Navigating dementia: Engaging with Informal Caregivers through Stories

Master thesis
by Ileana Díaz Couder Breceda
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Ileana Díaz Couder Breceda

MSc Design for Interaction

Faculty of Industrial Design Engineering
Delft University of Technology

Supervisory Team
Chair | Dr. ir. Sonneveld, M.H. (TU Delft)
Mentor | Ir. Romagnoli, L. (TU Delft)
Company mentor | Ir. Drs. van Zuthem, H.M.(Active Cues)

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i am the product of all ancestors getting together
and deciding these stories need to be told

- rupi kaur

Aknowledgements

This project has been one of the biggest challenges I have encountered and overcome (phew!), especially during the pandemic. I am happy to say that with this, I conclude my masters in “Design for Interaction”. One of my biggest learnings in this journey has been to reach out for support, to tell as clearly as possible what you need, and to speak up for myself.

Although the master’s and graduation journey was bumpy and uncertain, I can happily say: I did it!. Nevertheless, I have a lot of incredible people to thank because this would not have been possible without them on the road.

First to my mentors, **Marieke**, thank you for pushing my boundaries, although it was difficult at times. For your flexibility, patience, and academic expertise.

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Cesar, thank you for your openness to discussion and for participating in brainstorming with challenging ideas.

Marina and **Ale**, thank you for listening me, for your warmth, and your encouraging and non-judgemental words.

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Enjoy the read!

Executive Summary

According to the WHO, dementia is one of the main causes of elderly dependency and disability worldwide. People with dementia are not the only ones affected. As the demand for care is high, families and caregivers experience physical, emotional, and sometimes financial stress.

Up to date, there is no cure for dementia and its progression. The current research nowadays focuses mainly on strategies for preventing dementia and improving people with dementia's quality of life and those around them.

Active Cues (now 'Tover') is an organization based in Utrecht, the Netherlands, that aims to create moments of happiness in residential care. They do so with the ToverTafel, an interactive set of projections that stimulates each of the company's target groups, with games designed specifically for them. The starting point of this project aimed to enrich Active Cues' current design process to keep designing for People with Dementia.

In the first phases of the project, dementia and the needs of each of the individuals involved (Professional Caregivers, Informal Caregivers, and People with dementia) were researched through literature and generative techniques. It was found that people with dementia are fond of references to their past and that informal caregivers have access to it to a certain extent.

Meanwhile, family members who act as informal caregivers go through dementia grief, have deep bonds with the PwD, know their preferences, and develop effective ways of engaging with them.

Active Cues' way of working was also explored. In their design process, professional caregivers are the representatives of PwD living in nursing houses . They support Active Cues by helping understand what happens during their design iterations and bringing suggestions for new games and their improvements. However, professional caregivers are not always aware of people with dementia history and background, nor do they have time to access it to transmit this knowledge to Active Cues.

The generative techniques' interviews show that informal caregivers are potentially rich sources of valuable insights, and they are not part of Active Cues' design process. Integrating informal caregivers' input in Active Cues creative design process was proposed to gain contextual knowledge about people with dementia.

Based on the generative techniques' insights, a number of requirements were identified for both the informal caregiver and Active Cues. The project focused only on the informal caregiver's requirements: promoting reflection, being pertinent in the informal caregiver's journey, and being light-hearted. After experimenting with digital prototypes and performing co-creation sessions with informal caregivers, a concept called Remi was designed.

Remi is a digital journaling service that aims to provide informal caregivers space to decompress, reflect on one's feelings, connect with others by journaling and sharing stories with Active Cues to generate valuable insights for their creative process.

The concept was tested through storyboard sessions and an interaction test supported by semi-structured interviews. It was found that informal caregivers were willing to share personal stories with an organization such as Active Cues. They mentioned it would feel gratifying to know they are contributing to the big goal of improving the quality of life of people living with dementia.

Glossary

PwD
People with Dementia

Nursing home
A place where (ill) elderly live and receive 24/7 care

QoL
Quality of life - the level of satisfaction and comfort that a person or group enjoys.

Informal caregiver
Family members and friends that provide voluntary support and care, without pay, with day to day activities to an individual who is either temporarily or permanently unable to live independently.

Professional caregiver
People whose paid career is to provide a person with either medical or non-medical care to an individual who is either temporarily or permanently unable to live independently.

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01

Introduction & Project Setup

This chapter introduces the graduation project with contextual information, its aim and focus, the guiding research questions, and the project's approach. At the end of this chapter, a project overview shows the process followed on each stage of the project.

1.1 Dementia in the world

Around the globe, about 50 million people live with dementia, and every year there are approximately 10 million new cases (World Health Organization, 2019b). On average people live around 8 years with dementia and the severity of the symptoms increases along this time, they experience changes in their cognitive abilities, mobility and behavior.

Dementia is one of the main causes of elderly dependency and disability worldwide (World Health Organization, 2019c). In a research published by the Alzheimer Disease International (2018) , it was estimated that during the year 2015, the global care provided was the equivalent of 40 million full-time workers (that is around 2.3 times the population of The Netherlands), and it is projected that by 2030 that will increase to 65 million.

PwD (People with Dementia) are not the only ones affected. As the demand for care is high, families and caregivers experience physical, emotional, and sometimes financial stress. (World Health Organization, 2019c).

Some research focuses on strategies for prevention of dementia, such as being physically as much as cognitively active and having a balanced diet (Middleton & Yaffe, 2009) (Iuliano, E. 2019) as currently there is no cure for dementia and its progression. Nonetheless, other branches of researchers focus instead on improving the QoL (Quality of life) of PwD and the ones around them by targeting others aspects of life that enhance people's well being (Kenning et al., 2019,) such as the social, spiritual or the playful aspect of life to provide different resources for a worthy life, as everyone has the right for it.

1.2 Active Cues and their vision

This project was started and guided by Active Cues, an organization based in Utrecht, NL, that aims to create moments of happiness in residential care and education. This organization emerged from Hester Le Riche's Ph.D. at TUDelft, in which she designed a product called the ToverTafel (Image 1.1), an interactive set of projections that stimulates each of the company's target groups, with games designed specifically for each of them. One of Active Cues' cornerstones is research for product development, and they believe that everybody has the right to play.

When PwD move into nursing homes, their apathy increases, leaving them with little initiative for activation. The ToverTafel provides audiovisual triggers to the residents of nursing homes to play, and it is a means to support their activation for physical mobility and socialization (H. Anderiesen 2017).

1.3 Focus of the project

The project focuses on enriching Active Cue's current design process to keep designing for PwD by bringing the insight of informal caregivers.

Initially, the project aimed to address people

Image 1.1 The ToverTafel original in use

in the last stages of dementia that are likely to be confined to a bed, wheelchair, or room, as Active Cues is looking to design for this specific group. For the details of the initial project brief, see Appendix A.

Nevertheless, the planning of the project was adjusted on the go due to the COVID-19 pandemic, for example the visits to nurses homes could not be done. On top of that after concluding part of the research and getting to know Active Cues more (chapter 4), an opportunity presented: informal caregivers were not part of Active Cues design process, and the research showed that they could be a rich source of valuable insights. Hence, the project's focus shifted from the initial one.

The project explores PwD, the ones around them: formal and informal caregivers, and Active Cues. It also delves into understanding dementia and its demands for each of these individuals. As such, each of the above stakeholders were involved throughout the process of the project.

The leading research questions of this project are the following:

About PwD
- What are the emotional needs of people with dementia and those around them?

About Active Cues
- How does Active Cues currently perform design and research?
- Where does Active Cues lack knowledge and tools to design for people living with dementia?

1.4 Approach of the project

To execute the project, I took a collaborative and qualitative yet fuzzy approach divided into five phases:

- *Investigating* through literature
- *Exploring* the context,
- *Defining* - from insights to design,
- *Experimenting* with ideas, and
- *Developing* the concept.

An overview in Figure 1.2 illustrates these phases.

The goal of the *Investigating through literature* phase, Chapter 2, was to first understand what dementia is to later grasp the needs of PwD and those around them through literature.

After this, in the *Exploring the context* phase, that comprehends Chapters 3 and 4, together with peer student Hannah Pak, we delved into the context of dementia.Observations were carried out through documentaries; then, interviews led by generative techniques were done to formal and informal caregivers, and the resulted data was collected with cards in an adapted online version of an on-the-wall-analysis (Sanders & Stappers, 2012) to conclude with a Dementia Journey.

Later individually with Active Cues, semi-structured interviews were carried out with former and current Active Cues designers to find out their way of working.

In the *Defining - from insights to design* phase, which cor responds to Chapter 5, the insights shaped the problem definition, the design goal, and the design requirements for both Active Cues and informal caregivers.
To reduce the complexity of the project, it was decided to focus on the requirements of the informal caregiver.

During the *Experimenting with ideas* phase, Chapter 6, the ideation and iteration phases were executed by brainstorming and testing with peers and informal caregivers. This chapter concludes by merging ideas in a storyboard that explains the design direction.

Lastly, in the *Developing the concept* phase, that includes Chapters 7 and 8, the idea was refined with co-creation sessions with informal caregivers, to later assess the concept with storyboard evaluation sessions and an interaction test.

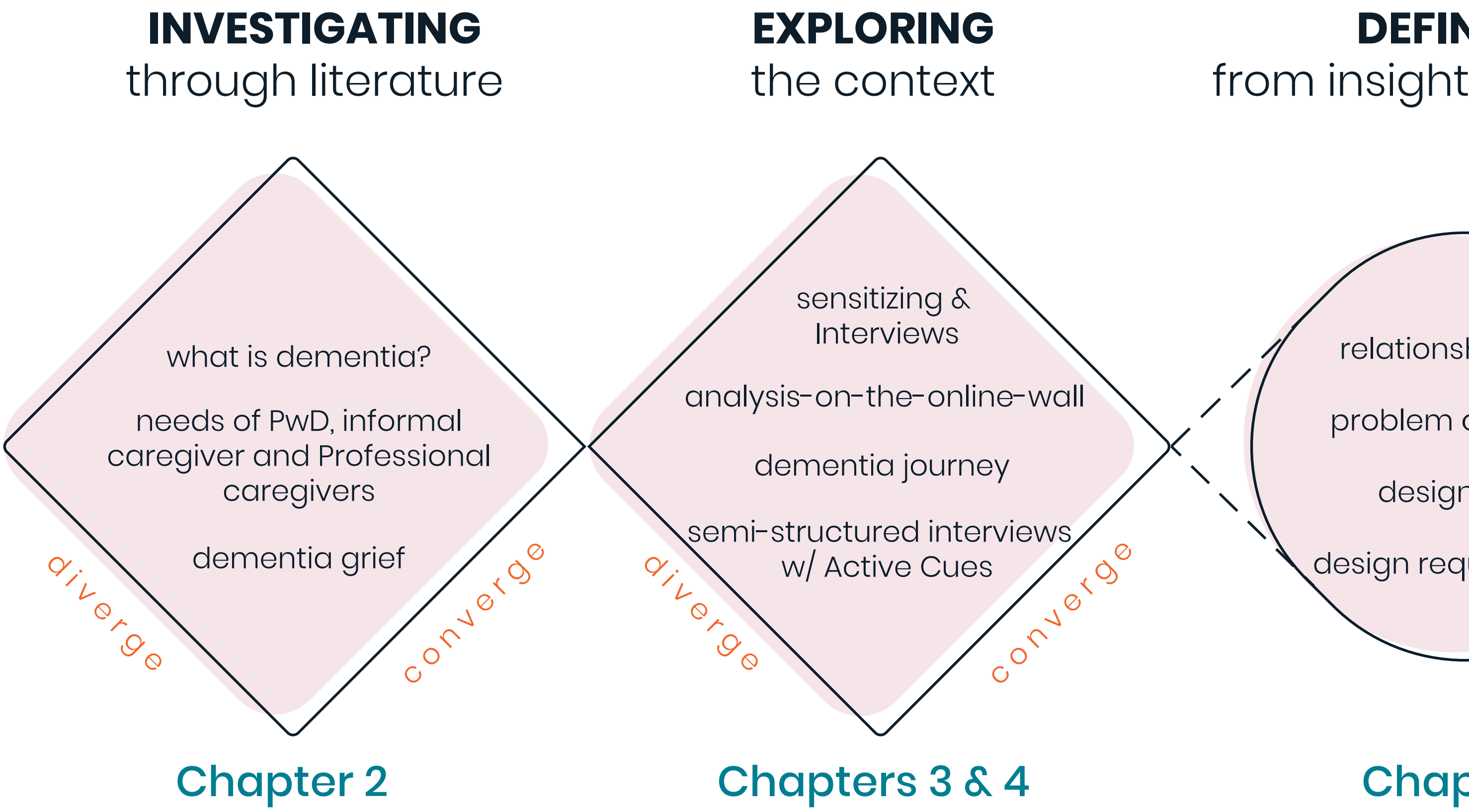
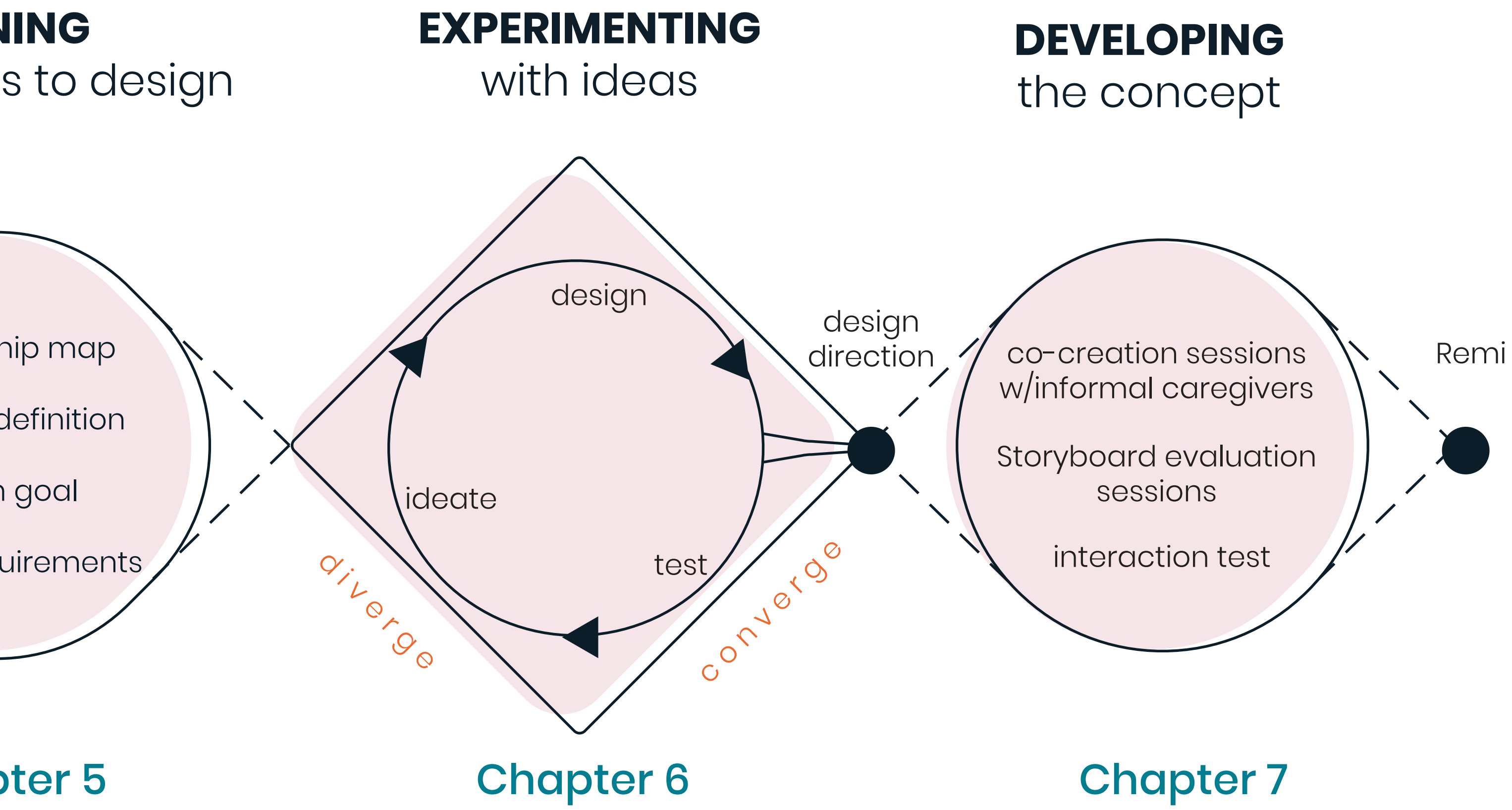


Figure 1.2 Project overview with the research activities carried out on each stage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Chapter 6
Chapter 7

02

Investigating through literature

This chapter defines through literature what dementia is and its stages. It also describes the needs of each of the individuals involved in the dementia journey: PwD, professional caregivers and informal caregivers. Later, the chapter defines the term "dementia grief" and finally the chapter closes with conclusions.

2.1 What is dementia?

Dementia is an umbrella term that covers symptoms of the following diseases: Alzheimer's disease - the most common form of dementia -, vascular dementia, dementia with Lewy bodies, Parkinson's Disease, and a group of conditions that contribute to frontotemporal dementia (Figure 2.1). As such, dementia refers to a syndrome because it is a combination of symptoms.

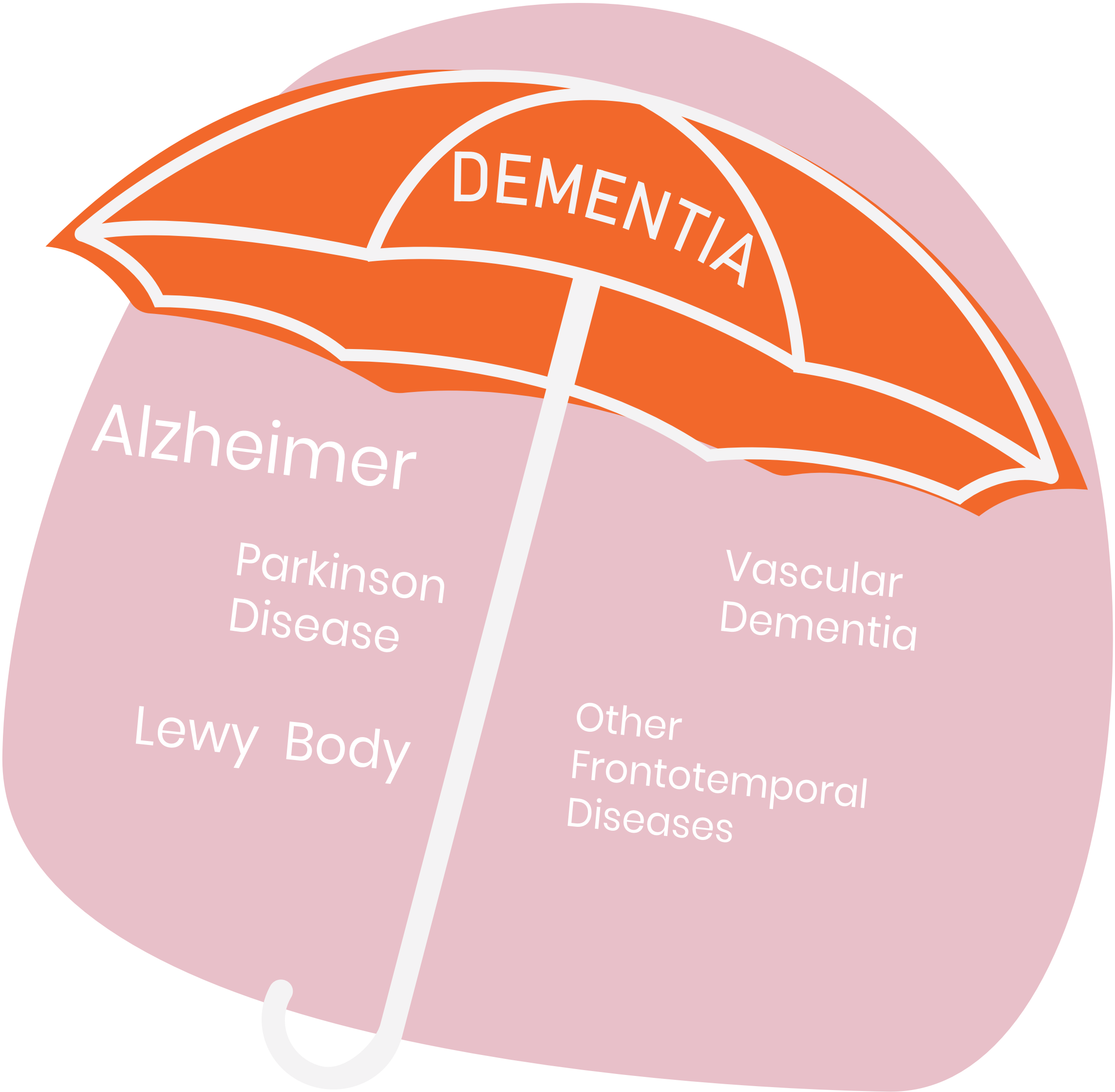


Figure 2.1 Diseases' symptoms that dementia covers

A common misconception is that dementia is part of normal aging; although age is one factor, it is a mistaken idea.

Dementia symptoms are classified into different stages; according to 7 stages of 'The Global Deterioration Scale for Assessment (GDS) of Primary Degenerative Dementia' (Reisberg, Ferris, de Leon, & Crook, 1982) and the World Health Organization (World Health Organization, 2019a) these phases are as follow:

Predementia stages or early-stages
On the Global Deterioration Scale for assessment (GDS) phase one to three fall under the predementia stages or early-stages. The symptoms include:
- Forgetfulness
- Losing track of time
- Becoming lost in familiar places.

Middle stage
Stage three and four are from the GDS are considered the middle stage. The symptoms include:
- Becoming forgetful of recent events and people's names
- Becoming lost at home
- Having increasing difficulty with communication
- Needing help with personal care
- Experiencing behavior changes, including wandering and repeated questioning.

Late Stages
From phases five to seven (GDS), the individual can no longer survive without assistance. Symptoms include:
- Becoming unaware of the time and place
- Having difficulty recognizing relatives and friends
- Having an increasing need for assisted self-care
- Having difficulty walking
- Experiencing behavior changes that may escalate and include aggression.

2.2 Needs of: People with Dementia, Professional Caregivers and Informal Caregivers

Care in the last stage of life generally focuses on minimizing physical symptoms. However, all people, including people with dementia, have other levels of needs than merely biological.

