and functions like the spider in the web, since they know everything about legislation, laws and indications. The biggest difference is that the *'verzorgende'* is more for the practical care someone needs. When it comes to case management, background does not matter but it is important to not be too practical. A lot of people who work in care or social work would be willing to do something extra to become a case manager.

When we asked about positive health, this particular social worker stated she already works with positive health in order to see what wishes and needs of the client are. The concept is very close to the way they already work, so she highly advises to work with positive health.

Case manager

The case manager we interviewed works for one of the bigger care organisations in Friesland. We were specifically interested in the diagnosis process, and when someone receives a case manager and if these are encountering problems with too much workload. We were also interested in where they acquired information about services and if this platform was being used in an efficient way. Moreover, we were interested if and what they knew about positive health.

The main tasks of the case manager is to provide information and to explain common characteristics of dementia. Most important, however, is guiding the clients. For example, through the WMO-loket for getting care or day-care possibilities. The case manager comes once every 6-8 weeks on average for a visit. She explains that they usually do not have waiting lists, but if someone has to wait longer than six weeks they will be contacted.

Since the case manager explained she was already using a social approach next to the practical matters, she thought that something like such an approach would already be in place. However, she was not familiar with the term positive health.

For referring the dyad to services, they use the social map that is located on a server within their organisation only, so neither the hospital nor another organisation can look into their social map. For example, physiologists, day-care activities, initiatives, AD Cafes, and nutrition services are in their social map. Most of the time, rather big initiatives are in this social map, the rather small ones are more difficult to approach. Finally, the municipality also has a publicly accessible social map that can be found online, but this is not specifically for PwD.

Neuropsychologist

A neurologist from Sneek was consulted to gain insights into how PwD related symptoms are diagnosed in the region. We specifically wanted to know what happens after people get

diagnosed with dementia within hospitals to verify whether the case manager position is already implemented and if so, how the system functions.

The neurologist explained how people with symptoms of dementia are being referred to the memory clinic by a GP. At the clinic, someone from geriatrics will do an assessment with the patient to ask about cognitive complaints and to examine via cognitive screening tests. The specialist will also talk to the relatives, and do blood tests. After the diagnosis, the health professional informs and advises the patient about having a case manager. However, this is not obligatory. The meetings with the case manager always take place within the home of the PwD. There is no contact between the neuropsychologist and the case manager, however, he maintained that they would benefit from the insights.

He explained that most neuropsychological cases are discussed once a week within an interdisciplinary team meeting. This team consists of: geriatrior, specialised nurse, psychiatrist, neuropsychologist, neurologist and in some cases a logopedic therapist or ergo therapist. We identified this as a chance for the case manager to be included within the meeting, so that the case manager will have a complete picture of clients and knows where their strengths and weaknesses are.

5.2.3. Conclusions field research

Based on these interviews, we were able to revise our final concept. First of all, it became clear that the connective person from the service scenario had already a place in the system. The initial connective person, the social worker, could be replaced by a case manager. However, the existing case manager could use an upgrade with regard to positive health. Generally, the positive health approach was by most of the people we interviewed perceived as a useful concept within case management. It is a rising approach within healthcare, but some experts were not familiar with the term positive health, while others were more or less. This indicates organisations should be made generally more acquainted with the positive health approach.

Another conclusion derived from the interviews is that the current approach is too medicalised. Instead, more focus should be on psychosocial care. One of the main reasons the case management care is too medicalised is due to the fact that the majority of case managers have a nursery background. Instead, more social workers should be aware of the option to become a case manager.

Moreover, care organisations also have to become more aware in the possibility to hire social workers as case managers, and not only people with a nursery background. This could result in a better balance between the psychosocial/medical approach, and would decrease the shortage of case managers. It also became clear that it would be beneficial for the case manager to be included in the meetings of the interdisciplinary team in the hospital to gain a better insight into the situation of the PwD.

Lastly, it can be concluded that there is a need for adequate guidance through the care organisations, as well as through projects and services. Currently the overview of services for the case managers is situated on the own drive of the organisation and not available for external parties. To create a more efficient platform, a more centralised overview is required.

5.2.4. Desk research

While testing our assumptions, we also did some additional desk research. First of all, we found additional information on the overarching plans in the Netherlands: The *Deltaplan Dementie*. This plan is about improving the living environment and care for people dealing with dementia. The initiative is amongst others set up by the government (Ministerie Volksgezondheid, Welzijn en Sport) and Alzheimer Nederland (Deltaplan Dementie, n.d.). Their aim is to work together towards a dementia friendly society within the Netherlands and to make people aware of dementia friendly approaches. Many organisations have joined the Deltaplan already and many municipalities have decided to work to become a dementia friendly society. Several universities are working together within this plan, but so are different volunteer websites (e.g. wehelpen.nl), several health insurances (e.g. Zilveren Kruis), and organisations focused on dementia care, such as TinZ Friesland and the Beroepsvereniging van Professionals in Sociaal Werk (BPSW) (Deltaplan Dementie, n.d.).

Secondly, we need to ensure enough case managers are available. The current numbers indicate shortages of case managers and waiting lists. Of all the people waiting for a case manager, 44% had been waiting longer than 6 weeks in 2018 (Homan, 2018). The results are variable within the regions, some do not have waiting lists, but others do (Homan, 2018). Moreover, according to the BPSW's Expertise Profile on case managers dementia (2018), 80% of the case managers have a background in nursing. Their advice is to also employ social workers with a specialisation in case management for this job. This might then result in a decline of the shortage of case managers and put a greater emphasis on the social aspect (BPSW, 2018) and would also be useful for lowering the caseload for the current case managers and the *wijkverpleegkundigen.*

Since we decided to focus on Súdwest-Fryslân, we looked into the history of the case management of Friesland. It appeared that the organisation for case managers in Friesland (TinZ) has been discontinued a few years ago and the branch of the case management has been divided over five care providers in Friesland. One expert on the case management situation in Friesland explained that the discontinuation of this organisation was due to high financial costs, with the split of TinZ as a result (TinZ, n.d.).

Lastly, after looking into existing platforms of overview of the services, the Digital social map from the municipalities was advised to us by one interviewee. However, this is from the municipality itself and if for example "Sneek, Súdwest Fryslân" and if the term "Dementia" would be included in the search, only seven possibilities are offered (Digitale Sociale Kaart, 2020).

5.3. Concept

Having acquired relevant feedback concerning our prototype and general idea, we were able to finalize our concept based on the insights we gained through our research and interviews conducted. This concept will present an aligned vision of our solution.

5.3.1. We-Reliance

As we identified in the previous phases, there are several obstacles when it comes to increasing self-reliance of Wytse. For instance, there is often a disconnect between the existing health structure and the PwD. Although there are many services available, the acquisition of these or the right fit, is often difficult to establish for a PwD or an ICT.

Next to this, the process is bureaucratic, leading to lengthy processes in application and delivery of services. This is unfavorable, as dementia is a progressive disease, leading to decreased self-reliance and thus a higher dependency on support and services. A system designed for PwD instead needs to follow a more future anticipated approach. To achieve this, it is necessary to move away from a one-size-fits-all approach towards a more personalized and positive approach to health. This will provide the person with support in varying aspects of life, such as bodily functions, mental and social well-being, and so on. Thus, there should be a person situated between the health system and the person with needs. This will bridge the gap between the system and the PwD. Moreover, a regional overview serving as a centralisation of services should be provided so that available services are easier to find and to access. To establish this, we developed ***We-Reliance - From patient to citizen***.

This is a service capable of connecting the existing health system with the specific needs of a PwD. With this, we want to move away from a medicalised health approach, to reaffirm that the PwD is a citizen like every other person.

Accordingly, the concept is built on a **three tier approach:**

1. It strengthens connections between the PwD and the system
2. It applies a positive health Approach in case management.
    A. Through training for case managers
    B. Usage of positive health principles
3. It provides an overview of existing services

Ultimately, the goal is to increase the quality of life for both the PwD and their caretaker so that they enjoy and prosper mindfully from the future.

5.3.2. The Three Tier Approach

5.3.2.1. Strengthening connections between the person with dementia and the system

While there are many services available, these are often hard to acquire for a PwD and their ICT. This indicates a waste of already existing resources as the person does not get in touch with them[2]. Consequently, we need to consider both spatial and social dimensions, in order to make the system more accessible for a PwD. Once a link has been established, the most beneficial and suitable services should be considered. If we take the case of Wytse, we know he likes to stay active and engaged in society. If he is no longer allowed to drive because of safety concerns, services such as therapists, supermarkets, or cultural events should be offered within walking distance or close to transport services so that his mobility and social circles stay intact.

Since PwD and their ICT require assistance to successfully navigate themselves through the system, there should be a person to provide them with emotional assistance and information while helping them to find suitable services. To put it more simply, we identified a last guiding question: "*How might we make the health system more accessible and interactive to support Wytse to remain self-reliant and Aaltje to have a bearable care burden?".*

As identified from our research and interviews within the testing phase, this person should ideally be a case manager as there is already a position in place for this within the existing health structure. However, this case manager should be trained within more positive health approaches. By employing a case manager trained within positive health, this service reduces stigma and creates acceptance of the disease within Wytse so that he can continue to live his life the way desired. Moreover, it simultaneously facilitates the distribution of relevant information and services to make them more accessible for the Care Dyad. Thus, the service moves away from a one-size-fits-all approach towards more patient-centered care.