Desk research was done to gain knowledge and understanding of each of the individuals involved in dementia: the person living with dementia and Professional and Informal Caregivers; the research was guided with the following research question:

- What are the emotional needs of PwD, and those ones around them?

2.2.1 Needs of People living with dementia

The needs of PwD are not different than any other human being; however, when the dementia symptoms increase and PwD move and live in a care facility, some needs are prevalent for their quality of life. For example, proper medication and pain management are fundamental; however, in different studies, most unmet needs are non-medical. The needs found have more to do with Safety (Black 2019), daily individualized activities (Cadieux 2013, Miranda-Castillo et al., 2010, Black 2019), social companion (Cadieux 2013, Miranda-Castillo et al. 2010), and management of psychological distress (Miranda-Castillo et al.,2010).

In another study, with the three individuals involved in the dementia journey: PwD, professional caregivers, and family carers (Orell, 2008)it was found that these three groups of participants identified relatively more unmet needs in the areas of daytime activities and social company.

Kitwood (1997) states, “a person with dementia must be recognized as a person with thoughts, emotions, and wishes” and in this manner the approach to PwD should be likewise. In a qualitative study involving PwD and their families in focus groups (R.Milte et al, 2016) it was found that a critical key concept in providing quality care was by supporting personhood.

The previously mentioned studies suggest that the social network of PwD is fundamental for their quality of life and maintaining one’s individual preferences for day-to-day life, especially when moving into a nursing house that implies a significant change of environment for the person living with dementia.

2.2.2 Needs of Professional Caregivers

The number of PwD living in residential housing has increased in the last decades, while professional caregivers have not kept the same pace (AARP Public Policy Institute, 2013). This situation puts the latter in a challenging position to provide tailored care. Various nursing homes accept the support from volunteers that assist some days in the week the residents, which helps alleviate the ratio caregiver: resident, with a tendency of residents going up.

Professional caregivers working in nursing houses are in constant communication with their residents as well as their families; They are aware that each of their residents has different preferences and needs; nonetheless, the reduced number of caregivers and the tasks that their work requires limit the time spent with each of the residents in nursing homes.

2.2.3 Needs of Family and Informal Caregivers

One of the first emotions that arise in the family members of PwD is the fear and surprise associated with the first manifestations of dementia (Delgado, C. M., 2016). Families experience mixed feelings when receiving a positive diagnosis of their relative’s dementia symptoms. On the one hand, they feel reassured because they know what is happening, and on the other, they also experience anguish and uncertainty because of thinking about how this will develop in the future.
Although the family of the person with dementia has the highest interest in providing the best care for their loved ones, many times in trying to meet their loved one’s needs, the family’s primary caregiver neglects theirs (Chenoweth, B 1986).

Family members of PwD would like to provide care at home and not to transition to institutional care or professional care. However, to a large extent, this transition is necessary not only for the well-being of PwD but also for family members, considering they provide care for their family members living with dementia while trying to balance other aspects of their life (career, family, relations, social activities).

2.3 Dementia Grief

The Cambridge Dictionary defines grief as a “very great sadness, especially at the death of someone.” With this definition in mind, within the context of dementia, Dupuis (2012) states that when family caregivers accompany their relative with dementia, they experience a period of ambiguous loss, in which the informal caregiver encounters the loss of their loved one, while the person living with dementia is still alive. This occurs as the person with dementia is no longer psychologically available due to increased dementia symptoms.

Since the person living with dementia passes through severe changes in memory, cognitive abilities, and behavior, their families, at some point in the dementia journey, feel like they no longer recognize the person they are taking care of. This is undoubtedly painful because what creates connection and attaches relationships are, to some extent, memories, and without these, sometimes, relatives of the PwD feel like the person they are taking care of does not appear to be the same person as their dad/mom/partner.

The dementia grief model explains how the process of pre-death grief occurs in caregivers. The model consists of three phases: Separation, Liminality, and Re-emergence (Blandin & Pepin, 2016). Figure 2.2 illustrates the model.

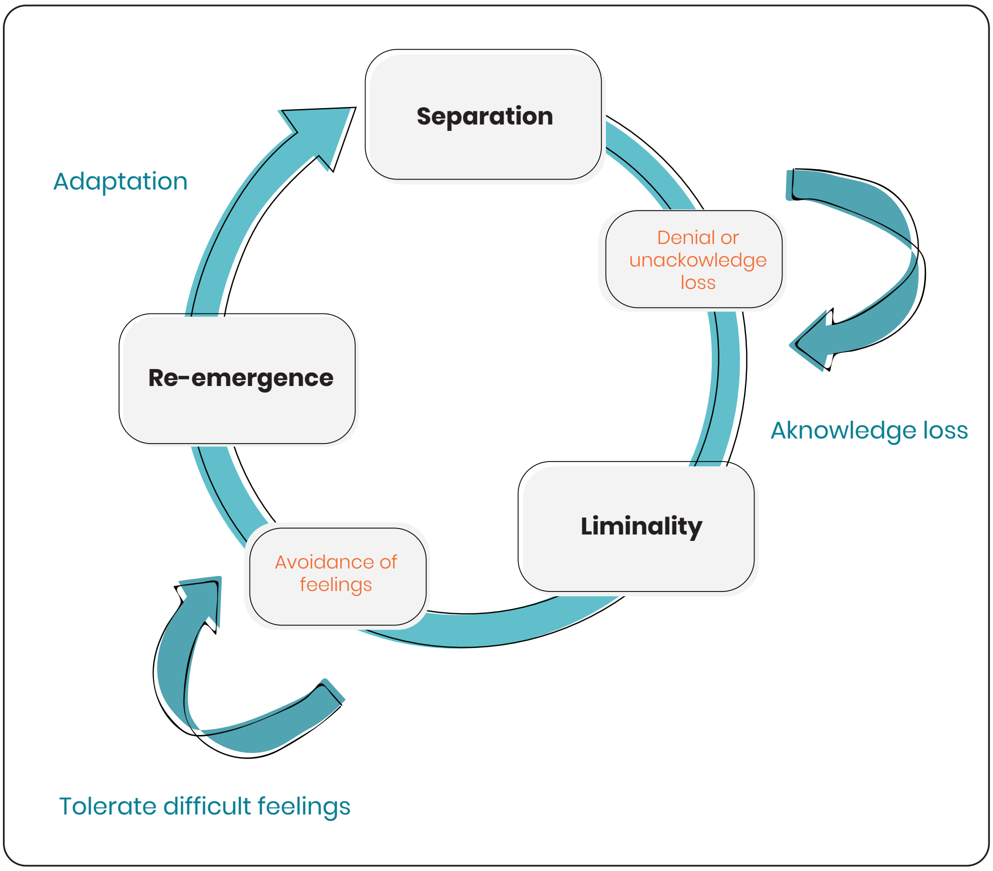


Fig 2.2 The dementia grief model by Blandin & Pepin 2016

Blandin & Pepin (2016) state, “Each state is characterized by a specific psychological state and has a dynamic mechanism that propels movement through the grief process. Failure of the dynamic mechanism is hypothesized to inhibit the grief trajectory, adding to the distress of the caregiver.”

The dynamic mechanisms for each state are: acknowledging loss, tolerating difficult feelings, and adapting to the new life circumstance or reality of the loss. (Blandin & Pepin, 2016). Although, in theory, as this model suggests, it is very straightforward, in practice, this is rather difficult.

2.4 Conclusions

As shown in the previous sections, each individual has specific needs when navigating dementia, which can create dilemmas while caring for PwD.

For PwD, it is beneficial to engage with personalized activities that evoke the individual behind the dementia symptoms. Although professional caregivers are aware of the benefit of customized care for their residents, the lack of staff does not allow them to do this to a full extent.

And finally, for the family and informal caregivers, their greatest needs are to provide this personalized care for their family members living with dementia while passing through the dementia grief, and to receive emotional support during the journey of dementia.

03

Discovering the context: Understanding that we do not fully understand dementia

This chapter explores the context of dementia through documentaries and generative techniques followed by interviews. Later a dementia journey is presented, which results from the explorations made; it maps each of the involved individuals' perspectives in the journey. The chapter closes with its takeaways.

3.1 Process overview

To have a general view of the process followed in this chapter see Figure 3.1

* (Sanders and Stappers, 2012)

Figure 3.1 Process overview of the methods and activities executed in chapter 3

3.2 Documentaries as observations

Initially, the idea was to visit the nursing homes that work closely with Active Cues, perform observations, and get first-hand experience of the nursing house dynamics. Due to the 2020 pandemic COVID-19, face-to-face observations were not feasible as nursing homes were closed to the public; alternately, the following three documentaries were used as observations:

- In de Leeuwenhoek (NPOstart, 2018)
- Wat ik nog ben (NPOstart, 2016)
- Alive Inside (Snagfilms, 2020)

After watching the documentaries, observation notes were gathered in Miro, an "online collaborative whiteboard platform" (Miro 2020). And later on, the observation notes were clustered along with the interview notes. Further, in section *3.3.4 Analysis*, the main resulting clustered themes from the documentaries and the interviews can be seen.

3.3 Generative Techniques

To have a deeper understanding of the experience of dementia, motivations, feelings and needs of the individuals involved in the dementia journey, generative techniques were carried out with formal and informal caregivers.

3.3.1 Participants

Participants were informally recruited via email through fellow student acquaintances, and later on, some participants forwarded the same email to their own contacts. Thanks to this, there were ten participants plus one that Active Cues provided.

In total, eleven caregivers participated in the interviews; Five of those participants were professional caregivers and/or staff from nursing homes, and the other six participants were family members from PwD that were the primary informal caregiver in their family. Table 3.2 shows an overview of the participants.

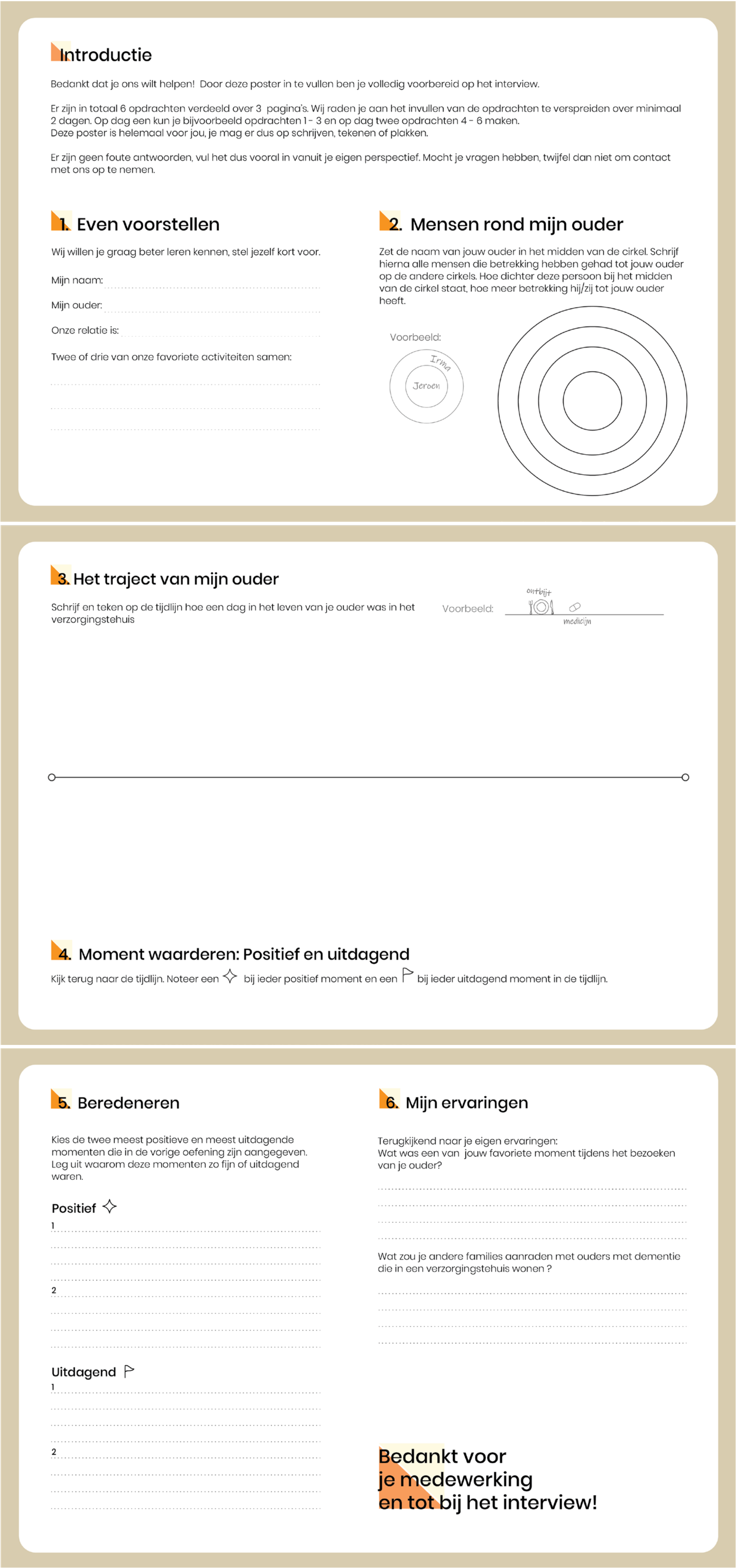
Professional caregivers			
#	**M/F**	**Function**	**Experience**
P1	F	Caregiver	30 years
P2	F	Activity supervisor	8 years (with this function)
P3	F	Activity supervisor	26 years
P4	F	Caregiver	2 (previous 5 year as help)
P5	M	Dementia Clown	1 year
Informal caregivers			
#	**M/F**	**Takes care of**	**Extra functionn**
I1	F	Mother	Volunteer at Alzheimer café
I2	F	Mother	-
I3	M	Mother	-
I4	M	Mother	Volunteers at trips for PwD
I5	F	Father	-
I6	F	Mother	Sound healer of PwD

Table 3.2 Overview of the participants in the generative techniques (Pak, 2020)

3.3.2 Sensitizing prior interviews

A 3-page poster was created as sensitizing material to explore the emotional needs of PwD and the caregivers around them. “The sensitization stage is a period before sessions take place with users”(Sleeswijk et al., 2005), and it helps participants to reflect on their past experiences. In the case of informal caregivers, a retrospective reflection was crucial as their parents living with dementia passed away between 3 months and five years ago from the interviews’ dates.

There were two different versions of the sensitizing material in the same visual style —one for informal caregivers (Image 3.3), the other for professional caregivers (Appendix B) —



Introductie

Bedankt dat je ons wilt helpen! Door deze poster in te vullen ben je volledig voorbereid op het interview.

Er zijn in totaal 6 opdrachten verdeeld over 3 pagina's. Wij raden je aan het invullen van de opdrachten te verspreiden over minimaal 2 dagen. Op dag een kun je bijvoorbeeld opdrachten 1 - 3 en op dag twee opdrachten 4 - 6 maken.
Deze poster is helemaal voor jou, je mag er dus op schrijven, tekenen of plakken.

Er zijn geen foute antwoorden, vul het dus vooral in vanuit je eigen perspectief. Mocht je vragen hebben, twijfel dan niet om contact met ons op te nemen.

1. Even voorstellen

Wij willen je graag beter leren kennen, stel jezelf kort voor.

Mijn naam: ....
Mijn ouder: ....
Onze relatie is: ....
Twee of drie van onze favoriete activiteiten samen:
....
....
....

2. Mensen rond mijn ouder

Zet de naam van jouw ouder in het midden van de cirkel. Schrijf hierna alle mensen die betrekking hebben gehad tot jouw ouder op de andere cirkels. Hoe dichter deze persoon bij het midden van de cirkel staat, hoe meer betrekking hij/zij tot jouw ouder heeft.

Voorbeeld:

3. Het traject van mijn ouder

Schrijf en teken op de tijdlijn hoe een dag in het leven van je ouder was in het verzorgingstehuis

Voorbeeld:

4. Moment waarderen: Positief en uitdagend

Kijk terug naar de tijdlijn. Noteer een ✧ bij ieder positief moment en een ⚐ bij ieder uitdagend moment in de tijdlijn.

5. Beredeneren

Kies de twee meest positieve en meest uitdagende momenten die in de vorige oefening zijn aangegeven. Leg uit waarom deze momenten zo fijn of uitdagend waren.

Positief ✧
1 ....
2 ....

Uitdagend ⚐
1 ....
2 ....

6. Mijn ervaringen

Terugkijkend naar je eigen ervaringen:
Wat was een van jouw favoriete moment tijdens het bezoeken van je ouder?
....

Wat zou je andere families aanraden met ouders met dementie die in een verzorgingstehuis wonen ?
....

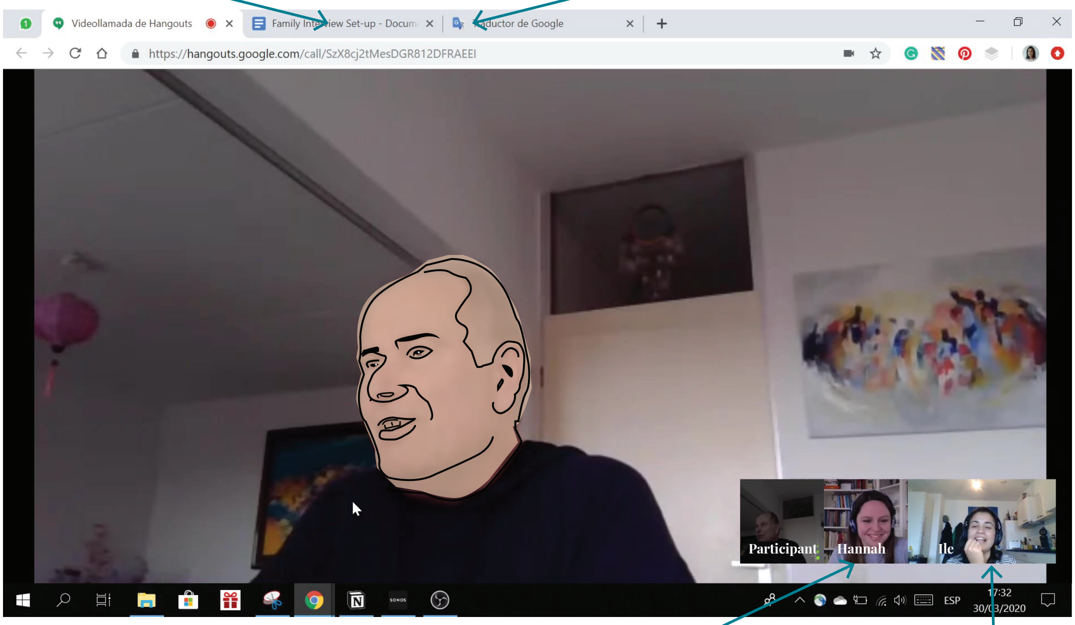
**Bedankt voor
je medewerking
en tot bij het interview!**

Image 3.3 The sensitizing material created for the informal caregiver

3.3.3 Previous and during the interviews

The sensitizing material shown in the previous section was sent digitally to print at home, as all participants stated to have a printer. They received the material along with a consent form from four to five days before the scheduled phone or video call. In Image 3.4a and 3.4b, a screenshot of a video call can be seen with one participant.

During the interviews, the sensitizing material served as a starting point to generate a richer conversation and as a way to structure the previously done interview scripts (Appendix C)



Interview script

Translator as my Dutch understanding is about 70% of the language

Interviewer

Listener

Image 3.4a. Setting of one of the online interviews performed

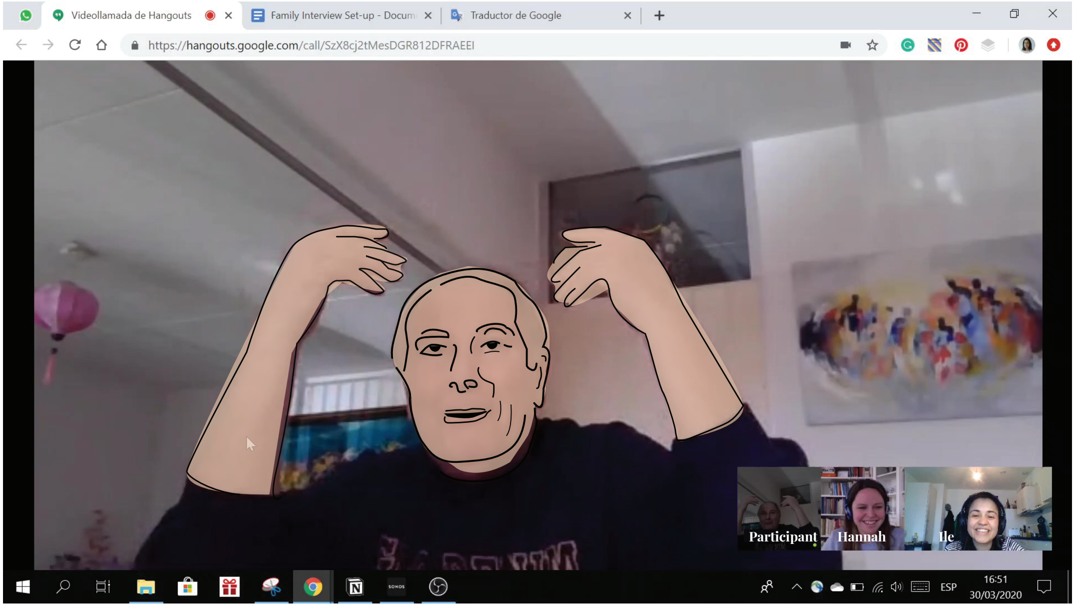


Image 3.4b. Although all the interviews were done via phone or video call, the participants expressed themselves in a rich manner.

3.3.4 Analysis

In order to analyze the interviews, these were recorded to hear them back. After listening to the eleven interviews, insights cards were created digitally supported by Miro.(Image 3.5). An online 'on-the-wall analysis' (Sanders and Stappers, 2012) was carried out, each participant got a different sticky note color, in order to trace back the source of it. Insights were written down, interpreted, and grouped in clusters to look for patterns and themes.

By all means, it is almost impossible to fully understand a person living with dementia as they themselves cannot report the condition in which they live at the present moment and compare it to their living experience in the past. Making sense of their syndrome comes from medical research that explains how parts of the brain deteriorate to grasp which cognitive and bodily functions are no longer possible. Alternately, from the experience, observations, and interpretations from caregivers and researchers doing their best to improve PwD's QoL.

Image 3.5. ‘On-the-wall’ analysis

With this said, the interpretation and categorization of the following themes come from the documentaries seen and the interviews made with professional and informal caregivers.

3.3.4.1 The world of People living with Dementia

“They live in their own cocoon” one of the interviewees from the professional caregivers said. PwD live in their unique and personal world. This world is situated most of the time in their early adult experiences or their childhood.
Sometimes PwD ask for their partners that have passed away or they show worry because they are waiting for children to come from school. They experience the worry because for them it is happening in the present time. Professional caregivers use resources as “white lies” to validate their feelings because mentioning that their partner no longer lives or trying to explain that children are not at school because they are grown up may cause a major distress that could bring health and emotional implications for their well-being.

> *“They live in their own cocoon”*
>
> - Interview professional caregiver 1

Oftentimes PwD create their own reality, they might for example mention to have gone outside during the day when they have not actually gone, at the beginning of the dementia journey family members tend to correct them, sometimes from a place of lack of knowledge on what is going on with their parent and some others attempting to bring them back to the “outer” world.
In the later stages of dementia people are withdrawn from the ‘outer’ world and they, most of the time, go inwards due to apathy that increases in these later stages.

3.3.4.2 Activities that PwD enjoy

The days in nursing houses can feel long if the residents do not experiment stimuli or triggers with different activities. Nursing houses usually have an activity leader who is in charge of recreational activities such as painting, elderly aerobics or board games. Interviewed professional caregivers mentioned that PwD also enjoyed helping with preparing food, especifically peeling potatoes, arguably being one of the most eaten vegetables in the Netherlands. As stated in chapter 2, this shows how the cultural background and personal history of every individual is important even when living with dementia (R.Milte et al, 2016).

When families visit their relatives living with dementia they show them pictures, or tell them stories about their past to provide hints about their history, to which PwD react positively.

Mostly, going outside alone it is not allowed for residents of nursing houses as there is a potential danger of getting lost. Family members of PwD mentioned during the interviews that an activity that both enjoy is to take a walk outside, looking at nature. Another activity that was mentioned a lot was to sit together with a cup of coffee or tea, and offer one of their favorite meals.

> *“Eating things that are not healthy is fine. It’s about enjoying life”*
>
> - Interview informal caregiver 3

All these activities have in common that PwD are in their family’s’ company as seen in section 2.2.1 “Needs of People living with dementia”. (Cadieux 2013, Miranda-Castillo et al. 2010,Orell 2008). Family members emphasized the importance of being present with their relatives living with dementia and showing it through the sense of touch when it cannot be shown verbally no more

3.3.4.3 Personalized attention ≠ Group attention

Life in a nursing home is structured, not only because it helps staff do their jobs but also because it helps residents acquire a routine and rhythm on a day-to-day basis.

The increasing number of people living with dementia is shifting care towards focusing on the group's needs instead of focusing on each of the individuals that make up that group.

Professional caregivers know that people living in care institutions live together because they have their dementia condition in common. They mentioned in interviews that each of the nursing home's residents has different preferences, cultural backgrounds, levels of education, and like each person, a unique history of their past.

For caregivers, this is a challenge, since, without much staff, personalized attention becomes difficult; they have the responsibility to facilitate and maintain a positive environment within the nursing home. However, what one resident likes might be different for the other.

> *"What someone prefers, someone differs"*

- interview professional caregiver 3

Moreover, caregivers face the dilemma of providing the freedom that each resident needs while also keeping things in control in the nursing house.

> *"As a caregiver sometimes you have to let things go unless they're going really bad for the resident"*

- Interview professional caregiver 4

3.3.4.4 Communication between PwD and their relatives

The dementia journey begins with the diagnosis that confirms this syndrome. This stage is emotionally difficult for both the person being diagnosed, and their family in which a member of it will turn into an informal caregiver. One can imagine that soon all the experiences and moments that connected him to his loved one could be gone.

As time passes, the family, generally, develops new ways of communication where the essential aspect is to keep their loved ones busy, accompanying them and letting them be, instead of communication where information about real events is exchanged.

The interviewees mentioned that it is crucial to try to get into their world and go with the flow when they tell a story instead of correcting them.
They also mentioned that another effective way is to provide two short options to promote agency in their preferences.

> *"I would ask my mom did you sunbathe or do crafts today? either that was true or not ... as a companion you have to let go if that story is true or nonsense, I would just take the story and kept with it, it doesn't matter. In that phase it is more about energetic communication rather than communication about facts"*

-Interview informal caregiver 1

3.3.4.5 A new child-parent relationship

Dementia brings challenges of course; however, something interviewees mentioned is that the relationship with their parents evolved, by being judgment and expectation free. They mentioned feeling energetically connected and being able to enjoy each other's company.

In some particular cases with interviewees, they said dementia brought the sweet side of their parents.

> *"My mother was a person that didn't like to be touched; she was very independent, she became a very warm and sweet mother, it was a sort of a gift that came with dementia"*

- Interview informal caregiver 3

This new relationship is the result of, most of the time, years of companionship, and it is undoubtedly something that does not happen at the diagnosis which is the official beginning of the dementia journey (Delgado, C. M., 2016). In most cases this new relationship originates from experiencing the loss of the personality of the person they are taking care of.

> *"The parent you knew all this time is gone. She is a different person now"*

- Interview informal caregiver 2

3.3.4.6 Pride in the history of one's parents

Interviewees with parents with dementia discussed how life in nursing homes is, the challenges and difficulties they face. Furthermore, a particular element during the interviews was that they made sure to let know with pride about the preferences of their parents before they developed dementia and the activities that they still did that connected them with their past.

> *"When we all lived together on Sunday evening we had dinner around 18:00 pm, we started with bread and then my mother suddenly wanted to sing together and everyone had to say a song to sing acapella ... singing together was always an important thing for her, she just liked it"*

- Interview informal caregiver 4

3.4 The dementia journey

The dementia journey map is the conclusion of the analysis of the observations and interviews performed. It visually represents the phases and perspectives of the three groups of people that go through it:

- The person living with dementia
- The informal caregiver
- The professional caregiver

Considering PwDs were not interviewed, their perspective on the dementia journey was done with the interviews' insights with professional and informal caregivers.

The dementia journey shows in the stages starting from getting diagnosed to the final days of life; Each of these stages contain different activities identified. Under the activities, for each of the individuals involved it is shown what they think, what they feel and what they need. For the needs row shown the Needs for Human-Centered Design by Desmet, P., & Fokkinga, S. (2020) were used (See Table 3.6). Later there is a row of *opportunities* that were found to help alleviate or improve the journey. Under the opportunites an emotional curve is shown, the high dots indicate that the needs in that activity are fullfilled and the low dots that the stated needs are not being met.

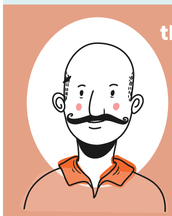
In the dementia journey in image 3.7 there can be seen blank spaces for some activities for each individual, this indicates that the individual does not participate in it.

Fundamental Needs	Explanation	Sub-needs
Autonomy	Being the cause of your actions and feeling that you can do things your own way, rather than feeling as though external conditions and other people determine your actions.	- Freedom of decision - Individuality - Creative expression - Self-reliance
Beauty	Feeling that the world is a place of elegance, coherence and harmony, rather than feeling that the world is disharmonious, unappealing or ugly.	- Unity and order - Elegance and finesse - Artistic experiences - Natural beauty
Comfort	Having an easy, simple, relaxing life, rather than experiencing strain, diculty or overstimulation.	- Peace of mind - Convenience - Simplicity - Overview and structure
Community	Being part of and accepted by a social group or entity that is important to you, rather than feeling you do not belong anywhere and have no social structure to rely on.	- Social harmony - Affiliation and group identity - Rooting (tradition, culture) - Conformity (fitting in)
Competence	Having control over your environment and being able to exercise your skills to master challenges, rather than feeling that you are incompetent or inefective.	- Knowledge and understanding - Challenge - Environmental control - Skill progression
Fitness	Having and using a body that is strong, healthy, and full of energy, rather than having a body that feels ill, weak, or listless	- Nourishment - Health - Energy and strength - Hygiene

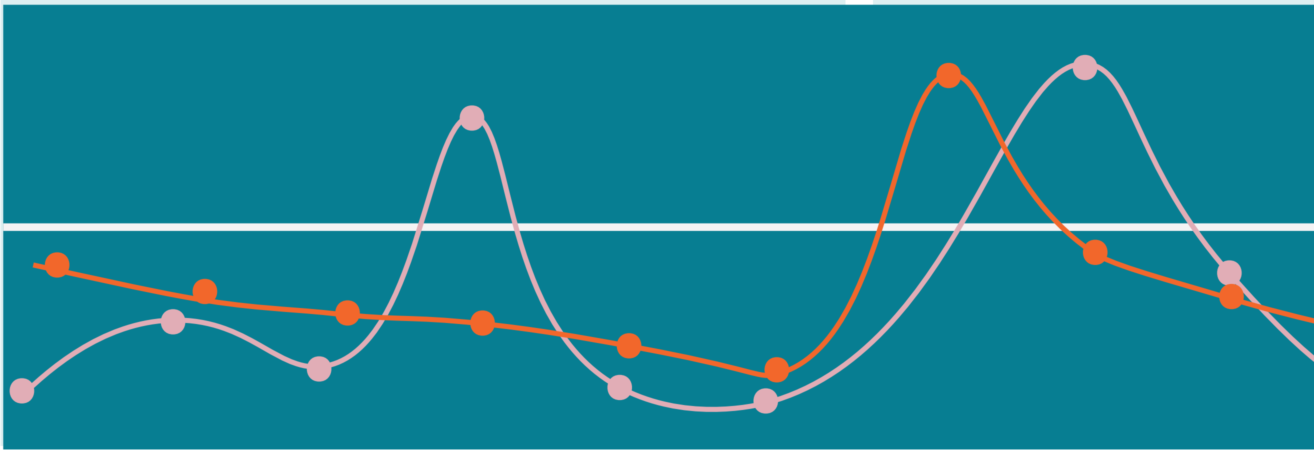
Fundamental Needs	Explanation	Sub-needs
Impact	Seeing that your actions or ideas have an impact on the world and contribute to something, rather than seeing that you have no influence and do not contribute to anything.	- Influence - Contribution - To Build something - Legacy
Morality	Feeling that the world is a moral place and being able to act in line with your personal values, rather than feeling that the world is immoral and your actions conflict with your values.	- Have guiding principles - Acting virtuously - A just society - Fulfilling duties
Purpose	Having a clear sense of what makes your life meaningful and valuable, instead of lacking direction, significance or meaning in your life.	- Life goals and direction - Meaningful activity - Personal growth - Spirituality
Recognition	Getting appreciation for what you do and respect for who you are, instead of being disrespected, underappreciated or ignored.	- Appreciation - Respect - Status and prestige - Popularity
Relatedness	Having warm, mutual, trusting relationships with people who you care about, rather than feeling isolated or unable to make personal connections.	- Love and intimacy - Camaraderie - To nurture and care - Emotional support
Security	Feeling that your conditions and environment keep you safe from harm and threats, rather than feeling that the world is dangerous, risky or a place of uncertainty.	- Physical safety - Financial security - Social stability - Conservation
Stimulation	Being mentally and physically stimulated by novel, varied, and relevant impulses and stimuli, rather than feeling bored, indiferent or apathetic.	- Novelty - Variation - Play - Bodily pleasure

Table 3.6 Typology of Thirteen Fundamental Needs for Human-Centered Design by Desmet, P., & Fokkinga, S. (2020)

DEMENTIA JOURNEY

STAGES	**Getting Diagnosed**						**Family Being Careg**		
Activities	Notice dementia symptoms	Talk about possibility of dementia	Go to the doctor	Perform dementia test	Receive Results	Trying to accept dementia	Gather info about dementia	Trying to set a routine at home	Change of child-parent interaction
Person with dementia  **thinks**	*"Is there something wrong with me?"*	*"Am I getting this right?"*	*"This is not necessary"*	*"That was quite easy"*	*"What does it mean?"*	*"This is my life now"*		*"I think I recognize this"*	*"I prefer a different approach now"*
feels		· Confused	· Nervous	· Doubting	· Vulnerable	· Frustration · Confusion		· Taken care of	
needs	· Security	· Familiarity	· Physical safety	· Simplicity	· Tranquility	·Purpose ·Simplicity		· Familiarity	· Respect · Nourishment · Rooting
Informal caregiver  **thinks**	*"I hope it is not dementia"*	*"What if it it really is"*					*"So, where should I start"*		
feels	· Insecure	· Hesitant	· Insecure · Determined	· Impatient · Eager · Doubtful	· Powerless · Vulnerable · Confirmed	· Overwhelmed · Sad	· Determined	· Determined	· Reluctant · Unfamiliarity
needs	· Security	· Ease	· Impact · Security	· Stability	· Emotional support	· Tranquility · Stability	· Fulfilling resposabilities	· Convenience	· Familiarity · Attachment
Professional caregiver  **thinks**									
feels									
needs									
Opportunities	Crash course on dementia ●	Ability to talk with others about experiences. DIY Test on dementia ●●		Information on how life looks like with dementia ●●	Step by step doctors visit guide with reminder to ask questions. Information on how to get support ●●	Highlighting positive sides/ Support Group ●●	Having a non-judgemental buddie ●	Keep an open conversation with the focus on own capabilities ●●	Acknowledge that personalities change with time and approach the changes in a positive way ●●

Emotional Curve

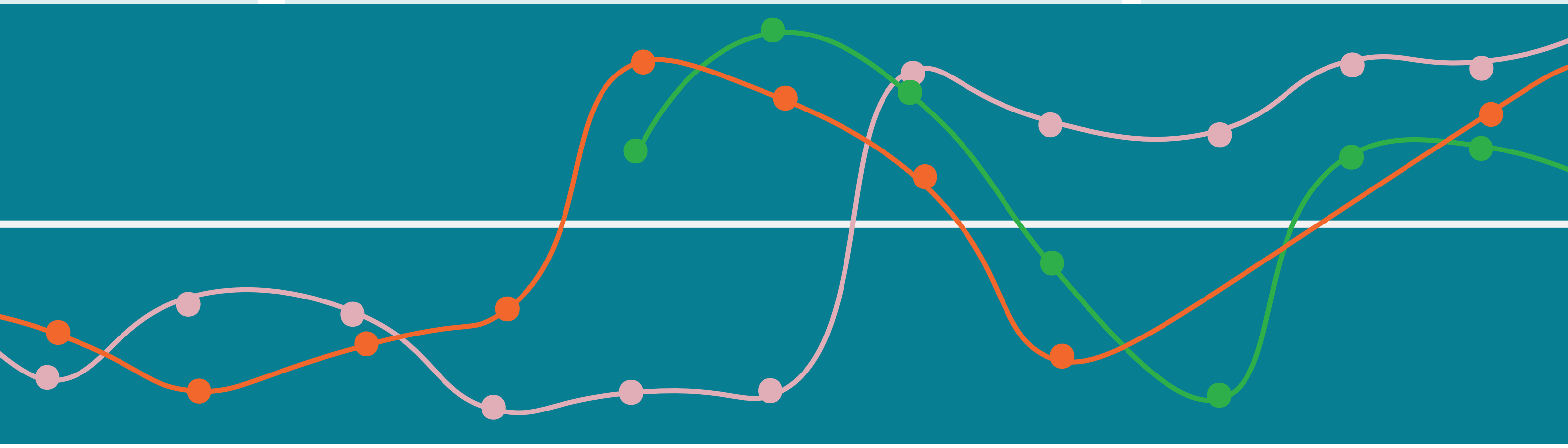


giver

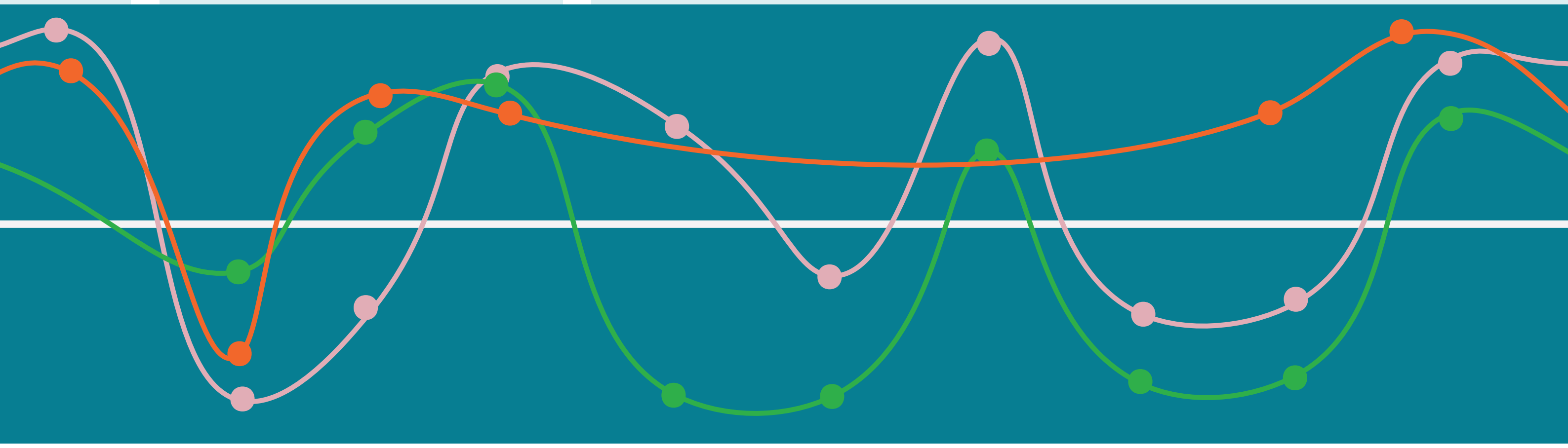
Transition to Nurse Care

At the Nurse Care

PwD is not independent anymore	Aknowledge PwD needs more help	Talk about nurse care	Decide to move to nurse home	Looking for the right nurse home	Move to nurse home	Inform nurse about preferences	Getting used to new living situation	Daily healthcare	Doing physical activities	Playing games
"Is all this help really needed?"		*"What do you mean?"*	*"What is going on?"*	*"This looks a bit like hospital"*	*"It is unnecessary, I don't understand"*	*"They seem nice, I hope they listen to me"*	*"I want to go home"*	*"I have good and bad days like everyone"*	*"This is fun"*	*"This is fun"*
· Discomfort		· Confused	· Worried						· Playful · Aroused	· Playful · Aroused
· Physical safety · Mental comfort		· Simplicity	· Freedom of decision	· Attachement	· Familiarity · Social support	· Attention	· Familiarity · Social support	· Familiarity · Social support	· Stimulation · Bodily sensations	· Creative expression
	"Some extra hel'p would be handy"	*"I can't handle this anymore"*		*"Would this place suit my parent and I?"*		*"I will make sure they know my parent"*	*"Did I do the right thing?"*			*"Too childish for my parent"*
Overwhelmed Grief	· Powerless	· Powerless · Open	· Hesitant · Accepting	· Determined · Content · Relieved	· Upset · Remorseful · Relieved	· Determined	· Guilt · Supported			· Creative · Loving · Judgemental
· Familiarity	· Competence · Experimentation	· Ease · Social support	· Morality	· Affiliation		· Attention	· Emotional support · Morality			· Intimacy
				"Is our place the righ spot for them?"	*"Oh a new resident, I'll welcome them"*		*"I'll anticipate the resident's needs"*	*"Pff so many things for the day. One step at a time"*	*"I hope the residents feel at ease"*	*"How else could I stimulate residents?"*
				· Curious	· Curious	· Inspired · Receptive	· Determined	· Determined · Overwhelmed	· Hopeful · Inspired	· Inquisitive
				· Impact · Purpose	· Purpose	· Respect · Stimulation	· Ease · Competence	· Oder · Convenience	· Acknowledgement	· Impact
Keepin focus on what is still possible. Leaving judgement behind: (no right or wrong) ●●	Aknowledging limitations ●	Keep an open conversation and hint to PwD that more care is needed ●●	Involve PwD in decision making process. Validation checklist for decision making ●●●	Way to present care values and practicalities from nursing homes ●●●	Provide communication options for personal preferences ●●●	Provide ways for PwD to express their wishes and for FM to visualize them to communicate it to CG ●●●	Visualization of resident's needs. ●●●	Make caregivers' role in society attractive for the youngers generation ●●●	Taking into account personal preferences ●●	Taking into account personal preferences during games. Provide interaction options ●●●



	Reduced Mobility			**A Day in Life at the Nurse House**						
Family visits	Getting around gets difficult	Finding options: rollator, wheelchair	Adjusting to rollator, wheelchair	Waking up	Getting dress(ed)	Breakfast	Medicine	Activity	Lunch	Activity
“They seem familiar”	*“Ouch, this is painful”*	*“What is going on?”*	*“This is not too bad”*		*“I can do this myself”*	*“Hmm lekker”*	*“I have to swallow?”*		*“Hmm lekker”*	
	· Physical pain	· Limited	· Supported	· Calm	· Offended · Helped		· Confused · Hesitant	· Curious · Inquisitive		· Curious · Inquisitive
· Valued · Intimacy	· Physical safety	Physical safety · Freedom of choice	· Individuality · Autonomy	· Physical comfort · Purpose	· Autonomy	· Nourishment · Freedom of choice	· Simplicity	· Stimulation · Novelty & variety · Fun	· Nourishment · Freedom of choice	· Stimulation · Novelty & variety · Fun
“I am here mom/dad”			*“This is the best option, I want him/her to stay mobile”*					*“Oh they are enjoying themselves”*	*“I brought a special treat for you”*	*“Oh they are enjoying themselves”*
· Sensitive · Loving · Intimate	· Stressed · Worried	· Determined	· Torn					· Thankful · Inspired	· Connection	· Thankful · Inspired
· Intimacy · Rooting	· Moral awareness · Tranquility · Convenience	· Tranquility · Preservation	· Familiarity · Preservation					· Seeing values in the world · Beauty	· Reminiscense · Intimacy	· Seeing values in the world · Beauty
	“The resident must be in pain or frightened”	*“There has to be a good option for him/her”*	*“Is this a good solution?”*	*“How am I getting out of bed all residents”*	*“Will the resident be calm or agressive today”*	*“I know their preferences. I'm not alone”*	*“Okay let's focus”*	*“How can I stimulate residents today”*	*“I know their preferences. I'm not alone”*	*“What is still physically possible for the residents”*
	· Worried	· Hopeful	· Optimistic · Doubtful	· Determined · Overwhelmed	· Determined · Worried	· Determined · Supported	· Determined · Worried	· Determined · Curious	· Determined · Supported	· Determined · Curious
	· Need to nurture · Order	· Contribution · Influence	· Achievement · Appreciation	· Ease · Order	· Physical Safety	· Appreciation · Convenience	· Structure & overview	· Influence	· Appreciation · Convenience	· Experimentation · Contribution
Provide interaction options to: Stimulate PwD senses to trigger interaction/ communication	Accepting physical limitations. Keep focus on what is still possible.	Overview of alternatives: Pro’s and con’s on resident and nuring house level	Clear validation moment. Seeing the aid alternative as an extension of themselves. Adaptability.	Provide PwD reminder of something to look forward to.	Collaboration approach between PwD and Caregiver” “Help me help you”	Visualization of PwD’s preferences and capabilities. Way to expres their wishes		Approach activities from resident's preferences perspective FM Provided with interaction options	Visualization of PwD’s preferences and capabilities. Way to expres their wishes	Approach activities from resident's preferences perspective FM Provided with interaction options
● ●	● ● ●	● ● ●	● ● ●	● ●	● ●	● ●		● ● ●	● ●	● ●