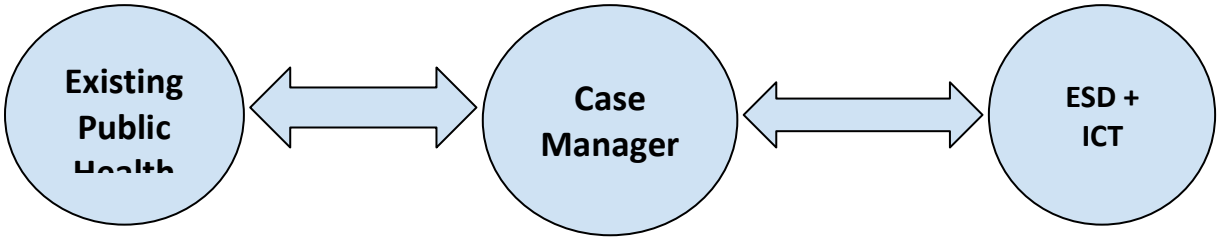

Figure 6. Bridging ESD and the public health system through the case manager

Through this, a more responsive system is created in which the needs of the PwD are considered and existing resources will be used more efficiently.

[2] More can be found in *Part 1: An analysis of Self-Reliance within (Early Stage) Dementia: A review of the Northern Netherlands*

5.3.2.1. Applying positive health in case management

As indicated before, health care is often concentrated on the medical care, and is thus more disease and symptom focused. Stigmatisation and acceptance are still huge topics as well as illness perception: "You have the illness, but the illness is not who you are".[3] This falls in line with positive health.

According to the Institute for Positive Health (iPH), health should be viewed from a broader perspective. For them, positive health results from the development of six dimensions: bodily functions, mental wellbeing, meaningfulness, quality of life, participation, and daily functioning. By including this approach, the ability of people to cope with the physical, emotional and social challenges of life will be strengthened so they can remain self-reliant as long as possible (Fig. 6). Within the positive health approach, people are not their disease, but themselves. It appears that positive health is a rising topic within health care. Therefore, more professionals need to be trained within this approach to overcome current discrepancies within the healthcare (Institute for Positive Health, n.d.).

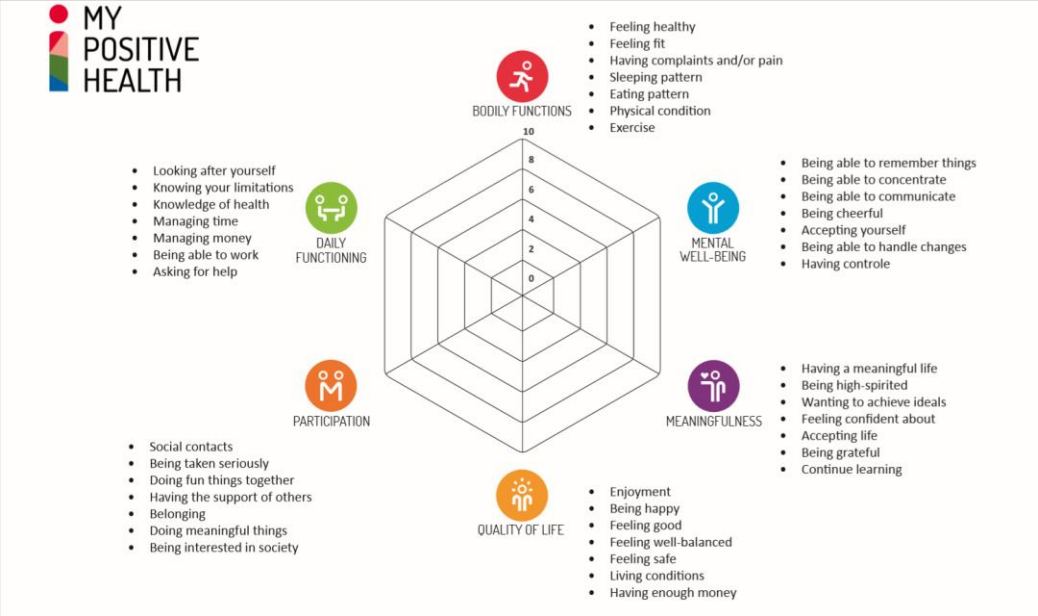

Figure 7. Positive health spiderweb (Institute for Positive Health, n.d.)

A. Principles of positive health

Therefore, we suggest case managers to apply the format from the Institute for Positive Health after a person becomes diagnosed with dementia. This form is especially designed for elderly people and has simple questions to evaluate their health from a broader perspective (see

[3] More can be found in *Part 1: An analysis of Self-Reliance within (Early Stage) Dementia: A review of the Northern Netherlands*

appendix). It can serve as a source of information, assessment of health in a broader sense, and support structures. The positive health approach could be used by case managers as follows:

1. The PwD and partner fill in a simplified questionnaire (see *annex IV*) together with the case manager. In this way, a spider web of six angles can be drawn. Topics such as happiness, satisfaction and loneliness are addressed, but also other topics such as hobbies, house chores or going to the supermarket. Someone could for example score less on participating in daily life, but more on mind and thoughts. By using a format and diagram like this (Institute for Positive Health, n.d.), the client will better understand and visualise what their needs are (Positieve Gezondheid, n.d.).

2. Next, the case manager and dyad could have a conversation about what someone thinks is important to them, and what and how they would possibly like to change something. This emphasizes the social aspect of the specialised dementia care.

3. After this conversation, they can think together about fulfilling the needs of the PwD and also ICT. This also helps them in finding the most suitable services and support if needed. Finally, it provides more support on the aspect of own abilities and self-control (Positieve Gezondheid, n.d.).

B. Training for case managers

In order to have the case managers work with the positive health approach, we would like to recommend a positive health training for the existing case managers. This would preferably be mandatory, so that all case managers have the same knowledge about the positive health approach and how to use it. This could for example be done by acquiring the relevant certificate for positive health.

The Institute for Positive Health already offers several training sessions, lectures and workshops to train people and organisations. It might therefore be possible to cooperate with the iPH and to create a training for case managers. However, another care organisation specialized in positive health would also be an alternative. This training only takes two and a half days which is preferable, keeping in mind the busy schedules and limited time case managers may have.

Since case managers are focal within our concept, we need to ensure enough case managers are available. The current numbers indicate shortages of case managers and waiting lists. The limited availability of case management for dementia was pointed out as a problem. Thus, to overcome the shortages of case managers, we would recommend to create more awareness for the option to educate social workers to become a case manager, and to make the position more attractive generally. While reducing the careload for the current case managers,

the psychosocial aspect will at the same time be more emphasised. This possibility will go hand-in-hand.

5.3.2.1. Overview of existing services

From interviews conducted within the Discover Phase[4], we concluded that it is still difficult for PwD to find the care they need. Since we are making use of the case manager for the guidance through the system, we would like to offer a central platform for the services, that is also available for external parties.

Therefore, in order to bring the services to the people, we would suggest to install a central log-in system for all case managers in Friesland. However, this overview should not only be visible for case managers from a particular organisation, but needs to be shared with other health professionals (e.g. GP, psychotherapist, nursing consultant) and social support professionals (e.g. leisure organisations and volunteer-, mentor- and buddy-organisations). This team could be described as Team Care Cloud. The network can strengthen its current connections and can also easily adapt itself to a greater and more complete network.

One of the main options for this central place, would be an easy sign up option joinable for bigger and smaller organisations and initiatives. Another aim would be to include also non-conventional services, as “Lifestyle Sneek Senioren Fitness”, “Sportief wandelen voor senioren Sneek” and “Gezelschapsassistentie Friesland”. A preliminary list of different sized services within Sneek is added to *annex V* as an example.

The next step would be to work according to the positive health principles in this central system in a specific place. In this case, an individual advice can be given to our personas: Wytse Venema and Aaltje Venema-de Vries. The needs of Wytse are already identified through the positive health format. For instance, if Wytse has scored less on “Zinvol Leven”, the case manager can look how they would improve this aspect with the possibilities offered in Sneek. Therefore, the WE-Reliance platform has been created. A short impression of a digital platform has been created. This website has been launched, but has not the aim to function. The website can be found through the following link: https://we-reliance.jimdosite.com/. Impressions of this platform can be found as screenshots in *annex VI.*

5.4. Action Plan

According to our research and the concept we developed, *WE-Reliance*, we are suggesting action on two accounts: we would like to run a pilot within Sneek, Frysland to test the developed positive health approach within existing case management structures. On successful completion

[4] More can be found in *Part 1: An analysis of Self-Reliance within (Early Stage) Dementia: A review of the Northern Netherlands*

of the pilot and after having evaluated the benefits and obstacles, the project could be realized on a larger scale. The timeline for this project can be found below.

5.4.1. Project Pilot

1. **Pilot Project - Sneek:** Trial run (12 months)

   Step 1: Setting up Phase:

   In the first phase, it is important that all the relevant stakeholders are coming on board so that information can be distributed. The relevant stakeholders in this case include: the municipality, the GGD in Súdwest-Fryslân, home-care organisations, the health insurance, Vitale Regio and possible other actors.