Final Days of Life

Dinner	(Activity)	Bed	Lying in bed as comfortable as possible	Long lonely days	Losing Appetite	Family Accompanies	Passing away
"hmm potatoes are familiar"		*"Sometimes it's painful when they help me move"*			*"I'm not hungry"*	*"I feel when someone is with me"*	
	(Eager)		· Vulnerable · Tired · Peaceful	· Lonely · Fragile			· Peace
· Nourishment · Fullfilling responsabilities	(· Stimulation · Novelty & variety · Fun)	· Individuality · Physical comfort	· Physical comfort · Tranquility	· Appreciation · Intimacy · Emotional support	· Integrity · Respect · Freedom of choice	· Relatedness · Physical safety · Tranquility	· Ease
			"What else can I do for him/her to be comfortable"	*"I'm here"*	*"If my parent doesn't want to eat, she doesn't eat "*	*"I'm here with you"*	*"I hope you are resting now. I will miss you"*
			· Worried	· Grief	· Torn	· Sad · Attached	· Sad · Grief
			· Emotional support	· Impact · Need to comfort parent	· Morality	· Simplicity · Rooting · Spirituality	· Emotional support · Respect
"Phew! I'm glad some residents can help with dinner"		*"Will resident be calm or agressive"*	*"How can we make the resident as comfortable as possible?"*	*"I'll visit the resident as often as possible"*	*"How do we stimulate residents to eat "*	*"I need to keep a peaceful environment "*	
· Relieved · Overwhelmed		· Nervous	· Determined · Overwhelmed	· Determined · Nurturing	· Determined · Curious	· Determined · Empathetic	· Supportive · Powerless
· Need to nurture · Ease		· Security	· Need to nurture · Acknowledgement	· Impact	· Need to nurture	· Security · Overview	· Respect
Visualization of PwD's preferences and capabilities. Way to expres their wishes ● ●	(Visualization of PwD's preferences and capabilities) ● ●	More user friendly bed-lifts for the PwD. Collaboration approach ● ●	Reminder for changing positions Open mind for experimenting ● ● ●	Way to interact with PwD for them to feel company ● ● ●	Showing that their will is respected and accepted. Understanding values ● ● ●	Guidelines to promote connection. ● ● ●	Stimulation to do what feels right Stimulate PwD to feel at ease to go. ● ● ●

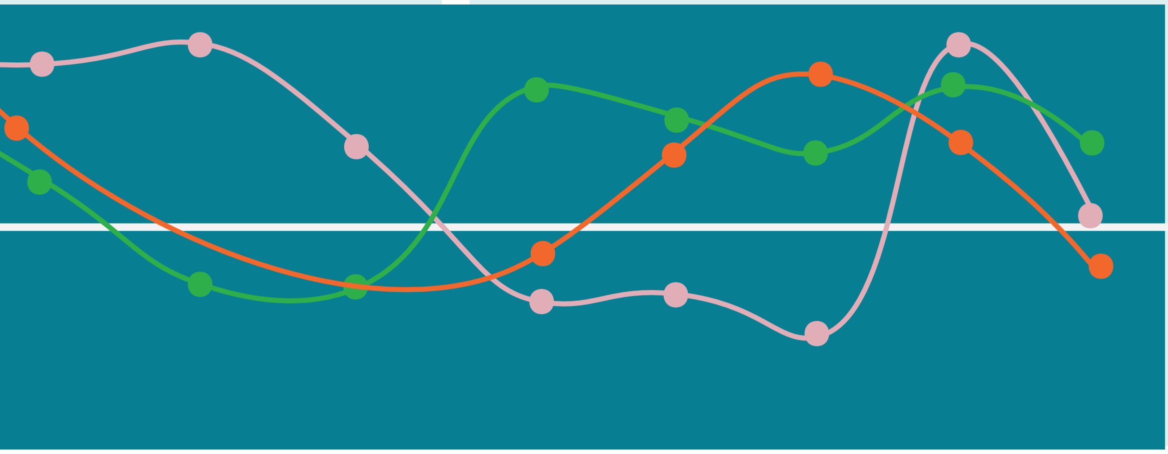


Image 3.7 The dementia journey

3.5 Takeaways

PwD display more focus and energy when others acknowledge who they are beyond their current condition. They are especially fond of references to their past.

Family members use pictures, songs or stories to provide comfort and acknowledge their life journey and their own personal identity.

"You moved a lot in your life, you lived quite long in Rotterdam; you also lived in France and moved to different places there. You were..." - SON

(chuckles) "Usually on the run!... It was joy and freedom" - MOTHER (In de Leeuwenhoek, NPOstart, 2018)

Activity/Method: Documentaries as observations

There is a shortage of professional caregivers. This creates a big challenge in personalized attention to residents of nursing houses.

Over the years, the number of people living with dementia has been increasing, while the number of caregivers has not kept the same pace. Although the quality of care is generally high, it is almost impossible to provide personalized care in nursing homes.

A professional caregiver is being interviewed, She started with her career when she was 14 as a side job and she speaks of the differences after 8 years of experience.

"When I started it was actually very different , I had more time for the people but now you have almost no time for the people. I don't think people have the attention they deserve. if someone asks: can I take a shower then I have to say most of the time not now .. I find that terrible." - Professional Caregiver (In de Leeuwenhoek, NPOstart, 2018)

Activity/Method: Documentaries as observations

Although PwD in the later stages might not be able to express their wishes, it does not mean that they do not have them.

Respondents mentioned that when asking PwD something, it is important to give them two short options, as many instructions or questions can confuse them.

"You tell things like do you want coffee? Questions with yes or no answers. Or you tell stories, and if my father didn't smile, I knew it wasn't fun for him." - Interview participant with father with dementia

Activity/Method: Generative research

Dementia transforms the child-parent relationship by making it expectation-free and judgment-free

It is never easy for families and partners that have a loved one living with dementia; In the beginning, they hold tight into the memories that bonded their relationship. The evolution of the relationship is hard in terms of acceptance. Later on, little by little, the relationship evolves into an expectation-free and judgment-free, compassionate, and loving relationship where the goal is to take care and provide your parent or partner comfort

"Being present is more important than having something to talk about" - Interview participant with mother with dementia"

Activity/Method: Generative research

PwD family members interviewed showed pride in their parents' stories.

During the interviews, the participants made sure to demonstrate their parents' personalities, affinities, and preferences prior to their current condition. They emphasized it with joy

Activity/Method: Generative research

The family accompanies physically and emotionally their loved ones living with dementia through the whole journey.

Although dementia is embodied in one person, and this person is the one who lives and experiences the symptoms naturally, the people around accompany PwD throughout the whole journey, from its diagnosis to their final days. Families must decide and define different tasks and roles that family members will assume while trying to accept the condition of their loved ones.

"I was always there, that was important" - woman telling host of documentary after her mother passed away.

"The hardest phase is when you realize that your loved one has dementia. When they are diagnosed" - Interview participant with mother with dementia

Activity/Method: Generative research

04

Discovering the context: Active Cues creative process

This chapter explores the way Active Cues performs their job through semi-structured interviews with former and current work members. The chapter closes with takeaways.

4.1 Process overview

To have a general view of the process followed in this chapter see Figure 4.1

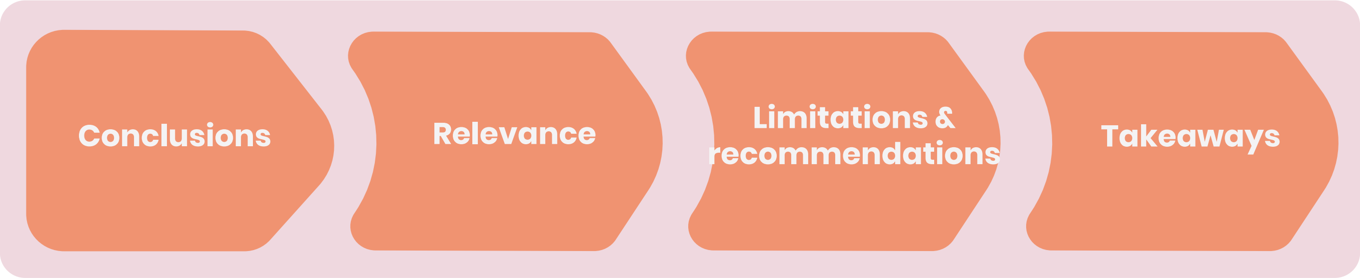


Figure 4.1 Process overview of the methods and activities executed in chapter 4

4.2 Getting to know Active Cues

As mentioned already, this project started at the same time as the 2020 pandemic of COVID-19, hence it was not possible to work in the Active Cues offices as initially planned.

As a starting point to get closer to Active Cues' team, without interfering in their daily task and work adaptation process to the pandemic, a questionnaire was created through google forms. Three members of the work team participated; they were asked about their job title, the description of their job, how they complemented each other, what they would change about their job and what they like the most.

At the end of the questionnaire, a focus was made on how creative sessions take place to better understand the ideation phase of Active Cues creative process. In Appendix D the complete form can be seen.

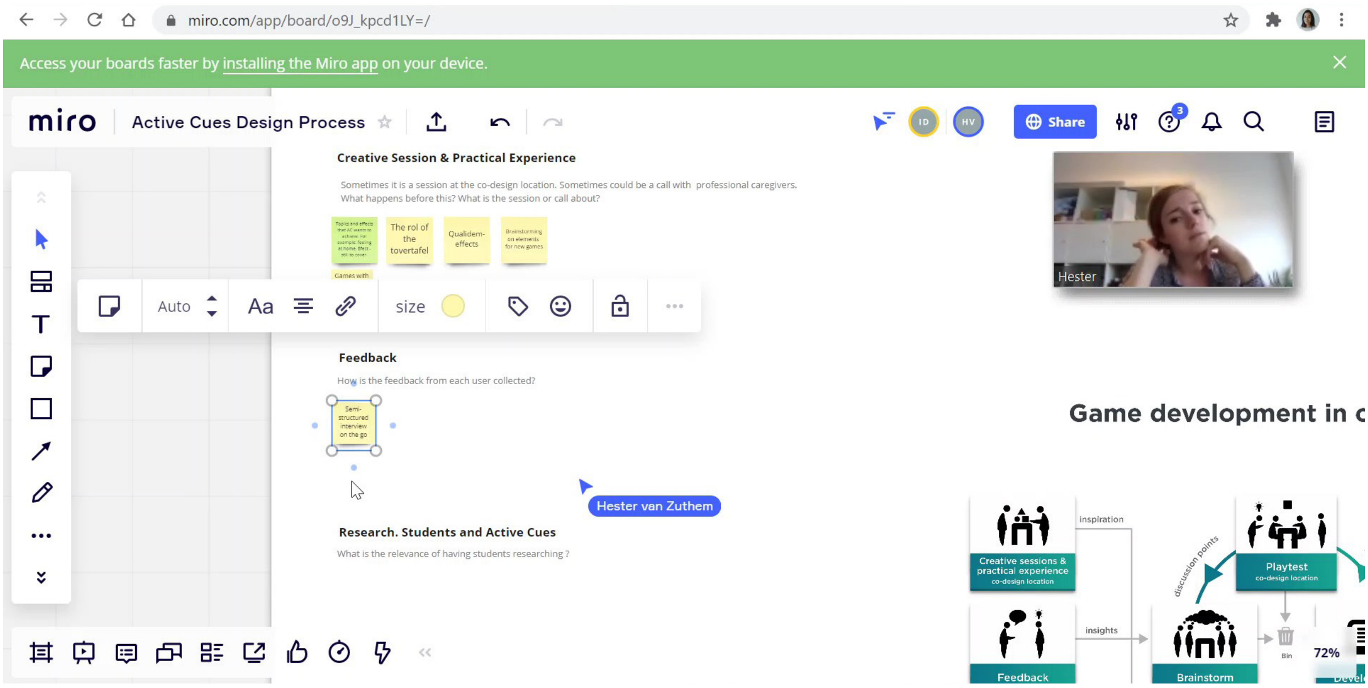
4.3 Semi-structured interviews

To focus more on how designers at Active Cues perform their job, semi-structured interviews were carried out with three different people from the design and research team:

- The current user-centred designer of the target group of PwD (ToverTafel original)
- The former designer of the PwD target group and
- The current designer in charge of the target group of children with learning disabilities (ToverTafel sprout)

The three semi-structured interviews took place online via zoom, and one of those was supported by miro. A glimpse of the interview is shown in image 4.2a. The interviews covered the following topics:

- Steps in Active Cues creative process (See Image 4.2b) and
- Current way of performing design and research for Active Cues



Creative Session & Practical Experience

Sometimes it is a session at the co-design location. Sometimes could be a call with professional caregivers. What happens before this? What is the session or call about?

Topics and effects that AC wants to achieve. For example: feeling at home. Effect - still to cover

The rol of the tovertafel

Qualidem-effects

Brainstorming on elements for new games

Games with

Feedback

How is the feedback from each user collected?

Semi-structured interview on the go

Research. Students and Active Cues

What is the relevance of having students researching ?

Image 4.2a. Video call supported by Miro with the Active Cues' designer of the group of PwD

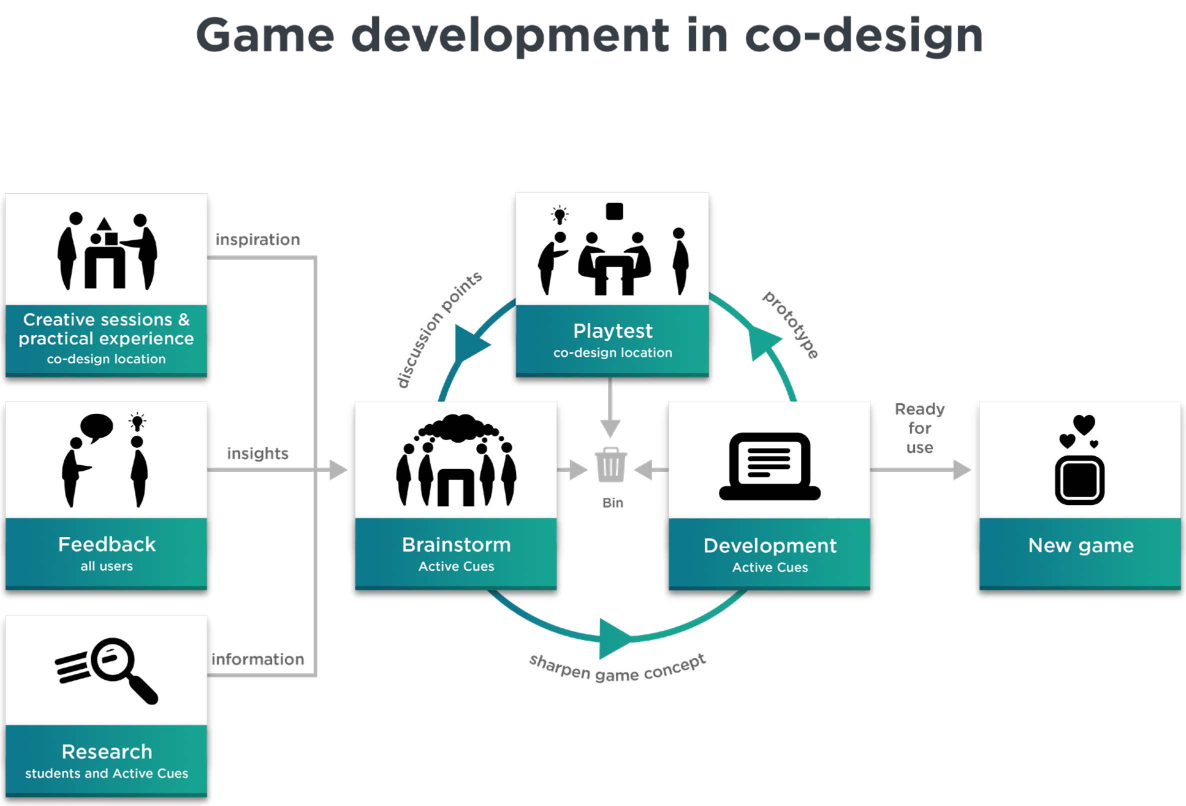


Image 4.2b. Process flow that Active Cues follows. (Active Cues, 2020)

4.4 Design cycle

To understand Active Cues' way of work, it is useful to know that the Tovertafel Original came about through co-designing with residents from an elderly care institution. (Active Cues, 2020). As Sanders (2008) argues, "co-design refers to the creativity of designers and people not trained in design working together in the design development process."

Up until now, Active Cues follows this collaborative approach to design their user-centered games. In their case, designers, game specialists, and researchers co-design with PwD and professional caregivers from nursing homes to generate new insights for games for the ToverTafel.

The organization is actively following research and developments for PwD. Also, they continuously guide students with their graduation projects from Psychology and Design who in turn provide fresh ideas that keep Active Cues challenged.

Active Cues has co-design location partners in the Netherlands, in which some ambassadors are the primary contact of professional caregivers. The latter play a significant role in their design research process; They act as representatives of PwD. Parallel to following research and developments in the field of PwD, Active Cues begins their exploration, mostly, but not limited, with phone calls or semi-structured interviews with the professional caregivers of the co-design location partners. Both parties discuss and exchange new ideas based on the current ToverTafel games.

After acquiring feedback from professional caregivers and collecting data from the current trends, the organization goes through sprints. First, in the fuzzy front, brainstorms are carried out to ideate new themes for ToverTafel games or to adjust existing ones. After the brainstorming, the most promising ideas are passed to the game designer and developers to code and refine the details. When these details are tuned, a prototype of the game is ready to be tested in the co-design partner locations.

Setting a playtest session requires much alignment between Active Cues and the co-design partner locations, consent for the residents to participate is done, and professional caregivers need to be available to help along with the playtest session. For Active Cues, it requires at least two people of their team members, one to greet and lead the session with the people, and another one to set all means of technology, making sure the prototype game is ready at the ToverTafel and setting cameras to capture the interactions that the residents have with the game prototype.
During the playtest sessions, professional caregivers support the interpretation of the residents; for example, maybe someone is withdrawn, and it is because the person is having a bad day. For Active Cues, this support is essential to understand the behaviours of residents, as reactions of PwD are unexpected, and these games should be suitable to PwD and be tuned with their vision of creating moments of happiness.

After the playtest session, the input gathered from professional caregivers and the observations performed at the location, the recording of the playtest session is analyzed and made sure that all the audiovisual details are compatible with PwD's abilities. If necessary, this may take a couple more sprints.

[During the pandemic Active Cues, like a many organizations, adapted their way of working in a remote-online way, for Active Cues it meant utilizing more online surveys, setting the playtest sessions remotely as well as performing the observations of it.]

Over the interviews with (former) team members, it was emphasized that for the three of the target groups that Active Cues has, there are professional caregivers that currently help along for the playtest sessions and that each of these groups has an informal caregiver. Interest was shown in including the latter's input since informal caregivers play a very important role for each of the target groups.

In the case of PwD, the informal caregiver has accompanied his family member on the dementia journey since the diagnosis, as seen in the dementia journey in chapter 3, and they have, to a certain extent, knowledge about the past, the personality, and preferences of their family member with dementia. Also, as discussed in section 3.3.4.1, PwD live in their own world regularly associated with their past. Therefore, having the informal caregivers' input in the ideation phase could be interesting for Active Cues to have as a channel of collaboration. This could support to find common themes or insights among generations of people in nursing homes. Optionally, it could help create personalized experiences for residents of nursing homes to expand more the reminiscence the current games the ToverTafel has.

4.5 Takeaways

Today, in the Active Cues design process, professional caregivers are the representatives of PwD living in nursing houses.

Given their education and experience, Active Cues believes that professional caregivers can help understand and support PwD. They support Active Cues by being around to help understand what happens during the playtest sessions

Activity/Method: Interviews

Informal caregivers, such as family members, are not currently involved in Active Cues creative process.

Despite the existing interest, Active Cues does not currently involve family members that act as informal caregivers. Their bond with the PwD and their history accompanying them could provide different and valuable insights to include in the ideation session for new games of the ToverTafel.

Activity/Method: Interviews

05

Defining :
From takeaways to design

This chapter functions as the bridge from the learnings and takeaways of the desk research, and context exploration to the design phase. First a relationship map is identified, hereafter the problem definition, design goal and requirements are established.

5.1 Process overview

To have a general view of the process followed in this chapter see Figure 5.1

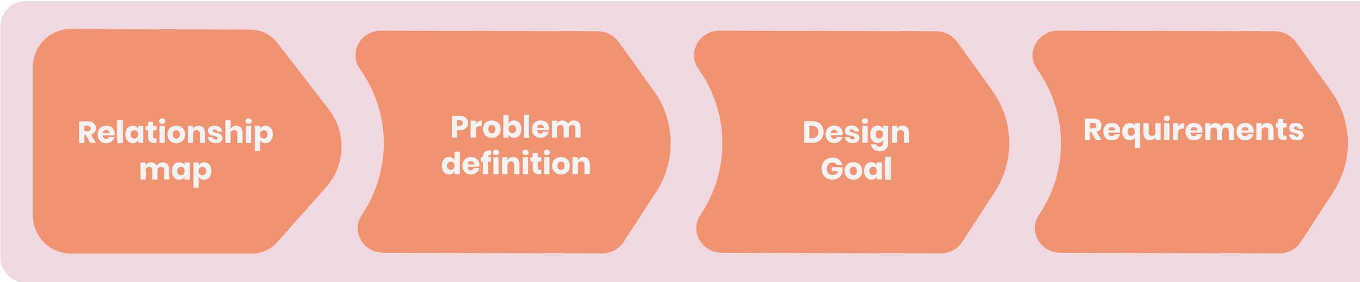


Figure 5.1 Process overview of the methods and activities executed in chapter 5

5.2 The relationships

Currently, researchers and designers from Active Cues collaborate closely with professional caregivers who, in turn, have a relation with the informal caregiver of the family and the PwD. Fig 5.1a illustrates the connections and most prominent actions of each individual.

A proposed approach (See figure 5.1b) for Active Cues to gain richer insights would be to collaborate or have the input of informal caregivers from PwD for the ideation phase of their creative process as they are part of the context. Consequently this could be beneficial for informal caregivers because it could propel a dynamic mechanism (Blandin & Pepin, 2016) for them to help alleviate the pain experienced from the dementia grief.

For Active Cues, it could be useful to gather data about the past, preferences, and themes of interest of PwD, which informal caregivers often have access to; And thus apply these insights within their products, as it was found in the research that PwD benefit from individualized activities.

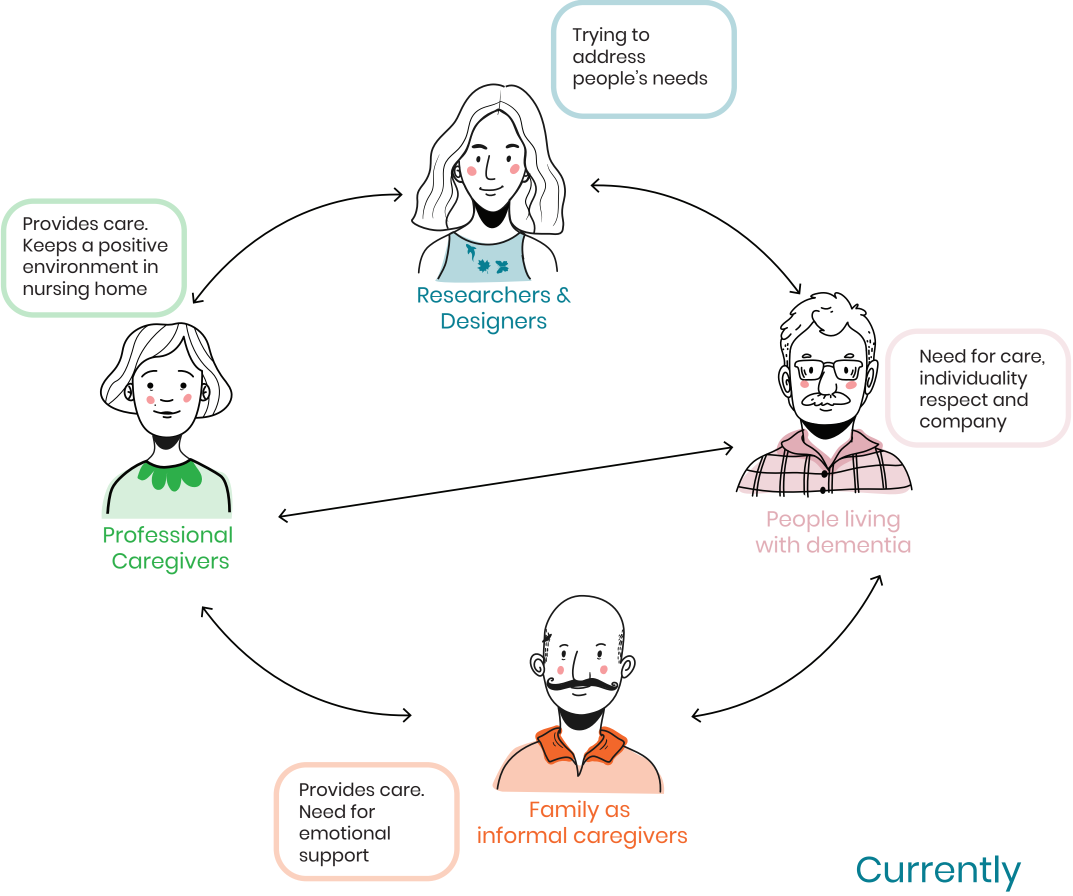


Figure 5.1a Current relationship map between designers and researchers from Active Cues, PwD, Professional and informal caregivers

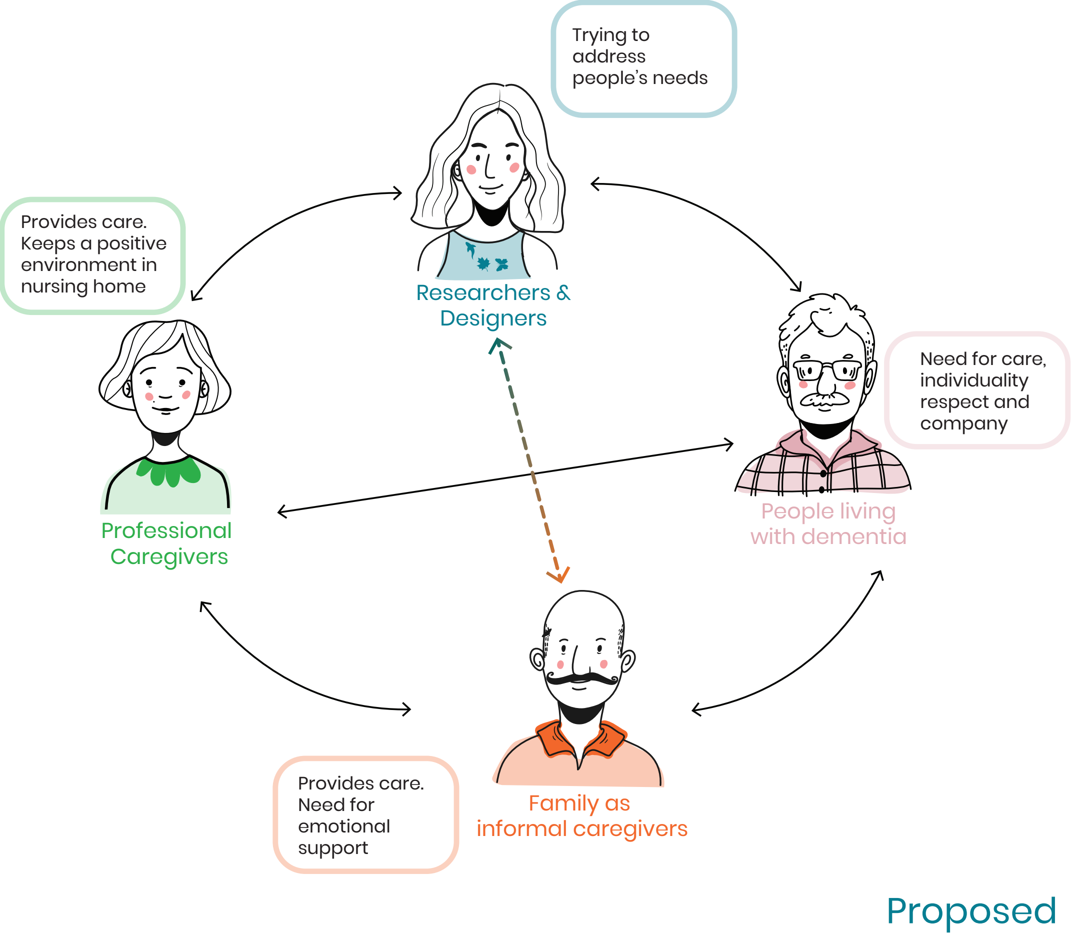


Figure 5.1b A proposed approach for Active Cues to keep desigining for PwD

5.3 Problem Definition

PwD feel more engaged and comforted when their identity is valued beyond their current condition as elaborated in chapter 3. However, professional caregivers are not always aware of their history and background, nor do they have time to access it to be able to transmit this knowledge to Active Cues. Meanwhile, family members who act as informal caregivers go through dementia grief, and nonetheless have deep bonds with the PwD, know their personhood, develop their own effective ways of engaging with them. Including informal caregivers' input in the ideation phase of the creative process could provide valuable insights for Active Cues to keep contributing to the PwD's QoL by creating even more tailored user-centered products and services.

5.4 Design Goal

Based on the takeaways of chapters three and four and the problem definition, a design goal was formulated. The design goal served to steer and guide the iterations and the concept development of the project.

The design goal is as follows:

"To gain contextual knowledge about PwD from informal caregivers for Active Cues to include it in their creative process".

5.5 Requirements and wishes

With the learnings and the takeaways from the previous chapters a list of requirements and wishes was set to guide the design goal. Being that the project covers the context of dementia, specifically informal caregivers, and also Active Cues, the design requirements are split into these two:

Informal Caregiver

- **Evokes reflection.**

A key aspect for acknowledging, tolerating and adapting, which are the dementia model phases (Blandin & Pepin, 2016) is being able to reflect on one's process. As such the design should promote this.

- **Pertinent**

The design should be considerate according to the informal caregiver's dementia journey. For example the design should not interfere with tough phases such as the dementia diagnosis, which is a distressing phase or when moving in the nursing home which is also an emotional for the informal caregiver.

- **Light hearted**

Informal caregivers have a lot going on in the dementia journey, so the design should provide a pleasant experience.

Active Cues

- **It generates rich insights about PwD**

The design aims to produce contextual elements of the past of PwD, their preferences and their interests.

- **Captures the produced data about PwD.**

The data should be stored in a way that can later on be used for Active Cues for brainstorming sessions.

- **Facilitates interaction with informal caregivers of PwD**. The design opens up a new communication channel for Active Cues to the world of informal caregivers

- **Provides a light hearted interaction between Active Cues and the informal caregiver.** Following Active Cues vision of providing moments of happiness the design should provide a pleasant experience.

While trying to brainstorm with all the requirements to move forward into an ideation phase, it was confusing and complicated to manage and consider every aspect of the requirements. Therefore, to reduce the project's complexity, it was decided to focus on the informal caregiver's requirements for developing and evaluating the concept.

06

Experimenting with ideas

Based on the design goal and the previous chapter's requirements, this chapter shows the ideation and iteration process prior to defining a design direction.

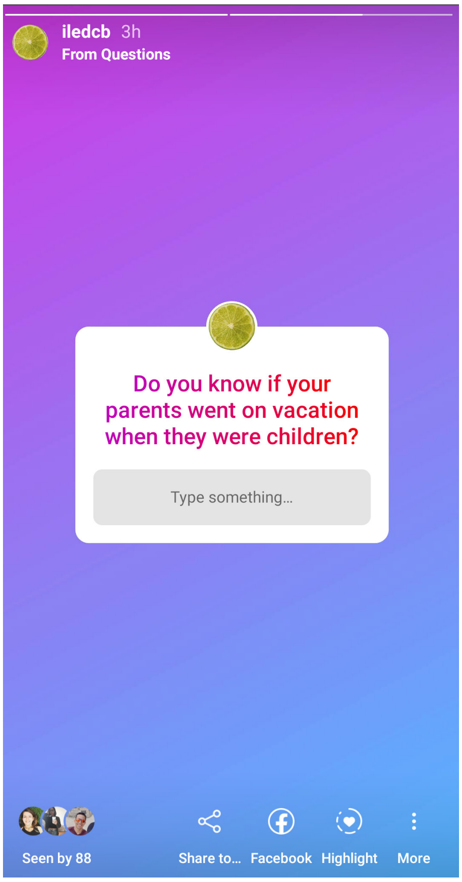
6.1 Process overview

For a general view of the process followed in this chapter see Fig 6.1

Figure 6.1 Process overview of the methods and activities executed in chapter 6

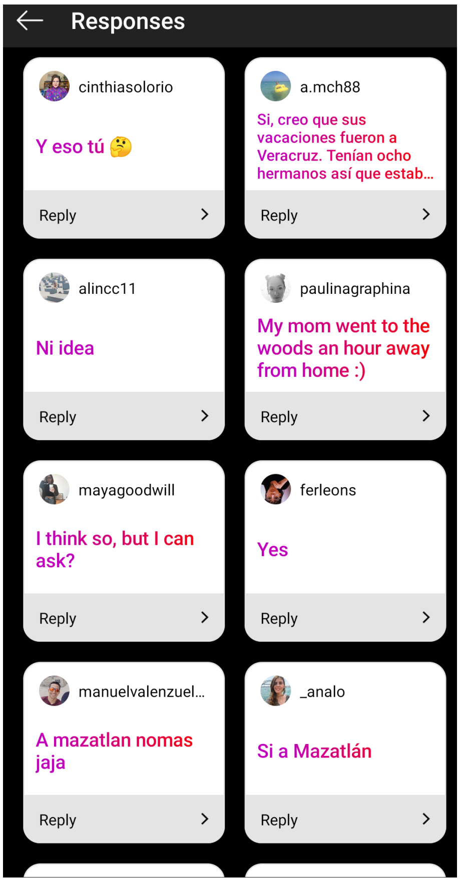
6.2 Instagram experiment

One of the assumptions to confirm was to test if people know about their parents' past life. Thus, a small experiment on instagram stories was set up. Instagram stories are images/videos that last 24hrs in one's profile, and one gets access to several resources such as polls or questions. Image 6.1a shows the question posted and in image 6.1b, some of the answers.



Do you know if your parents went on vacation when they were children?

a



cinthiasolorio: Y eso tú 🤔

a.mch88: Si, creo que sus vacaciones fueron a Veracruz. Tenían ocho hermanos así que estab…

alincc11: Ni idea

paulinagraphina: My mom went to the woods an hour away from home :)

mayagoodwill: I think so, but I can ask?

ferleons: Yes

manuelvalenzuel…: A mazatlan nomas jaja

_analo: Si a Mazatlán

b

Image 6.1 Question posted on instagram stories and received answers

After obtaining some answers, it was explained the reason for the random poll and it was asked directly to some of the respondents what else they knew about their parents and some of them shared some stories about their parents' youth.

6.2.1 Takeaway

The result of this little experiment showed that, adults know to some extent about their parents' past. With this in mind, the next iteration was carried out.

6.3 Digital Cultural Probe

Knowing that people know to some extent stories from the past of their parents, the next iteration was brainstormed on miro with the question:

- How can designers have access to the stories about PwD through informal caregivers?

Although straightforward, the most prominent idea was to ask informal caregivers by reflecting through questions. Considering that Active Cues already uses online polls with professional caregivers it was chosen to elaborate the next iteration in a digital format.

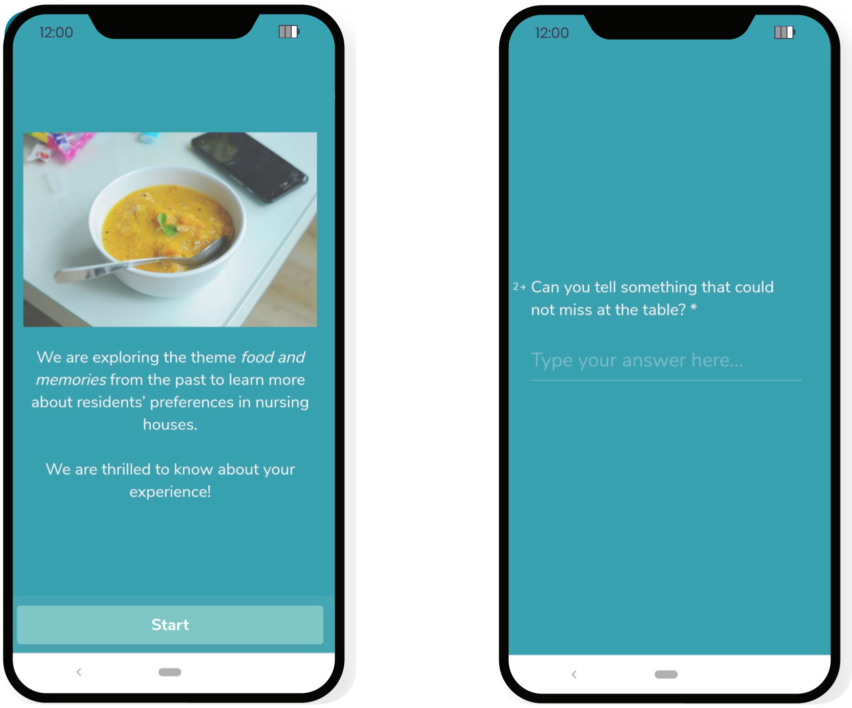
Inspired by research done at TUDelft during the pandemic 2020 about overall well-being (My Wellness Check, 2020), the next iteration was defined:
Informal caregivers would receive a text message (See image 6.2a) with a link to surveys when Active Cues wanted to explore a specific theme for a new game for the ToverTafel. To test the interaction the survey was prototyped with TypeForm (See image 6.2b), a web-based platform you can use to create anything from surveys to apps (Typeform,2020). The idea was worked out before testing it with informal caregivers and a pilot was conducted with a peer students to finetune any unclarities.

After the pilot, two informal caregivers participated in testing this prototype.
For the testing setup of this iteration, see Appendix E.

The sender does not support responses

There is a new exploring theme. Please fill out the next 5 quick questions. http://tinyurl.com/y9j4gbpc

Image 6.2a Text message sent for testing interaction



We are exploring the theme *food and memories* from the past to learn more about residents' preferences in nursing houses.

We are thrilled to know about your experience!

Can you tell something that could not miss at the table? *

Type your answer here...

Image 6.2b Prototype made in Typeform exploring the topic of food

6.3.1 Takeaway

With this iteration it was concluded that informal caregivers were willing to share stories or information; however, both of the participants showed interest in sharing more than just a few lines, they mentioned the collaboration felt short. So for the next iteration this was taken into account.

6.4 Brainstorming with peers

As mentioned in chapter 1, the approach of the project was fuzzy. So even though there were learnings in the previous iterations, I took a step back to comprehend those learnings. In this way, another brainstorming session took place with peer students to explore new perspectives; the session was executed via zoom and participants were presented with the problem definition, the design goal, and the relationships map from chapter 5.

First, it was made sure that the participants understood the elements presented to them mentioned above. After that, the dynamics of the brainstorming exercise were explained; they would have 30 seconds to think about an idea and then 2 min to discuss it with each other, all while the ideas were being written/drawn by the author (See image 6.3)

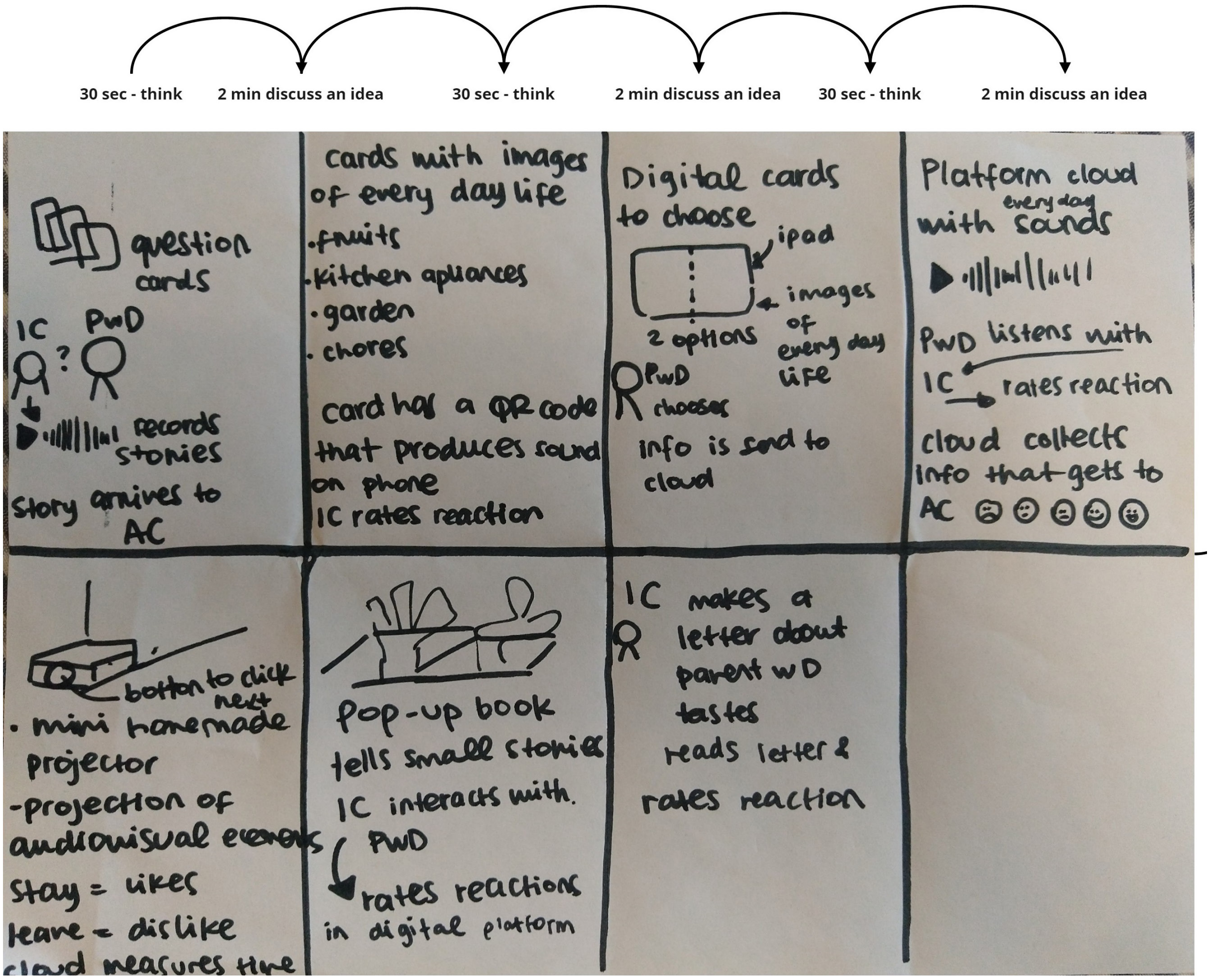


Image 6.3 Brainstorming session captured ideas

After discussing all ideas further with the participants, the last idea: Writing a letter about the preferences of your family member with dementia and reading it aloud, guided the conversation to the idea to write to yourself, like in a journal, as this seemed in line with being able to express longer stories as participants mentioned in the previous iteration.