   Step 2: positive health Training:

   For existing case managers (with a background in nursing or social work) *(2 months – continuously).* Once the first phase of gathering all the important stakeholders has been completed, the second phase can start. This phase will focus on educating case managers and social workers in positive health. For already existing case managers this means they will have to follow this additional training besides their work. Fortunately, the course only takes two and a half days. For social workers who are still in school, the positive training ideally will become part of the general curriculum.

   Step 3: Care Cloud Team formation:

   See Team in chapter 5.4.2 *(4 weeks)*. The third phase regards forming the CareCloud team. This would be a central log-in system for all case managers in a certain region. Moreover, not only case managers, but also the health professionals, such as general practitioners, and social support professionals would be able to login to this central log-in system. This network will strengthen the connection between the actors.

   Step 4: Trial Run for half a year with possibility of extension. The next phase is the trial run, the period in which the plan will be executed and tested.

   Step 5: Evaluation Phase:

   Feedback and reflection of the test group. During this phase, all the actors involved will look back and evaluate the whole plan. This an opportunity to decide on what went well, but also to point out aspects that can be improved in the future.

2. **Implementation (Municipality Moonshot)**

If the pilot in Sneek has successfully been completed, the aim is to implement WE-Reliance in Súdwest-Fryslân as the existing structure should offer possibilities for this. The moonshot will

then be to implement this within Friesland, and eventually within the Netherlands.

5.4.2. Who is needed to implement the pilot We-Reliance?

1. Team Care Cloud: This team consists of the case manager, health professionals and social support professionals and will work with the PwD and their caretaker.
Examples:
Case managers
Existing case managers
Nurses & social workers
Health professionals
General Practitioners
(Psycho)therapists
Neurologists
Nursing consultants

Social support professionals
Leisure organisations
Day-care organisations
Mentors, volunteers, buddies

2. Implementation team: This team will be concerned with the concept and the proper functioning of the pilot in Sneek.
Examples:
Project managers
Economics and finance team
Legal team
Public relations
Human resources

3. Partners: Ideally, these represent the supporters of We-Reliance.
Examples:
Vitale Regio
Municipality
GGD Súdwest-Fryslân
Health insurance
Home-care organisations
TinZ Friesland

5.4.3. Possible Obstacles and Challenges to the product

There are a few conditions that need to be met so that the pilot can work successfully. First of all, there has to be a high level of collaboration within both Team Care Cloud and Team Implementation. If not, the pilot and full implementation are more likely to fail. Of course, the case managers and home-care organisations play a crucial role within the success of the collaboration in both teams.

5.4.3.1. Pilot

When it comes to the pilot, not only the commitment of the teams is important, but also the commitment of the PwD and his or her partner/ICT. If they are not willing to work with the case manager or are not motivated, it will be difficult to make the system work properly.

The accessibility of the case manager is also still a challenge. When creating the system around the case manager, the steps through the system before acquiring a case manager also need some attention. Another challenge that can be encountered concerns isolated individuals with ESD. They often remain longer invisible to the system and receive attention when the disease has already progressed. Moreover, it is also more difficult to reach isolated individuals, because it is often the ICT who seeks help and not the PwD itself.

Secondly, an overview of existing services would be beneficial for the work of the case managers as it reduces timely processes. Currently, case managers are working with a social map, but this has to change to another platform. The social map offers an overview of services, but it is individually created by care organisations and not complete.

Another point to address, is the application of the positive health approach within the case management. According to the Institute for Positive Health, the advised basic module training takes 2.5 days. This training is not specific for case managers, but also for people working in other areas. For implementation, the Institute for Positive Health could be approached for creating a specific training for case managers and possibly other assessments for the partner or ICT.

5.4.3.2. Implementation

A relevant point of attention for the implementation of the concept is the financial aspect. Financing the pilot in Sneek is the first step. For this, the first point to look at is under which organisation or municipality the pilot will fall.

Moreover, the current legislations and role of municipality in the healthcare system are difficult to change. For now, the pilot will work on the existing structure, but afterwards the system could possibly be adapted according to the evaluation of the pilot. Another challenge that might be encountered while implementing the pilot is the limited number of case managers available. As indicated earlier, there are shortages, and waiting lists, which could make it hard to get the attention of the cast managers to work on this project. Also, the recent split of the case

management branch a few years ago in Friesland (TinZ) makes it difficult to connect all case managers and set up a united approach. Not all case managers work under one 'umbrella', but they are spread among multiple care institutions, which makes it more difficult to coordinate with each other.

Finally, case managers might have trouble getting used to the more psychosocial aspect, as now the focus mainly is on the medical aspect of the disease. Moreover, 80% of the case managers have a nursing background which is by definition more medical, making it for them even harder to get used to the psychosocial approach.

5.4.5 Conclusion Action Plan

As the product has shown, the challenge is to raise awareness among the home-care organisations to get them on board, which results in a greater likelihood that the collaboration will be successful. Communication is key and the system should function in a more interactive way so that the care dyad feel heard and included within the process. That being said, gaining access to a case manager after the diagnosis needs to be facilitated. This will increase the chance of self-reliance to remain stable over time. Moreover, it is necessary to find out why these individuals live so isolated and how they could be more visible to the system. Concerning the positive health program, questionnaires should be filled in by the PwD and their ICT. It is important that also the ICTs fill this in, because the ICT might have a different, and possibly more realistic view on the situation. This is especially crucial if the PwD is still in denial.

A centralised system would pool resources together and complement the overview. Therefore, the suggestion is to work with an expert to create this online platform to have a clear view on what should be on the platform and which options are not necessary. It would be an idea to have businesses sign up on the platform as this will keep it simpler. The aim of the platform should be kept in mind. The key then is simplicity. Additionally, when prospective members of the Team Care Cloud are aware of this platform, the network can strengthen its current connections and can easily adapt itself to a greater and more complete network.

As the past has shown, if the pilot appears not to be cost-effective, it will likely result in no future implementation. The ones financing will have a great role in the decision of declaring it being cost-effective. On the other side, proving that *We-Reliance* will be socially-effective is of great importance for implementation. For this to happen, we suggest to reinstall a program that would bring the case managers under one 'umbrella' again. With respect to this, positive health has to be turned into an established tool, which would benefit the current health structure.

As this product aims to intervene into the healthcare system, the moonshot would involve the three tier approach to become embedded into the existing health structure.

6. Conclusion

This report shed light on the question: *How might we create an environment in which people within early stages of dementia are enhanced/strengthened in their self-reliance?* While the Discover Phase contains more scientific results and is based on our own conducted research, the later phases focus more on creating a tangible product that can aid with solving the problem of self-reliance in Early Stage Dementia.

Firstly, there is no-one-size-fits-all approach to dementia due to the diversity of the disease. Nevertheless, the current approach taken is very medical and does not account for the progressive character of the disease, therefore a system is necessary that is more anticipatory towards the future needs of a PwD and his/her caretaker. To achieve this, we aimed to design a product that focuses more on the psycho-social aspect of the disease in order to make it more personal and individualized for the PwD and his/her caretaker.

With regard to this, we also found that PwD have difficulties with acquiring services and finding a good fit. As a result, they need an intermediate person that can help them to navigate through the system and to make the right choices when it comes to care. Based on our research, and feedback from stakeholders, we identified this person to be a case manager. This is favorable, as there is already a structure for this that can be ameliorated. With our product We-Reliance, we aim to improve the current case management by training them in positive health. This is crucial, as a PwD sometimes is in denial about his condition due to stigma and thus needs assistance in mentally processing the diagnosis and to achieve acceptance for the disease so that he or she can openly communicate his or her needs.

Nevertheless, due to the shortage of case managers, we suggest care organisations to become more aware of the possibility to hire social workers as case managers as these have the necessary psycho-social background. Simultaneously, social workers should also be more encouraged to become a case manager.

When it comes to services, we found that many services are available. Nevertheless, there is no centralized overview of services available within the regions, further complicating the process of delivering services to the PwD and his/her caretaker. Accordingly, we suggested a central online platform of all available services. This platform could be used by case managers, but also by other relevant persons and organisations. Through this, we will be able to build on existing structures while also making more efficient use of resources.

To conclude, We-Reliance will achieve a better connection between the existing health care service and the care dyad. Through a more individual and personalized system, we focus on increasing the quality of life for PwD and their ICT so that they can continue to live their lives in dignity. With respect to this: you have dementia, but you are not the disease. Accordingly, dementia does not have to be the end of the world, it can also be just another step in life.

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Annex

ANNEX I: Stakeholder Analysis

As we are aiming to develop a solution aimed to be patient-centered, our most important stakeholder is the person living with ESD. This is due to the fact that our approach aims to empower people within their communities so that people with the disease can stay longer in their homes instead of being separated from them. Accordingly, the focus should always be to increase the quality of life for the individual so that he or she can live a life with dignity. To ensure that this is possible, it is also necessary to have the family and the family caretaker as an important stakeholder. As dementia can become more difficult, and as changes can occur in the family life, it is important to ensure that the family and caretakers are involved at all times.

Lastly, in a primary health care system, the General Practitioner is the first person that will be contacted by a person with dementia symptoms. Therefore we have created a circular visualisation.