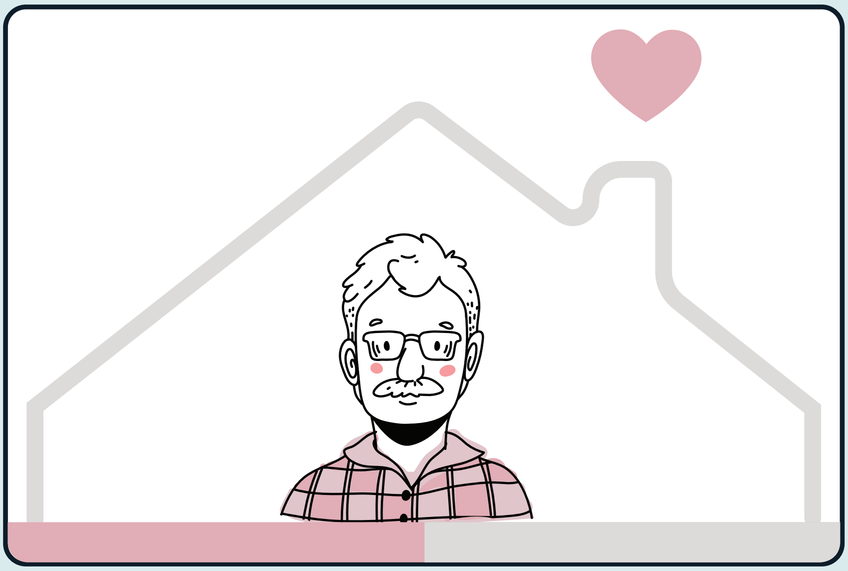
The concept direction was defined by merging ideas from this last brainstorming with peers and the previous iterations' learnings.

6.5 Concept direction

In a first attempt to define the concept direction, a storyboard (Image 6.4) was created to illustrate the concept's functions.

The concept consisted of an app for informal caregivers, in which there would be a space for reflection together with audiovisual tools to interact with their relatives with dementia. As a facilitator of the app, Active Cues would see how these tools' audiovisual elements resonated with the PwD and take those elements further to the ToverTafel games.

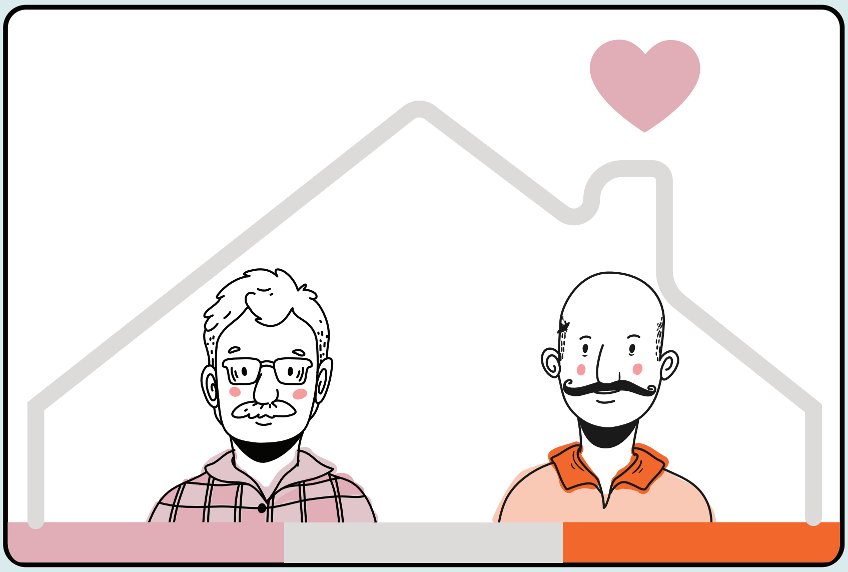
The storyboard served for review sessions with peers and experienced UX designers, in which it was identified that the concept had too many elements, and some of those were irrelevant for design goal, such as everyday sounds.



Meet Vincent

He has dementia and he moved three months ago to the nursing house: ExtendCare

1

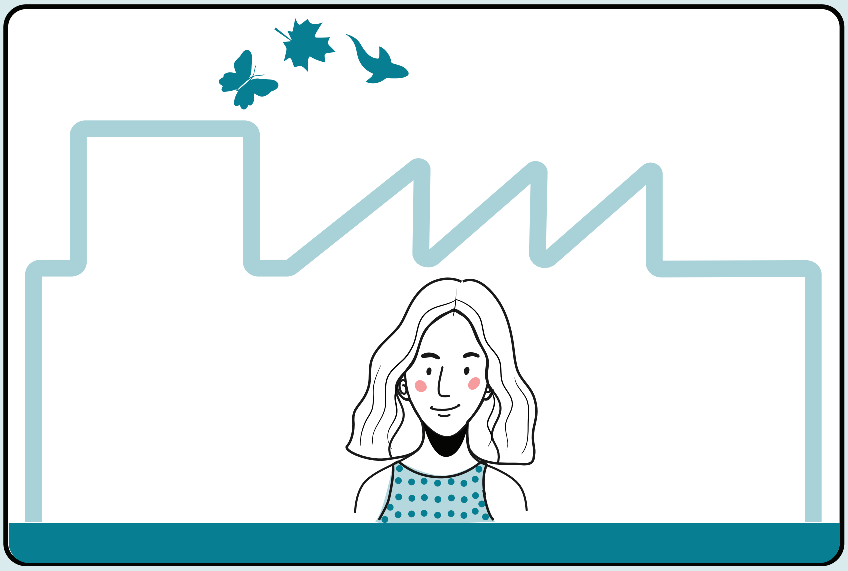


Meet Gus

He is the son of Vincent and also his informal caregiver.

Gus visits his dad once a week

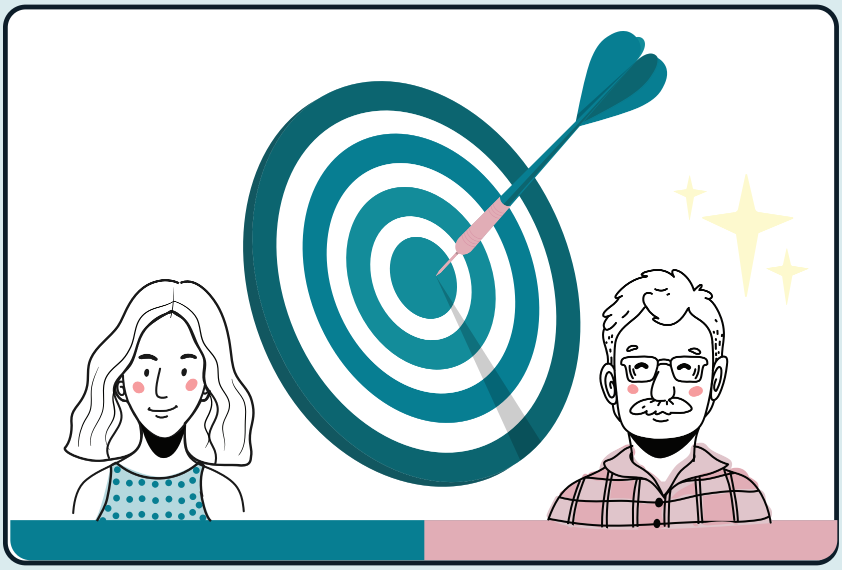
2



Meet Tina

She works at Active Cues, an organization that creates moments of happines in institutional care.

3

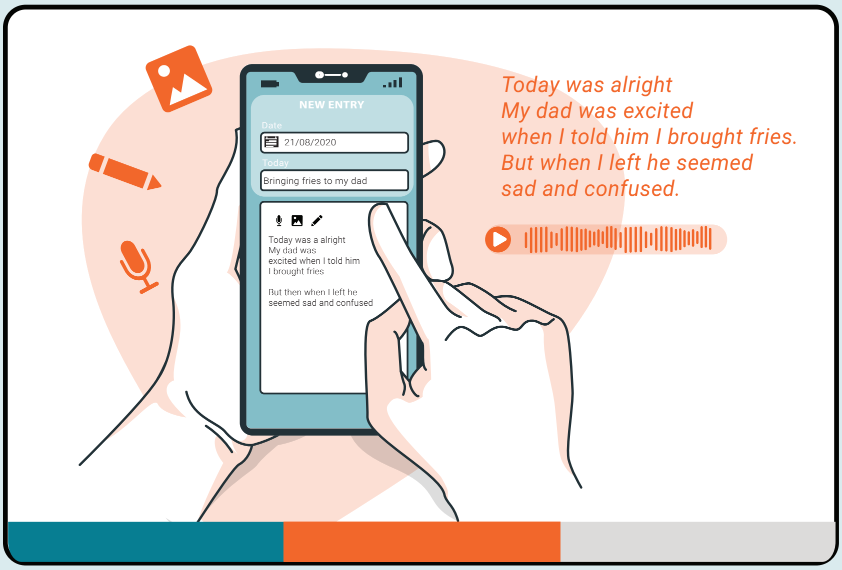


Active Cues ultimate goal is to improve the QoL of PwD.

They do so by designing user-centered games for the ToverTafel -an interactive table that projects audiovisual images that trigger PwD to move, play and socialize-

Active Cues offers an internal service to the nursing houses with a ToverTafel.

ExtendCare just acquired a ToverTafel.



21/08/2020

Bringing fries to my dad

Today was a alright
My dad was
excited when I told him
I brought fries

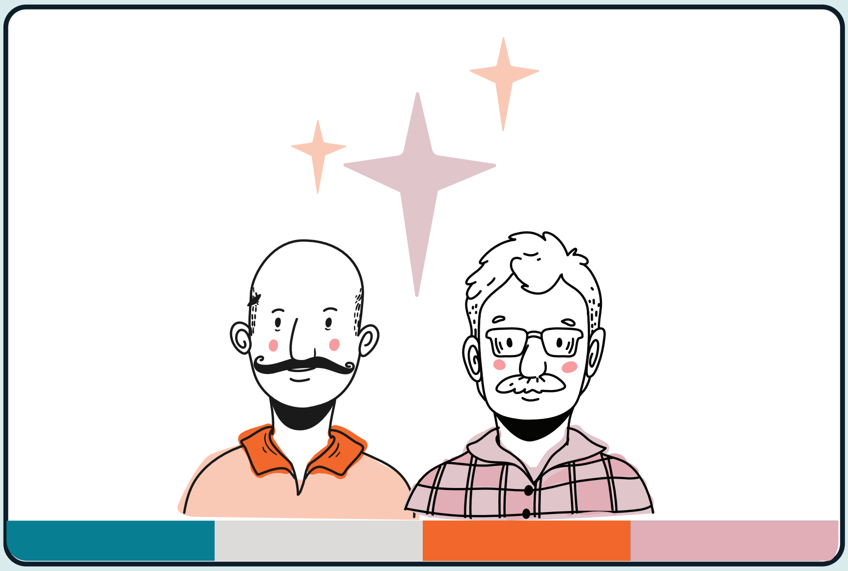
But then when I left he
seemed sad and confused

Today was alright
My dad was excited
when I told him I brought fries.
But when I left he seemed
sad and confused.

The service is offered to informal caregivers, like Gus.

Journaling is part of the service, Gus can
- Take pictures,
- Create audios or
- Write challenging and joyful moments

It provides a private space to decompress

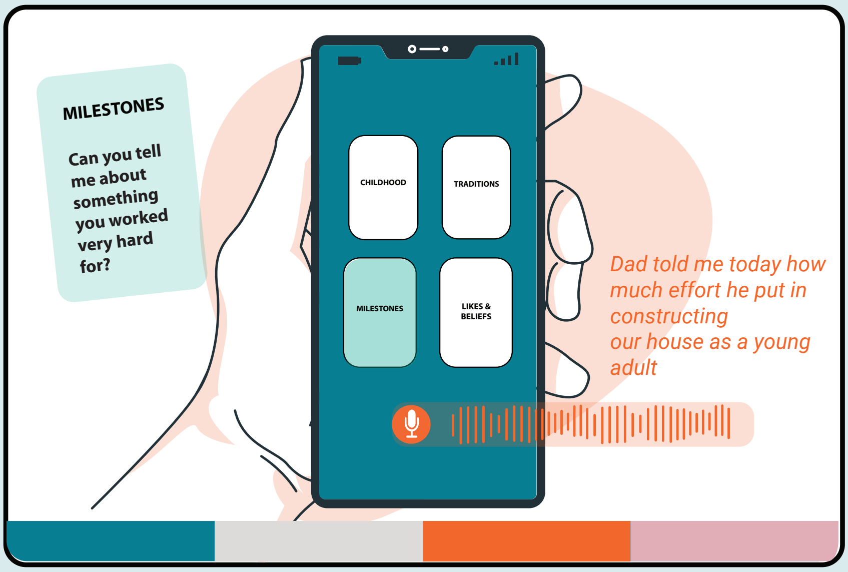


This service also offers two online tools:

- One for the early to mid stages of dementia and

- Another for mid to late stages of dementia

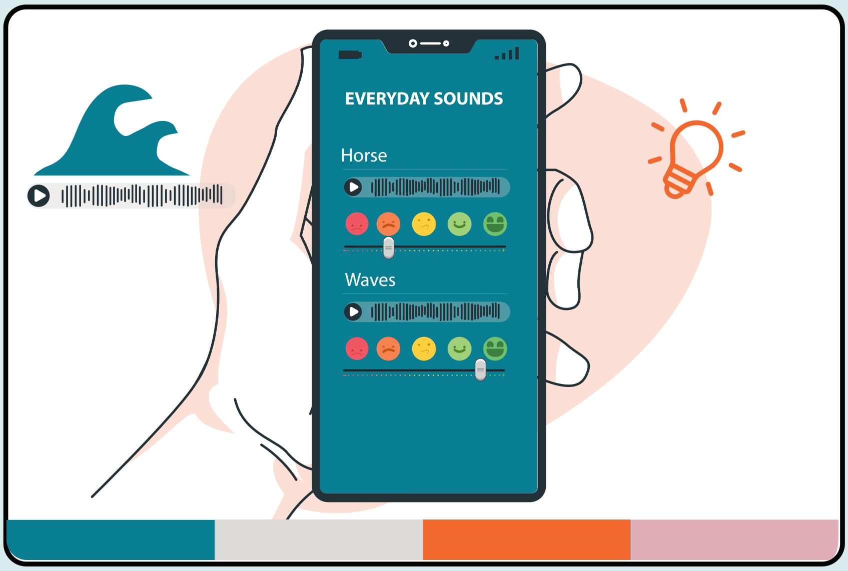
The tool aids Gus and his family to engage easily with Vincent when visiting the nursing house.



The first tool is : “Discovery Cards” for the early to mid stages of dementia.

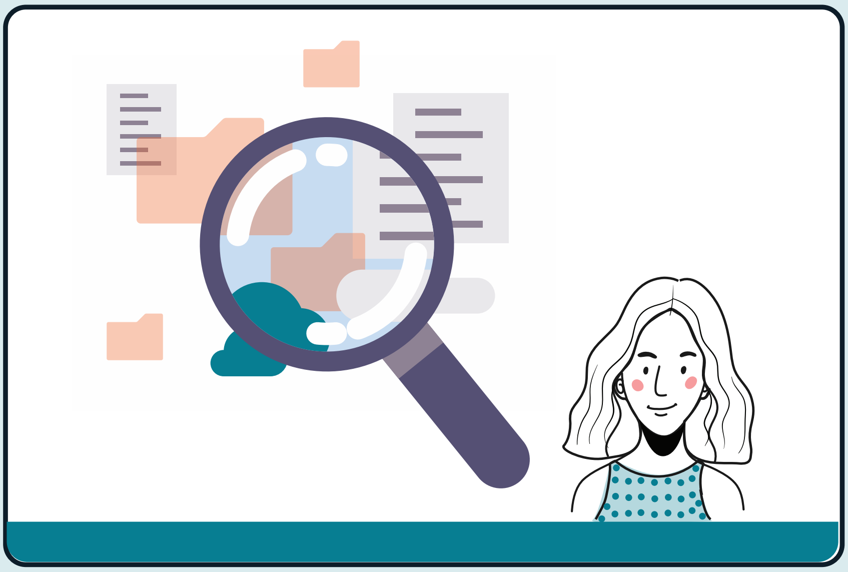
These are themed cards that allow Gus to rediscover his dad’s story.

Gus can record a small story about his learnings.

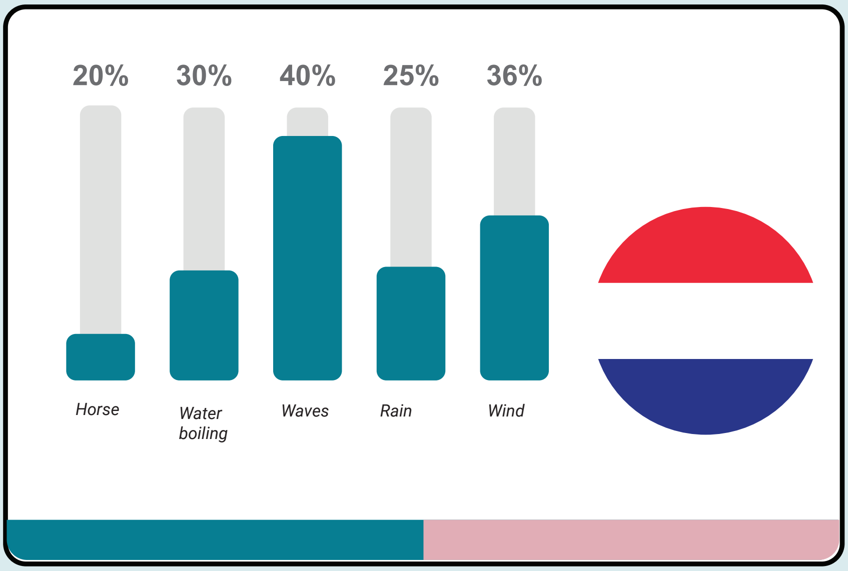


The second tool is: “Everyday sounds” focused from early to late stages of dementia.

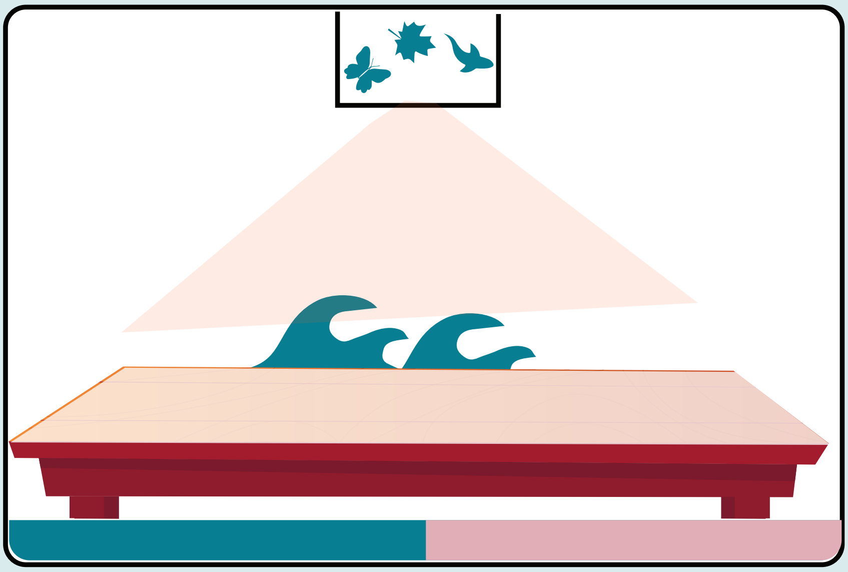
These sounds allow Gus to understand which noises may trigger Vincent.



With the consent of people like Gus, “Discovery Cards” and “Everyday Sounds” serve as a research tool for Active Cues.



Filters allow Tina to know which “Discovery Cards” generated more insights and how “Everyday Sounds” rate within regions and countries.



The data generated allows Tina to design even more relevant ToverTafel games for people like Vincent.

And in this way continue giving moments of happiness.

Image 6.4 Concept direction storyboard

6.6 Conclusions

Based on the storyboard review sessions' feedback,it was concluded to leave the components that did not align with the design goal and requirements, such as everyday sounds.

Journaling was taken as the central part of the next steps of the concept development as it was the component that resonated the most with the informal caregiver’s requirements.

07

Developing the Concept

In this chapter, in line with the project's collaborative approach, the concept is worked out through co-creation sessions with informal caregivers. In addition to co-designing, these sessions served to evaluate in an early stage at a conceptual level. Then with the learnings of the co-creation sessions, the digital concept is iterated and presented.
Later, to evaluate the concept, a storyboard is introduced for review sessions, and then one of the concept's interactions is tested. The chapter closes with the last iteration of a storyboard that presents the concept and, at last, the digital concept essential wireframe.

7.1 Process overview

For a general view of the process followed in this chapter see figure 7.1

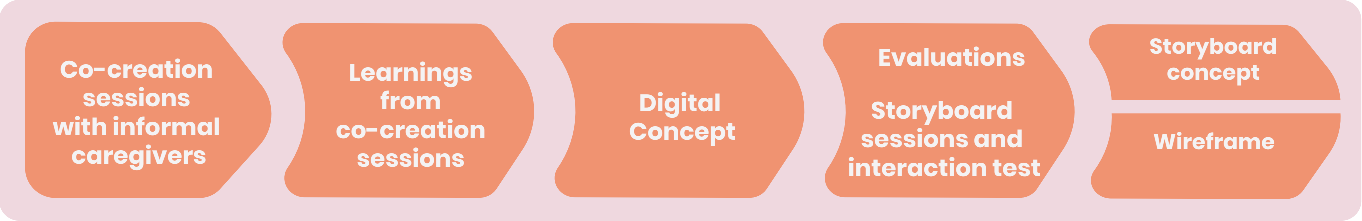


Figure 7.1 Process overview of the methods and activities executed in chapter 7

7.2 Co-creation session with informal caregivers

Taking journaling as the central component for the concept development, individual co-creation sessions were carried out with three different caregivers. One session was held face-to-face (see image 13a) and the other two were carried out via zoom (See image 13b)
An overviw of the participants can be seen in Table 7.2

F/M	Takes care of	Extra function
F	Mother	Housewife
F	Mother	Works M-F own business
F	Mother	Former nurse and director of a nursing home

Table 7.2
Participant's profile in the co-creation sessions

The research questions for the co-creation sessions were:

- How can informal caregivers be supported through the dementia journey by journaling?

- Are informal caregivers comfortable sharing stories with an organization such as Active Cues?

1.A collage making
2. A storyboard imagining use and
3. Discussing sketched key screens.

Before starting the co-creation session the participants were told what was the aim of the session and the description of the project. Later a consent form was signed. The co-creation session included 3 activities:

Collage making. Pre-selected random images were used (see image 7.3) for participants to create the collage. The activity started with the question:

- What characteristics has someone who is with you in good and bad moments? Think of how they look, how they make you feel and how they act. This, with the idea in mind that a journal accompanies you, ideally, in good and bad moments.

The goal of this activity was to uncover which values and app qualities informal caregivers would like to experience in the app.

Storyboard, imagining use. Two storyboards were made, one with a positive scenario and another one with a challenging scenario (to see these go to Appendix F). Participants told the storyline of the frames they were seeing (Image 7.4) and at the end they mentioned how they imagined the app worked.
The goal of this activity was to uncover additional functions or features that could potentially be included besides journaling.

Discussing sketched key screens. Three sketched screens were shown (Image 7.5): A screen notification after visiting your family member in the nursing home, the screen notification to share an insight with Active Cues and the home page. The goal of this activity was to gain an early input on the journaling app and to see if participants understood the concept overall. The screens were sketched by hand on purpose to encourage participants to speak openly as opposed to having digital screens that could intimidate them by thinking it was a finished product.

The breakdown of the co-creation session can be seen in Appendix G

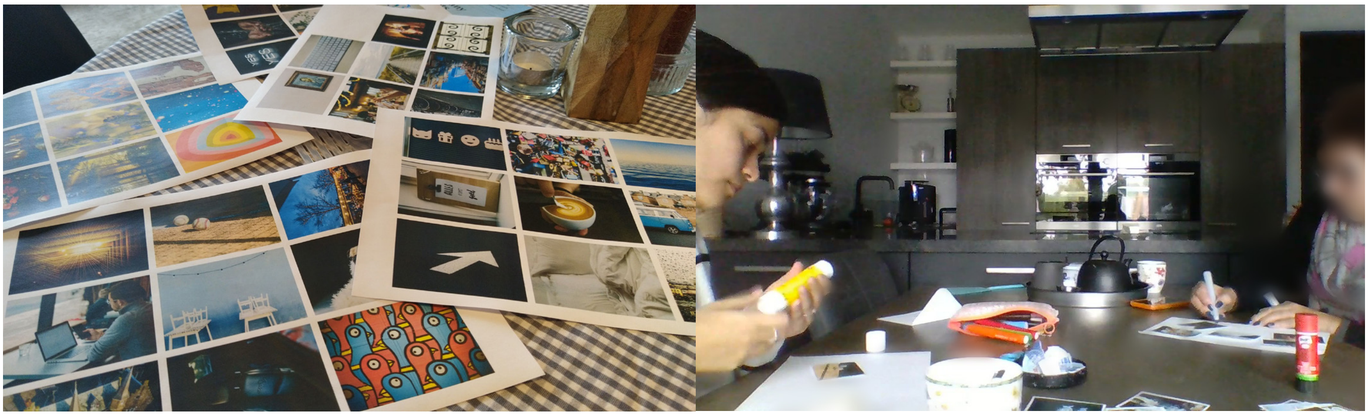
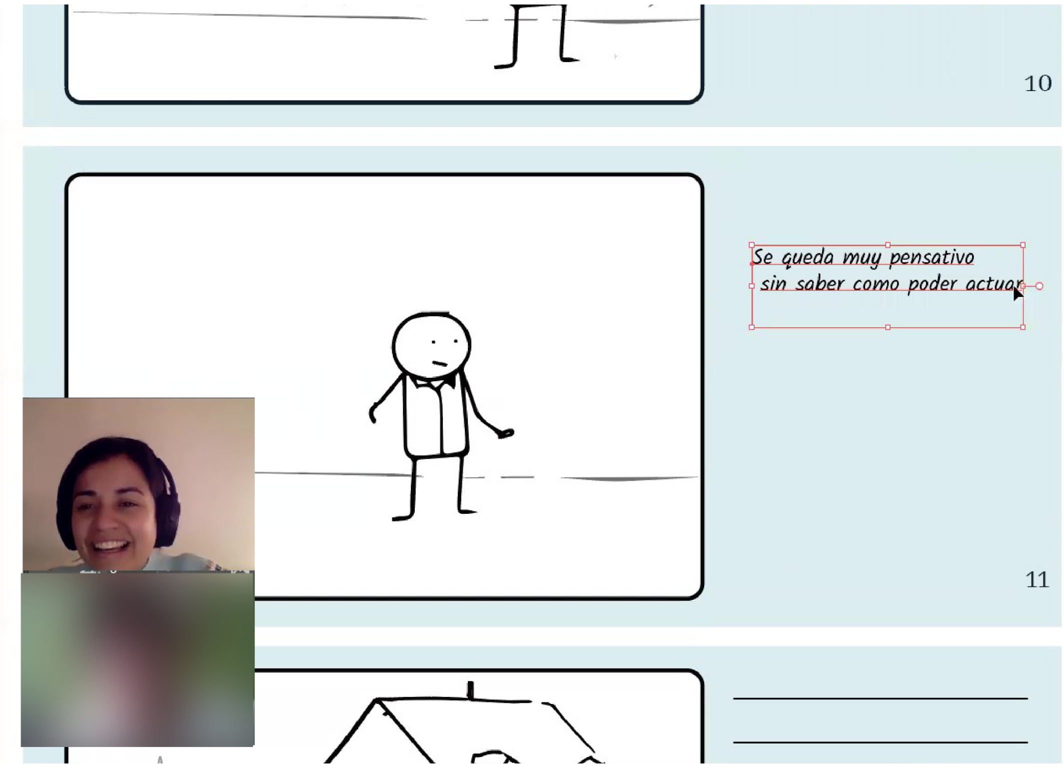
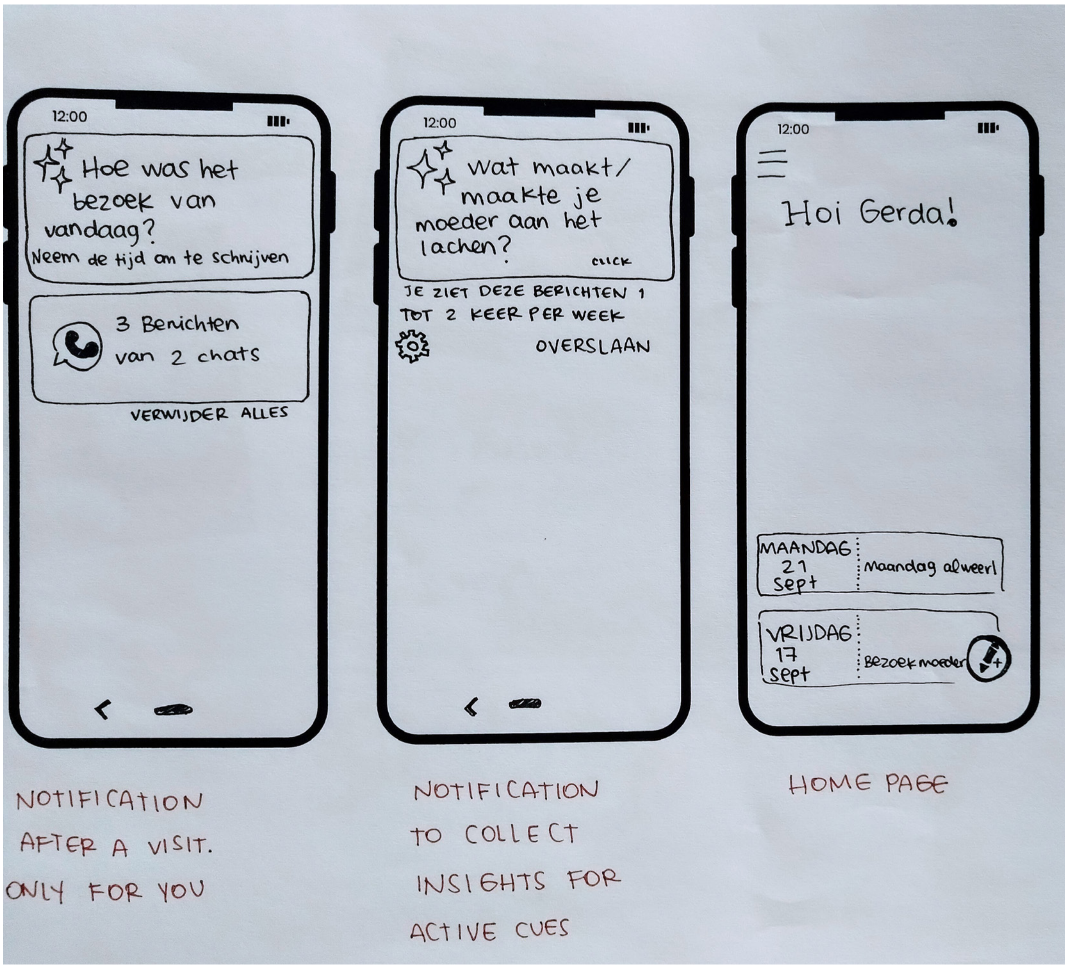


Image 7.3 At the left, the pre-selected images for the collage. At the right a participant and the author creating the collage



Se queda muy pensativo
sin saber como poder actuar

Image 7.4. A video-call with a participant, telling the empty storyline of the frames in a storyboard



Hoe was het bezoek van vandaag?
Neem de tijd om te schnijven

3 Benichten van 2 chats

Wat maakt/maakte je moeder aan het lachen?

JE ZIET DEZE BERICHTEN 1 TOT 2 KEER PER WEEK

Hoi Gerda!

MAANDAG 21 Sept : Maandag alweer!

VRIJDAG 17 Sept : Bezoek moeder

Image 7.5. Lo-fi screens discussed during the co-creation sessions

7.3 Learnings from the co-creation sessions

Supportive Network. People feel supported if they have a network that can relate to their situation as an informal caregiver.. They sometimes exchange, tips or encouraging words with acquaintances or friends that are passing through the same journey.

Collectingmemories. The three participants showed pictures about their mothers, which was very personal and at the same time empowering for them. Although their mothers were in the last stages of dementia they kept producing memories through photographs.

Sharing information with an organization such as Active Cues. The three informal caregivers that participated in the individual co-creation sessions mentioned that they would be comfortable sharing information regarding their parents preferences with Active Cues. They mentioned that being part of a bigger goal, such as contributing to the QoL of people with dementia, would make them feel flattered. They also said that they would appreciate if Active Cues would share how they are using the information or where they have applied it. Two of the informal caregivers mentioned that one notification would be sufficient for them to know.

Notifications. During the last part of the sessions, in the sketched screens, it was explained that as an initial idea there could be two types of notifications, one reminding people to add new entries to their diary and the other when Active Cues would add questions. The distinction of the notifications was not clear, so for the next iteration there should be a way to make a difference between those or to explore a different solution.

Another emergent topic was the ability to change the time of the notification to receive it before going to visit your loved one, one participant mentioned that she could appreciate encouraging words before visiting her mother.

The three co-creation sessions were very special because participants opened in a very personal and touching way. After one of the sessions one of the participant texted:

> *"I was very impressed with the research you are doing in your project... I never imagined that you could appreciate the work and dedication as a family member of a person with dementia, at least sometimes I minimize it and I even came to think that I was the one who was exaggerating ...you moved everything inside me and that is why I cried and right now that I write to you I am crying as well ... I think it helped me to know that taking care of my mother is not just anything, it is something very valuable that only the ones who live it know what it is like"*

- Informal caregiver after co-creation session

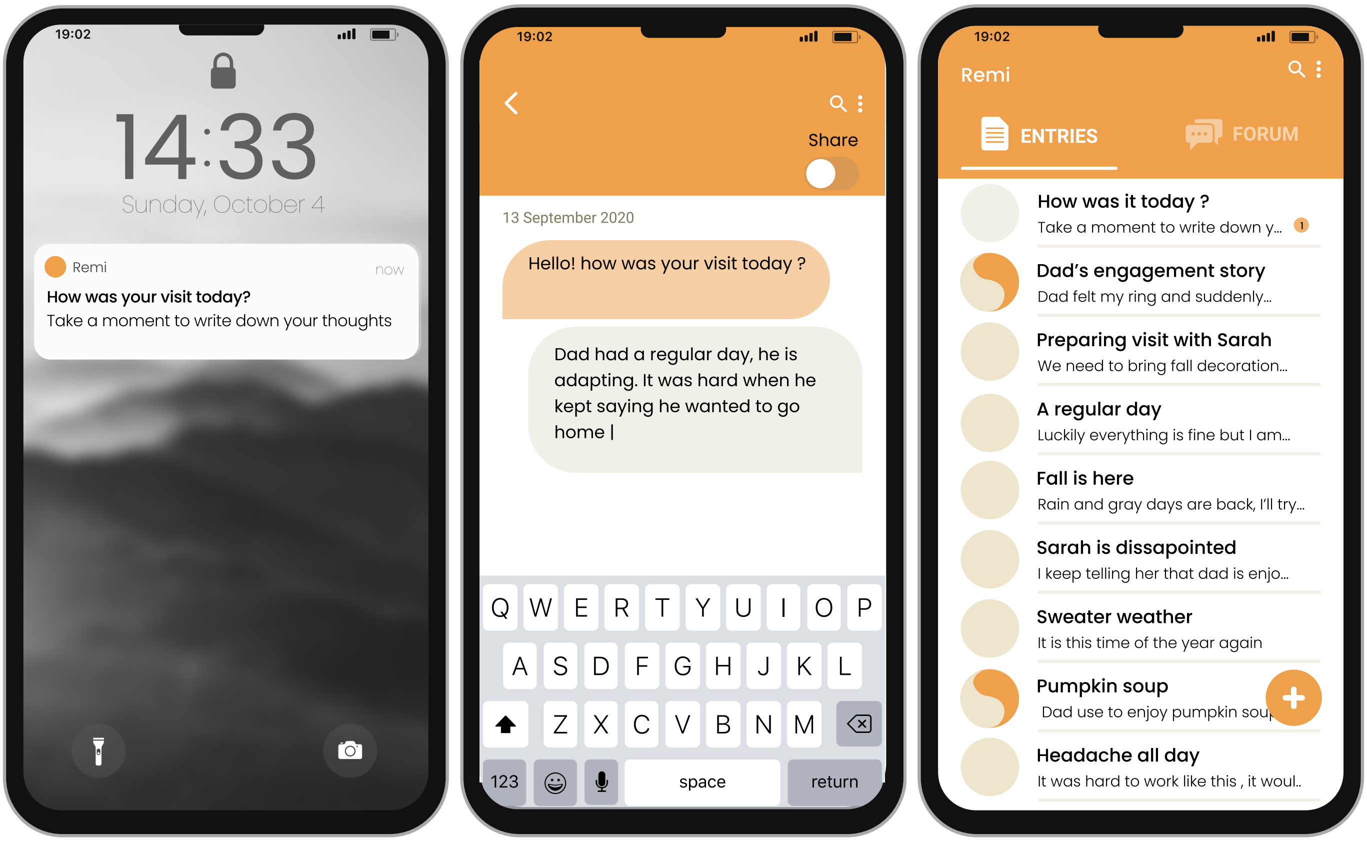
7.4 Digital Concept

Based on the co-creation sessions learnings, the digital concept was iterated. (See image 7.6)

The resulting iteration is Remi, an app for informal caregivers from nursing homes that have a tovertafel already. The app would be facilitated by Active Cues to these nursing homes.

The app has two purposes:

- Provide a space for informal caregivers to decompress, reflect about one's feelings and connect with others by journaling and
- Generate valuable insights for Active Cues' creative process



How was your visit today?
Take a moment to write down your thoughts

13 September 2020

Hello! how was your visit today ?

Dad had a regular day, he is adapting. It was hard when he kept saying he wanted to go home |

How was it today ?
Take a moment to write down y...

Dad's engagement story
Dad felt my ring and suddenly...

Preparing visit with Sarah
We need to bring fall decoration...

A regular day
Luckily everything is fine but I am...

Fall is here
Rain and gray days are back, I'll try...

Sarah is dissapointed
I keep telling her that dad is enjo...

Sweater weather
It is this time of the year again

Pumpkin soup
Dad use to enjoy pumpkin sou

Headache all day
It was hard to work like this , it woul..

Image 7.6 At the left the notification popping in after you visit your parent at the nursing home. In the center the informal caregiver replying to the bot. At the right the shared and non-shared entries.

Remi sends a notification to informal caregivers after visiting their parent living with dementia at the nursing home. The User Interface simulates a chat conversation where a chatbot replies to you. Informal caregivers can decide whether to share a story or not with Remi. To recognize that a story has been shared, a circle with two colors is shown on the left side of the entries.

Remi can also send notifications asking for stories related to the past or the preferences of PwD, intended to collect data that enhances the *reminiscence* of ToverTafel games for residents of nursing homes.

7.5 Evaluation

In order to assess the design goal and the requirements stated in chapter 5, an evaluation plan was set (Appendix H) with two different elements: Storyboard review sessions and an interaction test.
In total four people participated. Three people participated in the storyboard sessions: an informal caregiver, a sociologist with several years of being a nurse and a communications expert. And two informal caregivers (one from the storyboard session) participated in the interaction test.

7.6 Storyboard evaluation sessions

7.6.1 Research aim

The purpose of this evaluation was to validate the overall impression of the concept and the clarity of it through the storyboard from Appendix I.

The research questions for it are:
Overall impression
What do participants think about the concept?
Would they use such a service?
Do participants see the relevance of the concept?

Clarity
Does the storyboard clearly communicate the concept?
Are there unclear elements? If so, what is unclear?

7.6.2 Method and procedure

First the storyboard was sent to each of the participants for them to see it at their own pace. Then, a video call was set to discuss the storyboard further through semi-structured interviews; finally, after the semi-structured interview the basic UI of the app was shown and discussed thoroughly.

7.6.3 Limitations

Storyboard review sessions work well to evaluate an overall concept, yet the main limitation is that the participants are imagining the story, the feelings and situations and not actually experiencing it.

7.6.4 Results

Overall participants identified the relevance of the app, they mentioned things such as “I would feel supported if I were Gus”, “If I can help for the quality of life of PwD I would do it”. Also participants identified the relevance of journaling “It would help me to not carry my thoughts all day I think”.

Regarding sharing stories, people were curious and asked what other types of questions Remi would ask them. It was then discussed that it is about the preferences and interests of the residents in nursing houses, which tells that it should be clear in order to understand the whole concept.

An interesting point that one informal caregiver mentioned over the app was the possibility of serving as a communication channel between the nursing home and informal caregivers. Although it is out of this project’s scope, it showed the need for informal caregivers to be informed about different topics within the nursing home environment. It could be an additional point of engagement and a way to expand this communication channel.

For the clarity of the storyboard some fine tuning is needed, for example to emphasize that people decide whether to share or not a story and how they can connect to other informal caregivers. Once the UI of Remi was shown at the end these points were clarified.

7.7 Interaction Evaluation

7.7.1 Evaluation aim

The purpose of this evaluation was to understand on an interaction level the notifications that the concept sends. The research questions are:

- How do participants feel when receiving a reminder to journal?
- What kind of stories do participants share?

7.7.2 Method and procedure

Since the concept is inspired by a chat-like app to journal, the tests were carried out via whatsapp. The explanation of the test took place before the storyboard evaluation session and the concept was explained via the UI of the Remi.

It was asked to the informal caregivers which days of the week they visit their parents to be able to act as the notification to remind people to journal and to also share stories of their loved one. It was also told that they could share a story that came up to their mind if they felt like doing so.

The two participants visited their parents from two to three times in 9 days. After each of the visits they received a message that said: How was the visit to your mother today?

During one of the no-visit days a different question was sent: What was something that characterized your [Mother]?

At day 9 a semi-structured interview via telephone was carried out to know how their experience was.

7.7.3 Limitations

There are some limitations while assessing this interaction. First, the fact that I sent the notifications and not the chatbot that the concept supposes; this limits how the informal caregiver relates and feels in regards to a chat bot. Also, the fact that I was reading their stories and so it was not completely a space for themselves in that sense.
Another limitation, due to the project timeline, is the application's long-term interaction, since the test was performed during 9 days. This would affect a final limitation: the informal caregiver did not receive a feedback loop from Active Cues to communicate how the received stories are being used.

7.7.4 Results

Overall the two participants felt positive about receiving a message after their visit to their parent. One mentioned that with the first message she did not know how long she could write down, which also reflected in the second participant for the first message. At the end of the messages participants wrote more about their feelings compared to the first messages.

One of them mentioned that she was looking forwar for the message after her visit to her mother. And the other emphasized that it would have been nice to also be reminded to write during a no-visit day.
As for the notification regarding sharing a story both participants told a personal story in regards to their parent as an example:

> *"It was unthinkable for us to take a break from our house chores or to feel sick at home, my mother was very strict ...she didn't allow breaks"*
>
> - informal caregiver at interaction test

7.8 Final Iteration

In this final iteration the storyboard of the concept and the essential wireframe of the digital concept were worked out in alignment with the feedback received in the evaluation sessions.

Figure 7.7 shows the essential flow of the UX of Remi and Image 7.8 the story board that acts as a stand alone element to explain the concept.