ANNEX II: Peronas

Name: Wytse Venema

Identity:

- male, 67 years
- Married for 42 years with ICT 1 Persona
- Retired construction worker
- HBO
- 2 children, 1 grandchild
- Hobbies: Member of local football club
- Churchgoer
- Diagnosed with Dementia, but in denial

Behaviour:

- In denial of his condition & disease
- Disorientated
- Since his retirement, he takes care of the household chores
- Still does the chores well, relatively independent, but sometimes forgets basic tasks
- Problems with taking care of chores outside home, e.g. grocery shopping
    - Reduced mobility, disorientation
- Troubles remembering names (tools and persons)

Attitude:

- Too proud to accept help, still in denial of disease
- Doesn't want to be burden for wife
- Wants to keep a good balanced relationship
- Generally positive
- Satisfied with his life
- affiliated to community/working in a group

Goals:

- Make more reminders/task lists
- stay active and social in community (football, Church) for sake of well-being

- Wants to be able to spend time with/take care of grandchild
- Always lived an active lifestyle, wants to maintain
- Find the way to the supermarket and do groceries on his own

Quotes:

- “Where are my glasses? I just had them?!”
- “I just have a terrible memory, but I don’t have dementia, that’s for the old.”

Story:

“All my life, I have been a very active person and I like to socialise, and the only thing I want to do is just to be with my family and friends. Next to that I am very interested in sports. For example, I go once a week to the Football Club of my village. However, most of my day I spent at home where I do the daily chores of housekeeping, as I have retired 4 or 5 years ago and since my wife is still working as a secretary. I really love my wife! However, lately she’s been very belittling and double checking everything I do.. Just because, a few months ago, my doctor diagnosed me with dementia. Ever since, people have treated and talked to me differently. Everyone has some memory problems, and I mean I probably just hit my head at work once too often, but that’s not dementia. I almost feel like people see me as an old, helpless man but I am a very active person. Actually, since I retired I got so much time, but Aaltje thinks I cannot be left alone or that I can’t handle certain activities, but of course I can. Honestly, I’m a bit confused because I want to continue to live my life as usual”.

Name: **Aaltje Venema-de Vries**

Identity:

- Female, 64 years
- Married for 42 years with Wytse
- Secretary in law firm
- HBO
- 2 children, 1 grandchild
- Hobbies: sewing, book club member
- Churchgoer
- Good health

Behaviour:

- Difficulties with continuing work with care taking
- Gives up book club meetings because care takes up more time
- She is over correcting his behaviour & attitudes “show him how it’s done correctly”
- Tries to re-establish routines
- Does everything for her husband, takes vows very seriously

Attitude:

- Devoted, disregarding own needs and time
- Stressed and overwhelmed, sometimes helpless
- Looks for more support
- Unintentionally belittles Wytze
- Goes out of her way, exceeds the necessary

Goals:

- Get more professional support, gain better overview of affordable services
- Find more time for herself, book club
- Help husband to remain more independent
- Wants to support/facilitate the social environment of her husband
  → so he stays engaged and she has some free time

- stay more relaxed, less intervention for her husband's behaviour

Quotes:

- "Whenever I tell my friends that my husband has dementia, they tell me how sorry they are, this makes me feel even worse about it."
- "I used [to love] reading so much, now I barely find time."
- "I'm scared to leave my husband alone…"

Story:

"Ever since my husband developed dementia, our life has changed. We have always had a great family life together, but now sometimes it becomes difficult. Although I always took care of my family, things are getting so intense and my head is rushing. I feel like I am less able to find time for myself to do the activities I love. Nowadays, I find it more difficult to manage our lives together, especially because it is hard to communicate with Wytse as he's in denial of his dementia and does not want help.
Next to this, my husband takes care of our grandchild and does the chores at home, but now I am unsure whether it is safe anymore which makes family life even more tense. I have not been able to pick up a book or go to my book club because I am scared to leave my husband alone for too long. I feel like I always have to be two steps ahead of him. I think external support would help me to be less exhausted, but I don't know where to find or get affordable services, and what services even exist. I sometimes feel like people feel sorry for me and Wytse, which makes it more difficult to talk to them for me, but I think about the situation often. I hope things will become easier soon."

Name: **Louise van Dycke**

Identity:

- Female, 75 years
- Widow, married for 50 years
- Retired university professor
- WO
- No children, one favourite neighbour
- Hobbies: wine'n'travel, haute cuisine & fine dining, golf club, soap operas
- Atheist
- Diagnosed with dementia

Behaviour:

- Forgets she already had a glass of wine
- Stays mostly inside, watches her TV
- Sits a lot
- Visits her neighbour once a week for a cup of tea
- Not allowed to drive, goes for walks
- Is in charge of her own financial & medical life
- Needs to make her own doctor's appointments

Attitude:

- Doesn't move a finger for own needs no more, cleaning lady comes in twice a week
- Irritated and restless
- Overwhelmed, emotional, symptoms of depression
- Used to be outgoing, independent & talkative, now overburdened by social interactions
- Is irritated and sometimes restless
- Confused about financial & medical organisation

Goals:

- Wants to keep same habits, eg wine
- Wants to be able to travel to Italy again without problems
- Find more time for reading
- Stay more relaxed

Quotes:

- “Can people stop talking to me like a little kid? I am a respected professor”
- “I think I’ll have a glass now” [after her n wine]

Story:

“Although my husband died years ago, I tried to continue my life by travelling and enjoying the good things. After returning from Italy last summer where I lost my keys and had to get the spare ones from my neighbour. Because she had been worried about me for longer, we went to the GP together where he diagnosed me with dementia. Finally, things started to make sense to me, for example, I would wake up in the morning and find an empty bottle of wine in the kitchen. However, I was sure that I only had one or two glasses when watching my favourite soap opera. It’s expensive wine, you have to appreciate it and not binge it. As I don’t have any family nearby, I needed to get housekeeping and meal services. The people are nice, but I have the impression that the services are too generalized and not properly tailored to my needs. Also I wish, I would like to have more interaction with people to get out of the empty house, since I’m not allowed to drive anymore. With regard to this, since my dementia, it became hard to organise my finances and medical appointments. Lately, I’ve been noticing that I grew more restless and I feel more sensitive and emotional.”

ANNEX III: Customer Journey

Context	**Emotion/Feeling**	**Process**	**Contact**	**Opportunity**
Residence in Sneek/small village where people know one another	Realizing he has not eaten in a while	starts to think about eating	“I’m hungry”	
Wietse is alone at home,wife Aaltje is at work. He needs to organise on his own	unsatisfied	Deliberates what he wants to eat	What do I want to eat for “lunch”? “A Sandwich with Egg	
Kitchen	determined	Goes to the kitchen to check the fridge /pantry for ingredients		
Usually Aaltje does the shopping, but they must have run out of some ingredients	irritated	Notices does not have enough ingredients	“Then I am going to the supermarket to get the things”	Have meal plans, prepare meals
Hallway	Motivated, then confused	Gets ready to go, puts on shoes and jacket, assembles keys and bag.	“Wait, what do I need again to make an egg sandwich?”	
Kitchen		Checks fridge and pantry again for	“Ok we have bread and	Reminders, Grocery and

		ingredients,	tomatoes, so I need to buy eggs and cheese”	Task Lists would be a coping strategy But also need f. Acceptance of disease
Outside	Motivated	Leaves the house and goes onto the sidewalk to start walking towards the supermarket	People on the street “Hoi, goede middag”	
Busy street near the supermarket	Irritated, overwhelmed, sensitive to noise	Stops where he has to cross, because there is a lot of traffic	“Wow so hectic, where are all these cars coming from?”	
	Irritated still but trustful in his capabilities	Deliberates to cross the street but eventually does	“Ok after this car, let’s go”	Streetlight at cross for supermarket would help elderly people
Arrived at supermarket	Irritated, confused, upset and angry	Enters the supermarket	“Oh wait, do I remember all the ingredients? Wait what did I want to make?”	
Wanders around the supermarket	Confused	Looks at the aisles, but is unsure what he wants because he is generally		

		confused		
Neighbor appears and notices confusion of Wytse	Irritated, let-down, disoriented	Neighbor approaches him and asks whether Wytse was also here to get lunch? Wytse said yes but he was unsure what he wants	Neighbor who is familiar with the situation	
	Ashamed, distant, But thankful	Neighbor helps Wytse with Groceries then Wytse thanks him and goes into the direction of the checkout		Good example of someone who is aware
At the checkout of the supermarket	Panic, embarrassment, helplessness	Gives the grocery and when the cashier tells him the price, he realizes he does not have his wallet and panics	Cashier who does not know about the situation and does not realize the case calls her Manager Manager: knows about the situation and will fix the wife a bill	Example of lack of awareness, important to include business in the solution. Should train everyone for these type of problems
		Manager explains everything is fine, but Wytse is still completely	Manager	

		irritated. The manager asks if he should call his wife but Wytse says it is not necessary.		
Wytse goes quickly home and encounters no problems	Normal, engaged, routine	Wytse arrives at home, takes off the shoes and goes to the kitchen to make an egg sandwich.	"I need a pan, oil, my eggs…"	
In the kitchen	Disengaged, happy to hear his daughter, so excited he forgets what he was doing	Starts to prepare the egg and puts it into the pan Daughter calls the phone unexpectedly, he disengages with his task and forgets about the egg	Daughter on the phone	
Fire alarm goes off	Panic, irritation, embarrassment relief	Egg starts burning which triggers the fire alarm Daughter helps with the situation	"Oh god what is happening" Daughter notices the noise and panic and helps over phone.	Have more safe appliances (smart kitchen) Buddy system / Company Security Check List for cooking
Meanwhile at Aaltje's work she becomes a call from her	Shocked, frustrated, Relieved at the same time	Talks to daughter and questions whether she	"Oh no, where will this still go. Can I not leave him	

daughter telling her that the alarm went off but that everything is fine		should leave work?	alone at home anymore?"	
Calls Wytse on the phone	Worried, feels stressed, disappointed	Calls Wytse to ask whether she needs to come home. Wytse said that their daughter helped him manage everything and that he will watch TV now.	Wytse Phone Her thinking "We need to find a solution, maybe I cannot go to work anymore, I need some help"	
In Office	Confused, loss of words	Looks on the internet for services and information, but feels like she does not understand what is going on.		Case Manager helping with services Better information
Office before going home	Determined but worried	Confront Wytse with services and about his dementia		

ANNEX IV: Mijn Positieve Gezondheid Tool

Mijn Positieve Gezondheid.
De vragen gaan over jou.
En over hoe jij gelukkig kunt worden.
Hierna volgen vragen.
De vragen gaan over:

1. Lichaam

2. Gevoel en gedachten

3. Zinvol leven

4. Kwaliteit van leven

5. Meedoen

6. Dagelijks leven

Kies bij elke vraag het antwoord dat bij jou past.

Een voorbeeldvraag:

Voel jij je goed?

Nee	Een beetje	Ja	Hier wil ik over praten
○	○	☒	○

Vul in wat je zélf vindt.
Zet ook een kruisje als je erover wil praten.
Als je klaar bent gaan we bespreken wat er goed gaat in je leven.
En we bespreken wat je wil veranderen.

1. Lichaam

		Nee	Een beetje	Ja	Hier wil ik over praten
1	Voel jij je gezond?	○	○	○	○
2	Voel jij je fit?	○	○	○	○
3	Heb je pijn?	○	○	○	○
4	Slaap je goed?	○	○	○	○
5	Eet je gezond?	○	○	○	○
6	Ben je vaak ziek?	○	○	○	○
7	Kan je goed bewegen?	○	○	○	○

Je hebt nagedacht over je lichaam.
Welk cijfer geef je dit?

1 2 3 4 5 6 7 8 9 10

GA VERDER

2. Gevoel en gedachten

		Nee	Een beetje	Ja	Hier wil ik over praten
8	Kan je dingen goed onthouden?	○	○	○	○
9	Kan je goed nadenken?	○	○	○	○
10	Kan je goed zien en horen?	○	○	○	○
11	Voel jij je vrolijk?	○	○	○	○
12	Ben je blij met wie je bent?	○	○	○	○
13	Weet je wat je moet doen als het niet goed gaat?	○	○	○	○
14	Beslis je zelf over belangrijke dingen?	○	○	○	○

Je hebt nagedacht over je gevoel en gedachten.
Welk cijfer geef je dit?

1 2 3 4 5 6 7 8 9 10

GA VERDER

3. Zinvol leven

		Nee	Een beetje	Ja	Hier wil ik over praten
15	Vind jij je leven zinvol?	○	○	○	○
16	Heb je 's morgens zin om op te staan?	○	○	○	○
17	Zijn er dingen die je graag wil doen in je leven?	○	○	○	○
18	Maak jij je zorgen over je toekomst?	○	○	○	○
19	Accepteer jij je leven zoals het is?	○	○	○	○
20	Ben je dankbaar voor je leven?	○	○	○	○
21	Heb je zin om nieuwe dingen te leren?	○	○	○	○

Je hebt nagedacht over een zinvol leven.
Welk cijfer geef je dit?

1 2 3 4 5 6 7 8 9 10

GA VERDER

4. Kwaliteit van leven

		Nee	Een beetje	Ja	Hier wil ik over praten
22	Geniet je van het leven?	○	○	○	○
23	Ben je gelukkig?	○	○	○	○
24	Voel jij je goed?	○	○	○	○
25	Kan jij je leven aan?	○	○	○	○
26	Voel jij je veilig?	○	○	○	○
27	Ben je tevreden over hoe je woont?	○	○	○	○
28	Heb je genoeg geld om je rekeningen te betalen?	○	○	○	○

Je hebt nagedacht over jouw kwaliteit van leven.
Welk cijfer geef je dit?

1 2 3 4 5 6 7 8 9 10

GA VERDER

5. Meedoen

		Nee	Een beetje	Ja	Hier wil ik over praten
29	Heb je contact met andere mensen?	○	○	○	○
30	Nemen andere mensen je serieus?	○	○	○	○
31	Heb je vrienden?	○	○	○	○
32	Heb je mensen die je kunnen helpen?	○	○	○	○
33	Heb je het gevoel dat je erbij hoort?	○	○	○	○
34	Heb je werk of doe je andere dingen die je belangrijk vindt?	○	○	○	○
35	Wil je graag weten wat er in je dorp of stad gebeurt?	○	○	○	○

Je hebt nagedacht over meedoen.
Welk cijfer geef je dit?

1 2 3 4 5 6 7 8 9 10

GA VERDER

6. Dagelijks leven

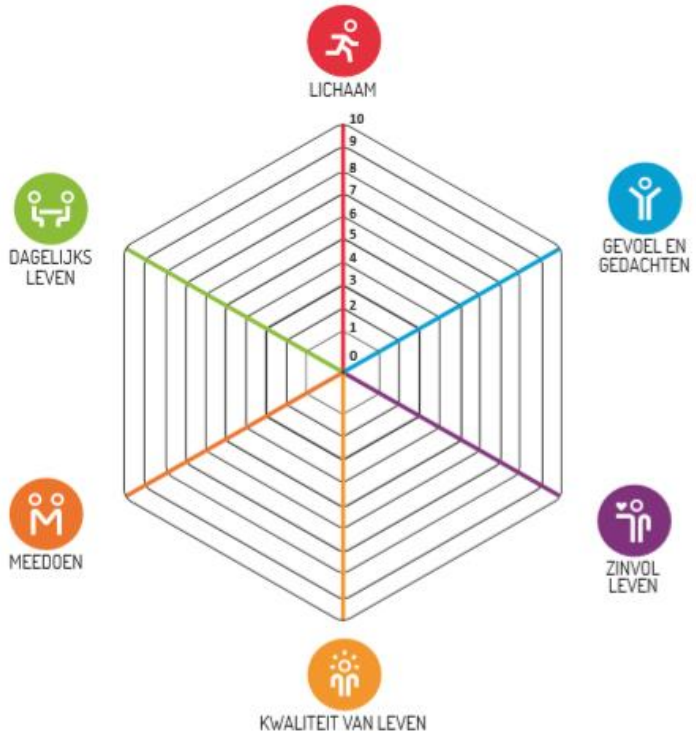
		Nee	Een beetje	Ja	Hier wil ik over praten
36	Kan je goed voor jezelf zorgen?	○	○	○	○
37	Weet je wat je kan en niet kan?	○	○	○	○
38	Weet je hoe je gezond kunt leven?	○	○	○	○
39	Kan jij jouw dag goed indelen?	○	○	○	○
40	Geef je meer geld uit dan je hebt?	○	○	○	○
41	Kan je werken?	○	○	○	○
42	Weet jij hoe je hulp kan vragen?	○	○	○	○

Je hebt nagedacht over het dagelijks leven.
Welk cijfer geef je dit?

1 2 3 4 5 6 7 8 9 10

GA VERDER

Je bent klaar met de vragen.
Pak het spinnenweb erbij.
Zet een rondje om het cijfer dat je gegeven hebt.
Doe dat voor elk onderwerp.
We gaan nu een figuur tekenen.
Trek lijnen tussen de rondjes die je hebt gezet in het spinnenweb.
Dat figuur heet het spinnenweb Positieve Gezondheid.



Wat zou je als eerste willen veranderen om gelukkiger te worden?

.....

.....

Wat kan jij doen?

.....

.....

EINDE

ANNEX V: Sneek Activities & Services

Dementia activities:

1. Alzheimer Café Sneek

Description: Alzheimer Café Sneek is a meeting place for people with dementia, their partners, family members and other interested people.

-**Contact**: g.muller@alzheimervrijwilligers.nl

-**Address**: Frittemaleane 5, 8604 AA Sneek

Sport Activities:

1. Lifestyle Sneek Senioren Fitness

Description: Our exercise and lifestyle advisor focusses especially on the growing group of elderly people to offer useful, pleasant and effective training in groups. Of course not everybody likes working in groups, which is why we also offer intensive guidance for the individual elderly athlete. This way it is possible for everyone to keep moving effectively. Join us wihtout obligation whenever you want.

Address: Westereems 18, 8602 CR Sneek

Contact: info@lifestylesneek.nl

Website: https://lifestylesneek.nl/fitness/senioren-fitness

2. Sportief wandelen voor senioren in Rasterhoffpark Sneek

Description: Every tuseday and Friday afternoon from 13:30 – 14:30 in the Rasterhoffpark in Sneek there is a sporty walkinggroup for elderly, led by Henny Jellema, organised by the municipality of Sudwest Fryslan under the name: Sneek beweegt. The group walks thorugh the park and along the route several exercises are performed, all the while being in the fresh air. There are activities available for elderly in Sneek, Bolsward, Koudum, Workum, Schaarnegoutum and Wommels.

Contact: jellemahennie@hotmail.com

3. Vietaal Sneek - Geriatrie fysiotherapie

Description: People who get older and move less can experience complaints because of this. They usually get into contact with a physiotherapist for elderly, the geriatric physiotherapist. The geriatric physiotherapist has specialised in the care for vulnerable elderly people and clients/patients at a high (biological) age who deal with complex health problems. This is not always about elderly but also patients who show signs of old age due to a stroke, dementia, Parkinson's disease or a fractured hip. This physiotherapist works from specific knowledge about the target group and their associated illnesses. The patients mostly do exercise therapy, aimed at regaining and dealing with the loss in mobility and independence.

Website: https://www.vietaalsneek.nl/therapie/geriatrie-fysiotherapie/

Contact: Info@vietaalsneek.nl

4. Ouderenfysiotherapie – Fysio-Actief

Description: With getting older or during/after an illness it is possible to experience limitations in your freedom of movement. This can result in a decrease of mobility, fitness, balance and strength. Our geriatric physiotherapists are specialized in the most optimal treatment for elderly people.

Website:https://www.fysioactief.nl/fysiotherapie/behandelingen/ouderenfysiotherapie/ **Contact:** tel. 0515-434355

5. Gezond Natuur wandelen

Description: Gezond Natuurwandelen, offers walking groups all over the Netherlands. In Sneek there is a walking group every Monday at 19:00 hours. It is completely for free and those interested can join whenever they want.

Website: https://www.gezondnatuurwandelen.nl/wandelen/vind-een-wandeling/

6. Swimming Sneek

Description: The swimming pool in Sneek offers Aquavitaal lessons three times a week especially for elderly people. The lessons are guided by a specialised instructor.

Website: https://optisport.nl/locaties/rak/aquavitaal

7. Soccer in Sneek

Description: The soccer club in Sneek offers walking soccer for people over 60 years of age. The training takes 20 weeks each season and the season is closed with a championship. The training is offered on different levels for the different participants.

Website: https://swzbososneek.nl/1747/algemeen/

Social Acitivities

1. Cultuurkwartier "Een tegen Eenzaamheid in Sudwest-Fryslan"

Description: Participation in culture and sports plays an important role in battling loneliness. Together you can enjoy music, walking, dancing, cooking, having a place where you can tell your own story where words may fail. A lot of people over 65 are lonely. They need a little nudge to find connections in society. By participating in sporty or cultural events vulnerable seniors may feel less lonely and more vital.

Address: Westersingel 29, Sneek
Contact: Info@cultuurkwartier.nl
Website: www.cultuurkwartier.nl

2. Wijkvereniging Het Eiland Sneek

Description: Neighbourhood association 'Het Eiland' is an active association with many activities for both young and old. The association organizes activities like billiards, jass, bingo, barbecues, gymnastics and singing groups.

Address: Valkstraat 17, 8605 AV Sneek
Contact: wvheteiland@gmail.com
Website: http://wvheteiland.weebly.com/

3. Stichting 'Vier het Leven'.

Description: Foundation 'Vier het Leven' organizes cultural activities for elderly who prefer not to go out alone. They get picked up at home by a host from Vier het Leven and together with other guests they go out for a visit to the cinema, a concert, the theater or a museum. The participants can enjoy a drink during the outing, enjoy eachother's company and get brought back home safely after the trip.

Email: info@4hetleven.nl
Website: www.4hetleven.nl

4. Met Je Hart – Sneek

Description: Foundation 'Met je Hart' works in every municipality together with Gp's, geriatric nurses, home care workers, district nurses, pastors and local residents. This is an intensive process but it also makes sure we can help that invisible and vulnerable group of elderly to participate in society. Our care partners have a good view on vulnerable elderly with feelings of loneliness and a lack of social contacts. Elderly are invited the first time to take away the first threshold. All our guests are invited personally and the team of 'Met je Hart' will get into contact with them personally to talk about the wishes and possibilities. We reach a forgotten group of elderly people and take away all the possible hurdles for social contacts.

Contact: info@metjehart.nl
Website: https://www.metjehart.nl/gemeenten/sneek/

5. Patyna Noorderhoek

Description: In the 'Noordhoek' we organise a lot of activities in the field of culture, leisure, sports and games. We would love to hear what you like to do, because we like to organize activities that connect to your wishes, needs and habits.

Website: https://www.patyna.nl/wonen-bij-patyna/sneek/noorderhoek/wat-is-er-te-doen/

6. Gezelschapsassistentie Friesland

Description: Gea means Gezelschap en Assistentie (company and assistance), Gea is both a companion and assistant. Your usual Gea will come to your home to have a nice and meaningful time with you. Gea will help you with all kinds of chores and has time for you.

Website: https://www.gezelschapenassistentie.nl/

Contact: Post@delindeborgh.nl

7. Dementie-koor

Description: Music addresses a part of the brain that stays intact far into the dementia process. Singing is possible for a very long time and with that focusses on what is still possible. Music and singing also evoke positive memories. The dementia choir is for people with dementia, both living and home and living at a nursing home, and their family members or informal caretaker.

Contact: annemarie@ruimte-muziek.nl

Website: http://www.ruimte-muziek.nl/dementie-koor

8. Library Sneek

Description: The library in Sneek offers a Senior Café for elderly people which takes place every week. Elderly people are welcome to go there, drink a cup of coffee, read a newspaper or have a chat with other guests. They also offer a digital café to assist people with digital appliances. Every once in a while the libraries in Sneek and Bolsward also offer creative cafés, where people can work on all sorts of arts and crafts.

Website: https://www.bmf.nl/agenda.html

Day Care / Care Farms

1. Dagbesteding Ontmoeting

Description: Daycare 'Ontmoeting' is a small daycare for elderly people with dementia who still live at home.

There is also space for people who live in social isolation, especially since people have to stay at home linger. The charm of this daycare is that all the activities are in a homely setting. There is a varied program with a lot of attention for memory training, mental relaxation, creativity and exercise, all with having a good time being the most important. All the guests are treated with respect and we offer a good program of activities, so the informal caretaker can take some time for themselves without worrying. We also guarantee personal guidance with lots of attention for the guests. The group consists of a maximum of 6 guests.

Address: De Strikel 10, 8604VV Sneek

Contact: dagbestedingontmoeting@gmail.com

Website: http://www.dagbestedingontmoeting.nl/page/home

2. Jeltehof Hommerts – Dag- en Zorgboederij

Description: Our day- and care farm opened on November 1st 2014 and is situated next to the Jeltewei. A beautiful location to share! Situated between green meadows and a beautiful view, but also in the middle of the village. We like to offer people who enjoy the outdoors the possibilities of our farm. We think of people with (early stage) dementia, who are dependent on guidance but also like to keep the reigns on the program in their own hands. We are very flexible when it comes to age. It is most important for us that the elderly people are happy at the Jeltehof! Of course we also look at group composition and we like to listen to your wishes and questions to make your day at Jeltehof as pleasant as possible.

Contact: info@jeltehof.nl

Website: https://www.jeltehof.nl/ouderen.html

3. Care Farm Parrega - Veldzicht

Description: Care Farm Veldzicht in Parrega offers daycare for people with dementia. They provide care and activities, all based on the wishes and needs of the guest and their caretaker(s). They work according to a care plan, which is evaluated every six months.

Website: https://zorgboerderijveldzicht.nl

Contact: info@zorgboerderijveldzicht.nl

4. Care Farm Idzega – It Klokhus

Description: Care Farm It Klokhus offers daycare for all elderly people and not specifically focused on dementia. They do have employees who are specialized in caring for elderly people with disabilities, such as dementia. They offer their guests a small taste of the farm life, with a lot of rest and social contacts.

Website: https://www.itklokhus.nl

Contact: zorgboerderij@itklokhus.nl

5. Day care/Care Farm Slachtehiem

Description: Daycare at Slachtehiem is a special form of care at a beautiful farm on the Frysian countryside. This person centered care is focused on the quality of life, improving the wellbeing and the optimal functioning of the daily life of the patient.

Website: https://dagzorgslachtehiem.nl

Contact: info@slachtehiem.nl

6. Tinga State

Description: Tinga State is a small living and care farm for people with dementia and memory problems. Both the young and old receive the attention, care and guidance they need 24 hours a day. Hospitable and caring, that's what we stand for.

Contact: klantadvies@meriant.nl

Address: Molenkrite 115, 8608 XK, Sneek.

Website: https://www.meriant.nl/over-meriant/locaties/836285-tinga-state-label-friese-staten

7. Beleef Dagbesteding

Description: Beleef Daagbesteding is a dayacare in Sneek and surrounding areas for people with dementia or memory problems who still live independently. Our guests are the most important and really get the attention and care they deserve. Beleef is situated in the pretty and rural Oppenhuizen in the municipality of Sudwest-Fryslan. At this beautiful and spacious location we offer an entirely renewed form of daycare for a maximum of 6 people.

Address: Tsjerkenbuorren 34, 8625 HD Oppenhuizen.

Contact: eperridon@beleefdagbestedeing.nl

Website: https://beleefdagbesteding.nl/

8. Boerenblij Care Farm

Description: Boerenblij Care Farm offers specialised day care for ederly people dealing with Alzheimer's, dementia, Parkinson and other illnesses. They have several types of activities available for the guests, such as gardening, sports, cooking and working outdoors.

Website: https://www.boerenblij.nl

Meal Services

1. De Maaltijdbutler

Description: Looking for a meal service in Sneek? By means of our Mealbutler you get insight into the most important deliverers in the area. Look at experiences from others, and order your meal on the internet or phone. Always delivered quickly and in many cases for free. It is very popular among elderly.

Contact: Info@maaltijdbutler.nl

Website: https://www.maaltijdbutler.nl/

2. Tafeltje Dekje Sneek

Description: Many elderly people discover the ease of Tafeltje Denkje in Sneek. There reason? First of all we see that the number of options to choose from is growing. Secondly, the delivery of the meals is for free. You can enjoy dishes however you like. Added to that, you do not have to deal with contracts. Living independently but need some help in the kitchen? With the meal service in Sneek, Tafeltje Dekje, you can enjoy your daily meal.

Website: tafeltjedekjemaaltijd.nl

3. Uitgekookt

Description: Uitgekookt offers mealservices, delivering freshly cooked meals right to your doorstep twice a week. They use pure and fresh ingredients in their meals, offering a healthy and tasty meal every time. They have a wide range of choices, so there is a good meal for everyone!

Website: https://uitgekookt.nl/maaltijdservice/bestellen

Contact: info@uitgekookt.nl

4. Eten met gemak

Description: Eten met gemak offers a meal service that delivers once a week, so the recipient does not have to stay at home. They cook with fresh ingredients and have a wide range of food options.

Website: https://www.etenmetgemak.nl/hoe-werkt-het/

Contact:

5. Apetito

Description: Apetito offers frozen meals in Sneek and surrounding areas, they do not yet have fresh meal delivery available in the region. They do have a wide range of frozen meals available for delivery.

Website: https://www.apetito.nl

6. Van Smaak

Description: Van Smaak is a meal delivery services that focuses specifically on elderly in the three northern provinces. They deliver both fresh and frozen meals, but also groceries straight to the client's doorstep. They have a large number of choices available, also for different types of diets, and cook the meals with fresh and healthy ingredients.

Website: https://www.vansmaak.nl

Home care services

1. Thuiszorg Zuidwest Friesland

Description: Thuiszorg Zuidwest Friesland offers all types of home care, such as general care, nursing, nightcare, 24-hour care, home care technology and vacationcare. They also offer personal alarm buttons for vulnerable patients.

Website: https://www.mijnantonius.nl/thuiszorg

2. Thuiszorg het Friese Land

Description: Thuiszorg het Friese Land offers home care all over the Frysian province. They have different types of care available, such as help with household tasks, nursing at home and personal alarm buttons.

Website: https://www.thfl.nl/zorgaanbod

3. Kwadrantgroep

Description: Kwadrantgroep is a network organization that offers complete care for people with dementia, because they work together with different organisations. They have all types of home care and also provide case managers.

Website: https://www.kwadrantgroep.nl

Religious meetings/Zingeving

1. Baptistengemeente Sneek

Description: The Baptistengemeente Sneek offers monthly meetings for elderly people to get together and organize different activities. Some are for fun, some with a more religious sense.

Website: https://baptistengemeente.nl

2. KBO – Activities (Katholieke ouderenbond)

Description: The catholic elderly association organises activities for its members about once or twice a month. Some of them are leisure activities, others have a more religious theme.

Website: http://www.kbofryslan.nl/afdelingen/?page=detail&id=23&subID=180

Volunteer websites

1. Handen in Huis

Description: Handen in Huis is an organisation that offers volunteers who can take over for the informal caretaker for a few days, so they can take some time to catch a breath. The volunteers stay with the person who needs care for at least 3 days and 2 nights. The volunteer and caretaker/carereceiver are matched according to their wishes, so they will have the perfect match.

Website: https://handeninhuis.nl

2. NL voor elkaar

Description: NL voor elkaar is a platform designed for people to offer volunteer services or to find someone who can help them. This is not specifically for people with dementia, though they may find some helpful assistance.

Website: https://www.nlvoorelkaar.nl

3. Vraag Elkaar

Description: Vraag elkaar is a platform designed for people to offer volunteer services or to find someone who can help them. This is not specifically for people with dementia, though they may find some helpful assistance.

Website: https://vraagelkaar.nl

4. We Helpen

Description: We helpen is a platform for people who want to offer their (volunteer) services to someone in need. They have the possibility to look specifically for volunteers who would like to assist elderly people or people with dementia.

Website: https://www.wehelpen.nl

5. Hulpstudent

Description: Hulpstudent is a platform that mediates between students and individuals. The student can offer their services and earn a little money, while the individual (with or without dementia) receives the help they need. The platform is not specifically for dementia but it might be helpful for the caretaker to receive some extra support.

Website: https://www.hulpstudent.nl

6. Woonmaatjes

Description: Woonmaatjes acts as a mediator between students/starters looking for a room/house and elderly people who have space leftover. A woonmaatje can assist with all sorts of tasks, but can also just be there as company.

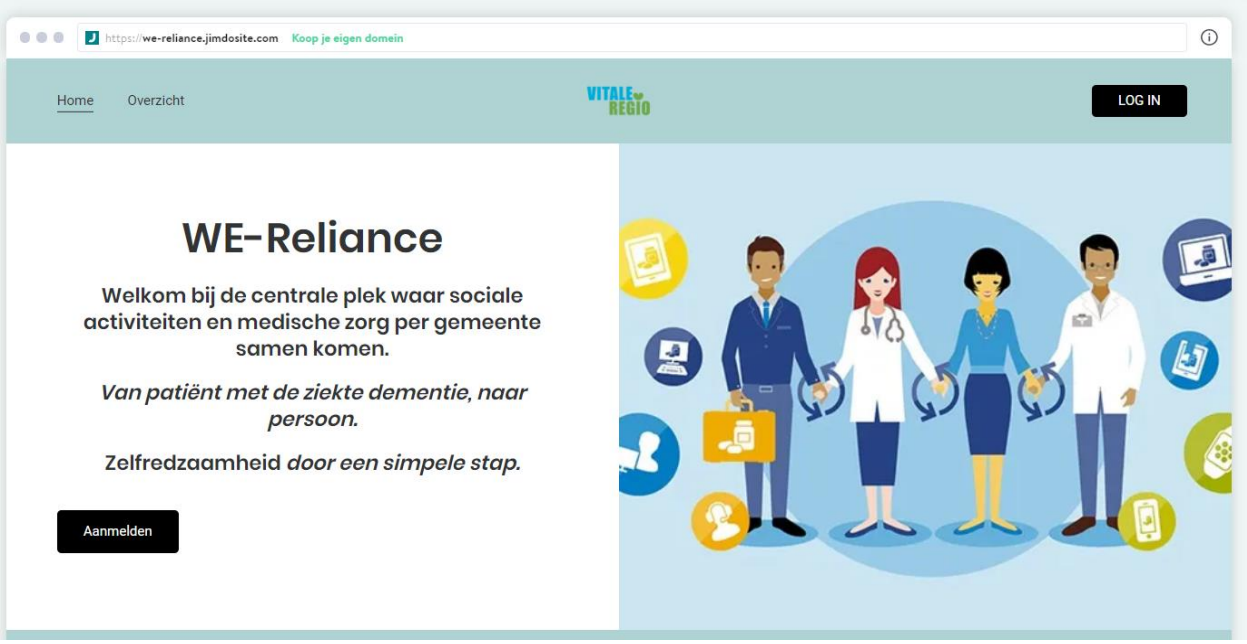
Website: https://woonmaatjes.nl

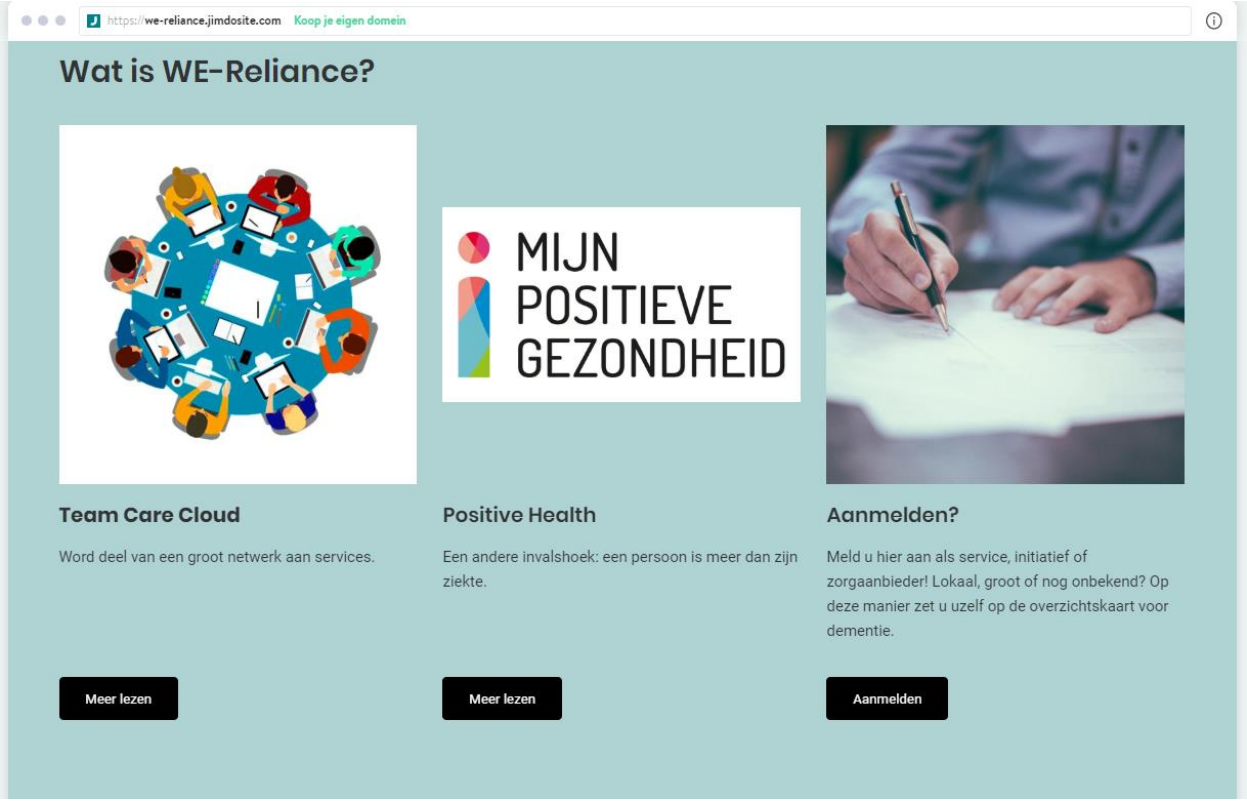
7. Senior en Student

Description: Senior en Student acts as a mediator between students who would like to work and elderly who require help. It is specifically focussed on elderly and students, but not specifically on people with dementia. The students can be hired to do all sorts of tasks or simply be there for companionship. It is paid for by the PGB.

Website: https://www.seniorenstudent.nl

ANNEX VI: Visualization Platform





Care Cloud Overview

Persoon Wytse Venema

Lichaam

Gevoel en gedachten

Zinvol leven

Meedoen

Dagelijks leven

https://we-reliance.jimdosite.com Koop je eigen domein

Aanmelden?

Naam

E-mailadres (Verplicht veld)

Bericht

Ik heb het Privacybeleid gelezen en begrepen. (Verplicht veld)

Versturen


Home
Overzicht
VITALE REGIO
LOG IN
Persoon: Wytse Venema - Sneek
Positive Health: Zinvol Leven
Alzheimer Café - Sneek
Description: Alzheimer Café Sneek is a meeting place for people with dementia, their partners, family members and other interested people.
Address: Frittemaleane 5, 8604 AA Sneek
Contact: g.muller@alzheimervrijwilligers.nl
Stichting "Vier het Leven"
Description: Foundation 'Vier het Leven' organizes cultural activities for elderly who prefer not to go out alone. They get picked up at home by a host from Vier het Leven and together with other guests they go out for a visit to the cinema, a concert, the theater or a museum. The participants can enjoy a drink during the outing, enjoy eachother's company and get brought back home safely after the trip.
Contact: info@4hetleven.nl
Website: www.4hetleven.nl
Cultuurkwartier
"Een tegen Eenzaamheid in Sudwest-Fryslan"
Description: Participation in culture and sports plays an important role in battling loneliness. Together you can enjoy music, walking, dancing, cooking, having a place where you can tell your own story where words may fail. A lot of people over 65 are lonely. They need a little nudge to find connections in society. By participating in sporty or cultural events vulnerable seniors may feel less lonely and more vital.
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Website: https://www.metjehart.nl/gemeenten/sneek/
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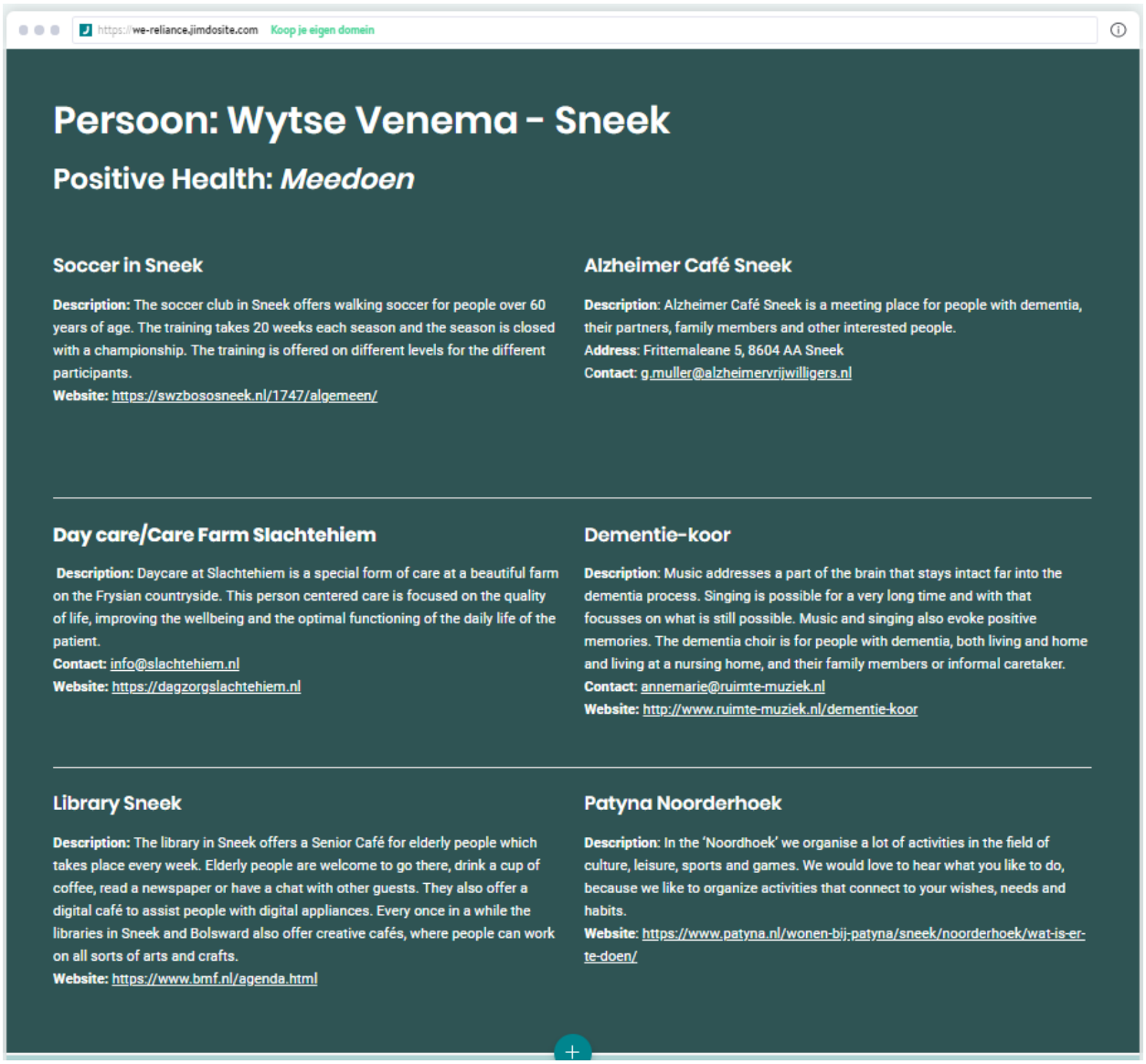
https://we-reliance.jimdosite.com Koop je eigen domein
Persoon: Wytse Venema - Sneek
Positive Health: Meedoen
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Website: https://dagzorgslachtehiem.nl
Dementie-koor
Description: Music addresses a part of the brain that stays intact far into the dementia process. Singing is possible for a very long time and with that focusses on what is still possible. Music and singing also evoke positive memories. The dementia choir is for people with dementia, both living and home and living at a nursing home, and their family members or informal caretaker.
Contact: annemarie@ruimte-muziek.nl
Website: http://www.ruimte-muziek.nl/dementie-koor
Library Sneek
Description: The library in Sneek offers a Senior Café for elderly people which takes place every week. Elderly people are welcome to go there, drink a cup of coffee, read a newspaper or have a chat with other guests. They also offer a digital café to assist people with digital appliances. Every once in a while the libraries in Sneek and Bolsward also offer creative cafés, where people can work on all sorts of arts and crafts.
Website: https://www.bmf.nl/agenda.html
Patyna Noorderhoek
Description: In the 'Noordhoek' we organise a lot of activities in the field of culture, leisure, sports and games. We would love to hear what you like to do, because we like to organize activities that connect to your wishes, needs and habits.
Website: https://www.patyna.nl/wonen-bij-patyna/sneek/noorderhoek/wat-is-er-te-doen/

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