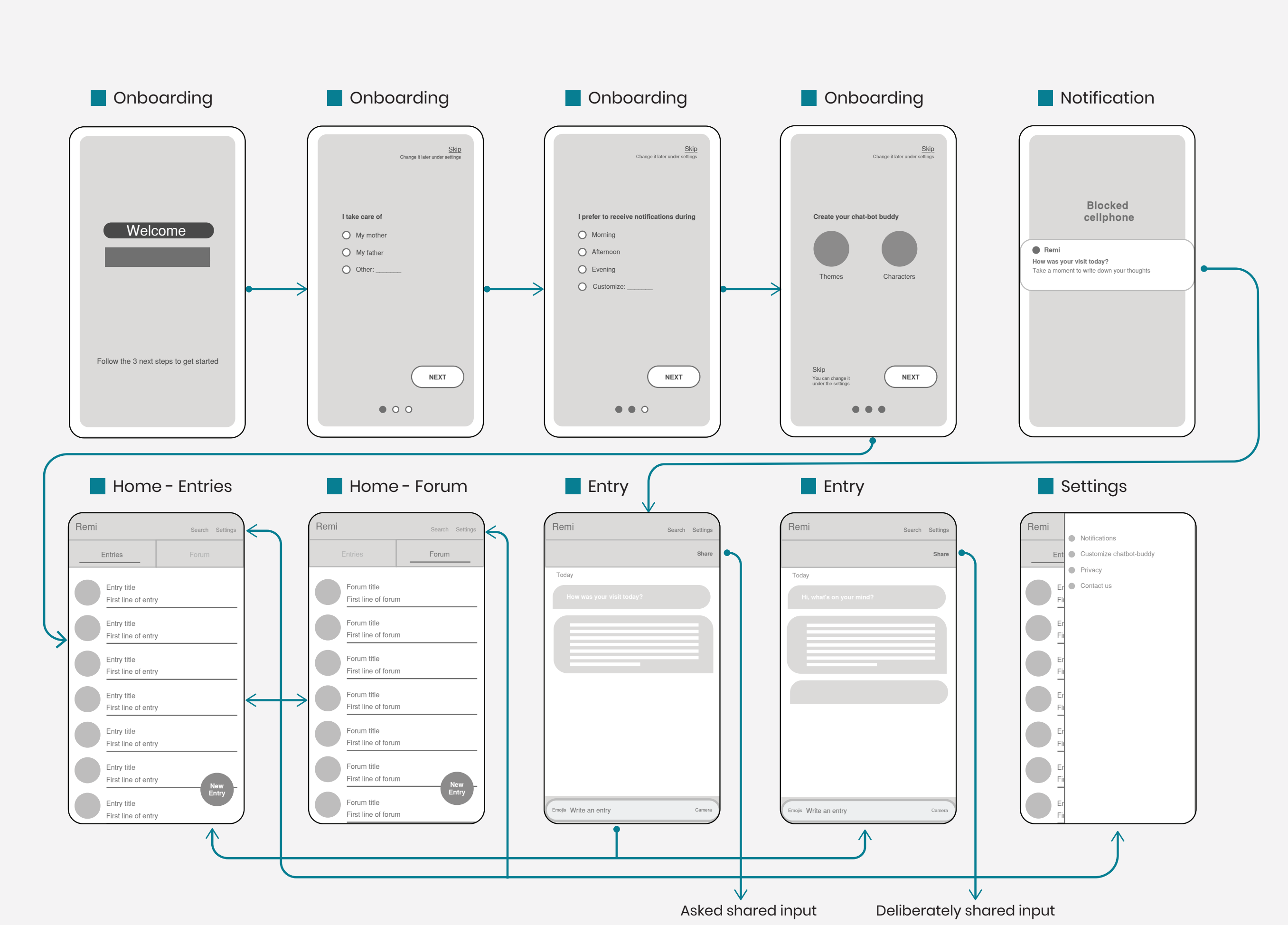
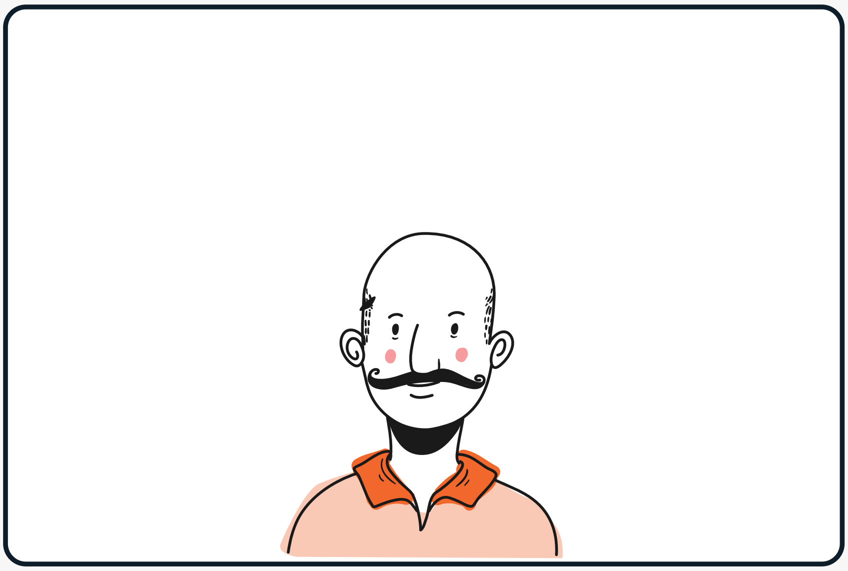


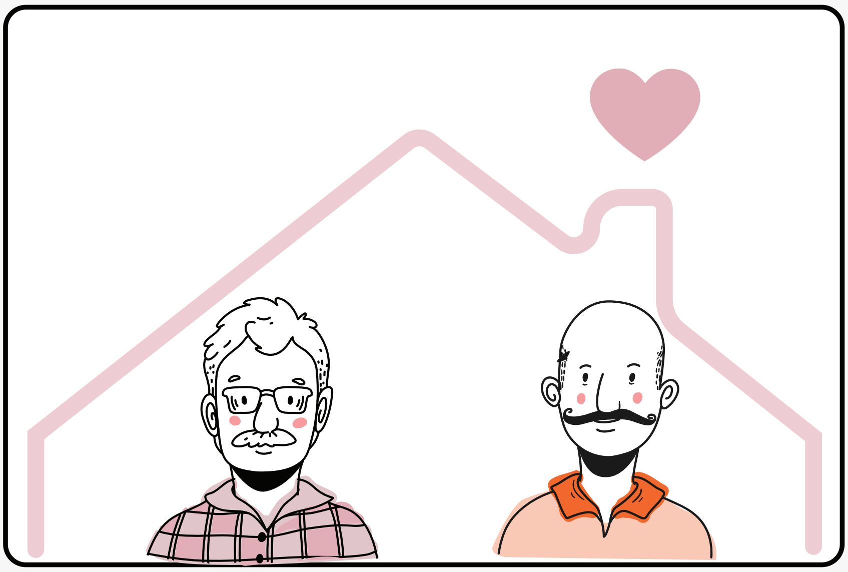
Image 7.7 Essential wireframe flow of Remi. In the onboarding screens, three steps show the optional questions for informal caregivers when signing in: who they take care of, when they prefer the notifications, and the option of personalizing their chatbot.
The entry screens show how Active Cues could filter the input: Shared entries from notifications and deliberately shared entries.



Meet Gus

A kind man, who provides care to his father. He is his dad's informal caregiver.

1

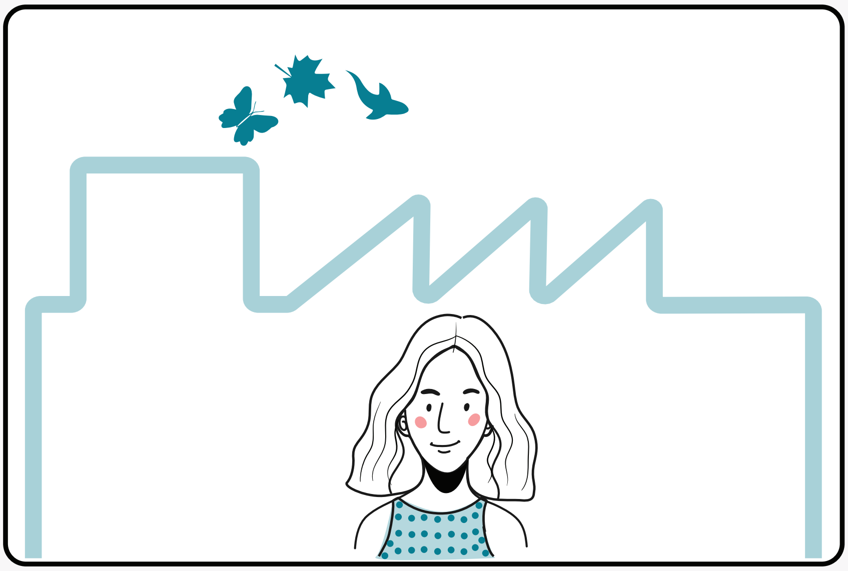


Meet Vincent

He is the father of Gus and lives with dementia; Three months ago he moved to a nursing home.

Gus visits his dad once a week.

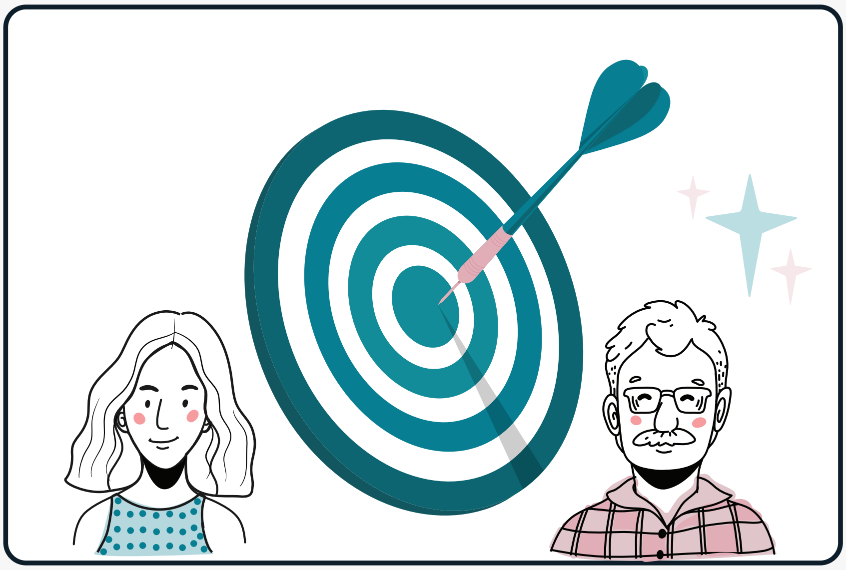
2



Meet Tina

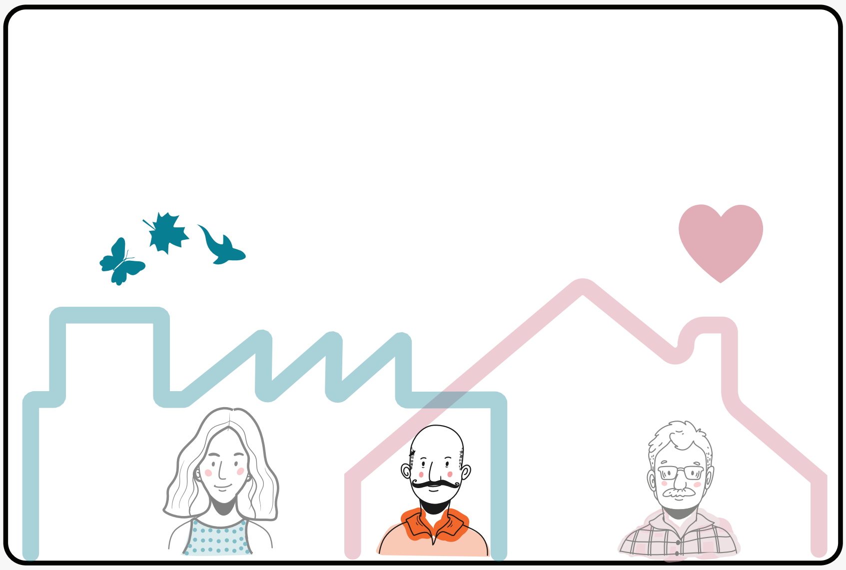
She works at Active Cues, an organization that creates moments of happiness in residential care.

3



Active Cues ultimate goal is to improve the quality of life of people with dementia. They do so by designing user -centered games for the ToverTafel - an interactive audiovisual experience that triggers people with dementia to move, play and socialize -.

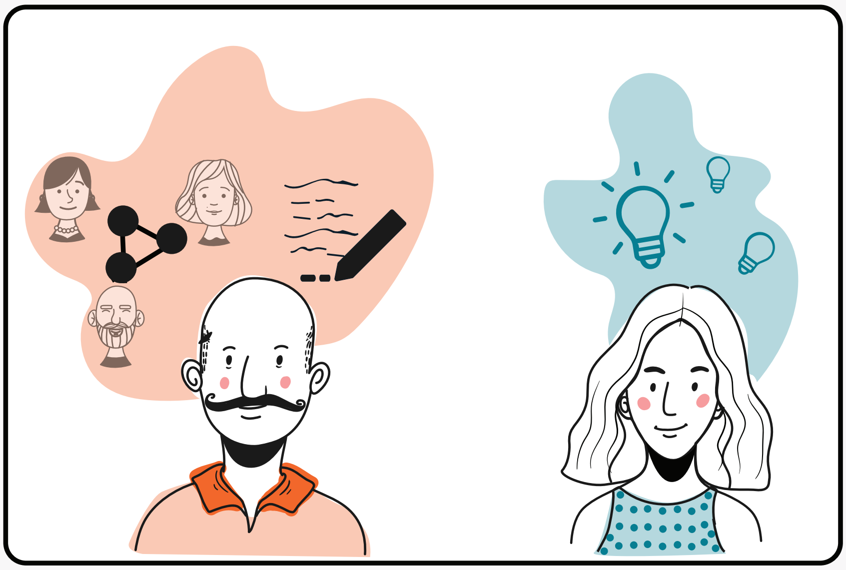
4



Active Cues offers a digital service for informal caregivers like Gus.

This digital service is named Remi.

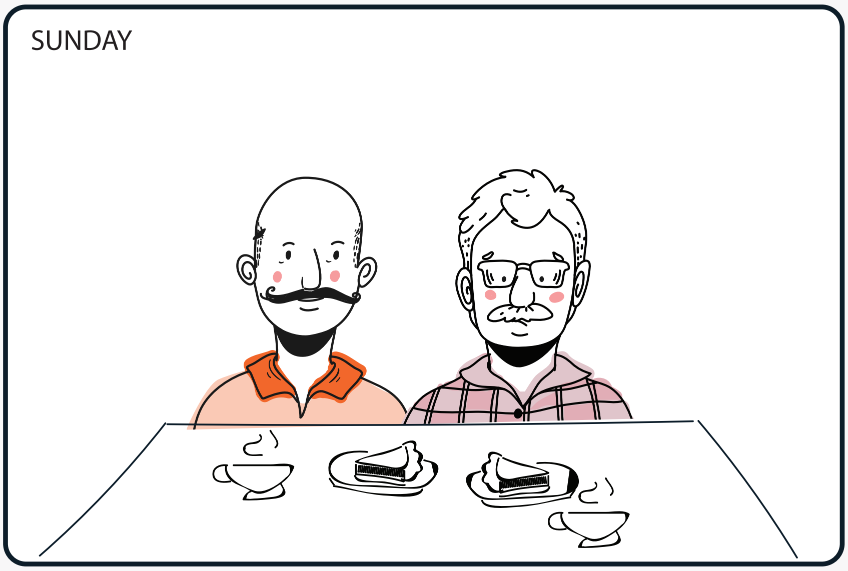
5



Remi aims to provide informal caregivers a space to decompress, reflect on their feelings by journaling, and connect with other informal caregivers.

The data resulting from these actions contain valuable insights for Active Cues.

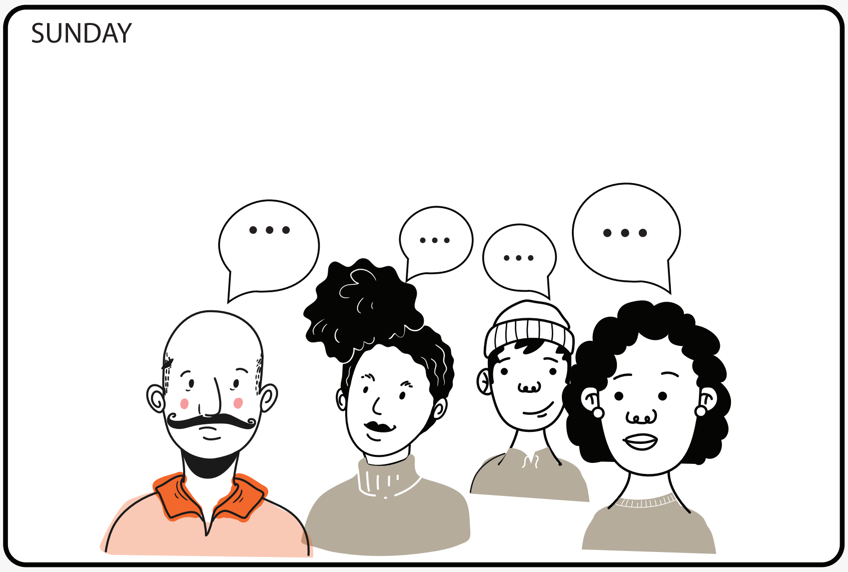
6



Like every Sunday Gus is visiting his dad and today Vincent is not having a good day, he seems to be withdrawn.

This is hard for both Gus and Vincent.

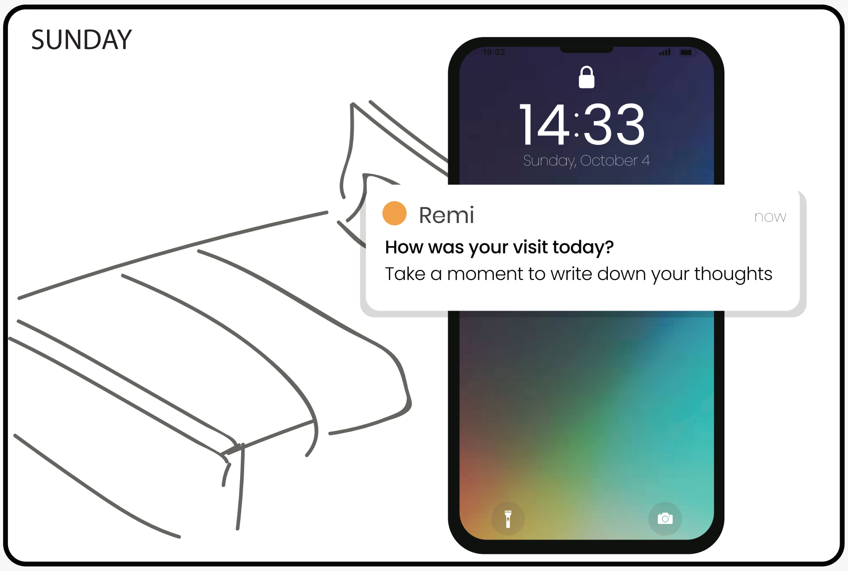
7



After the visit, Gus feels a bit down.

Later he comes back home with his family to continue with the rest of his day.

8



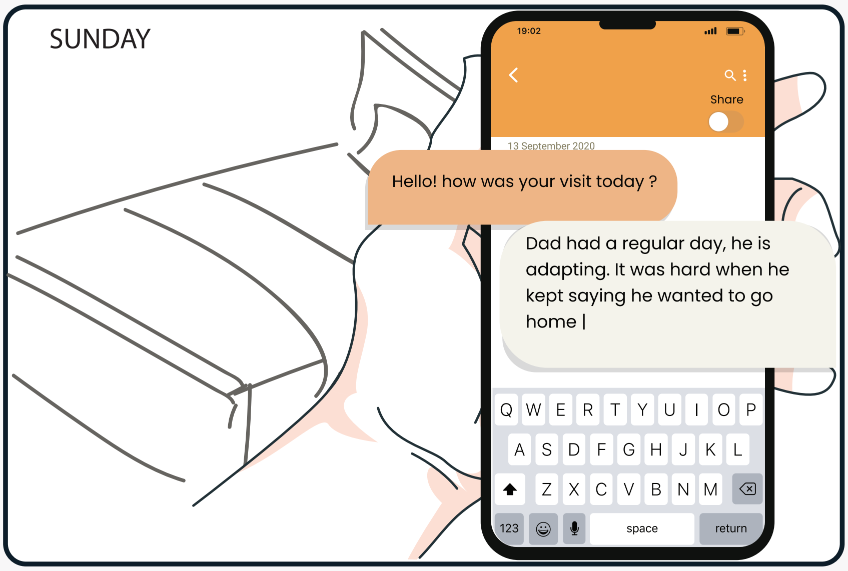
Remi now

How was your visit today?

Take a moment to write down your thoughts

Later at home, before going to bed Gus receives a notification.

9



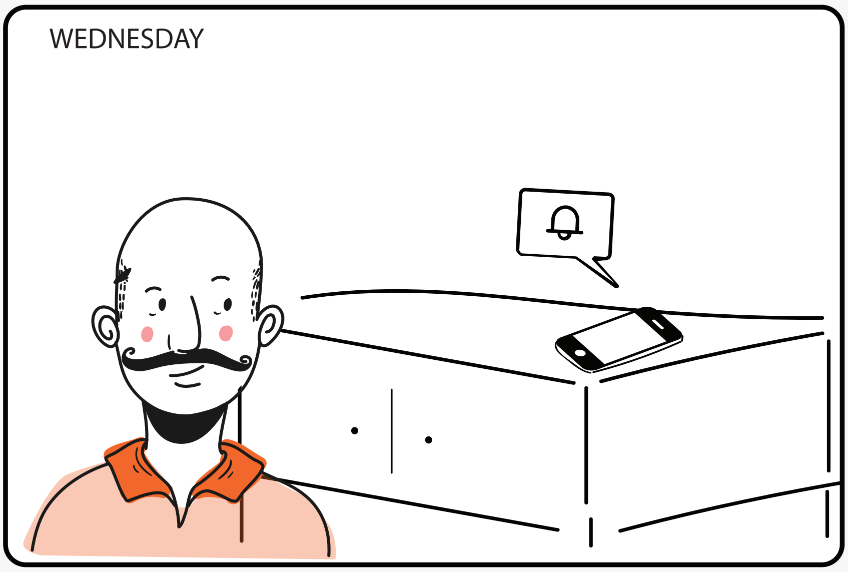
Hello! how was your visit today ?

Dad had a regular day, he is adapting. It was hard when he kept saying he wanted to go home |

Gus takes his phone and writes down his thoughts.

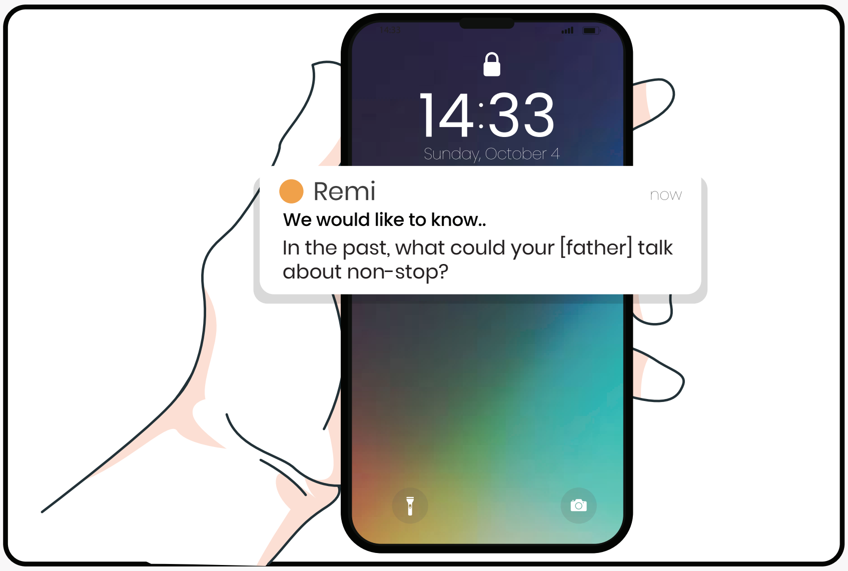
He feels relieved to put his feelings into words. After that, he enjoys a good night.

10



The week goes by, it is Wednesday, and Gus receives a notification from Remi.

11



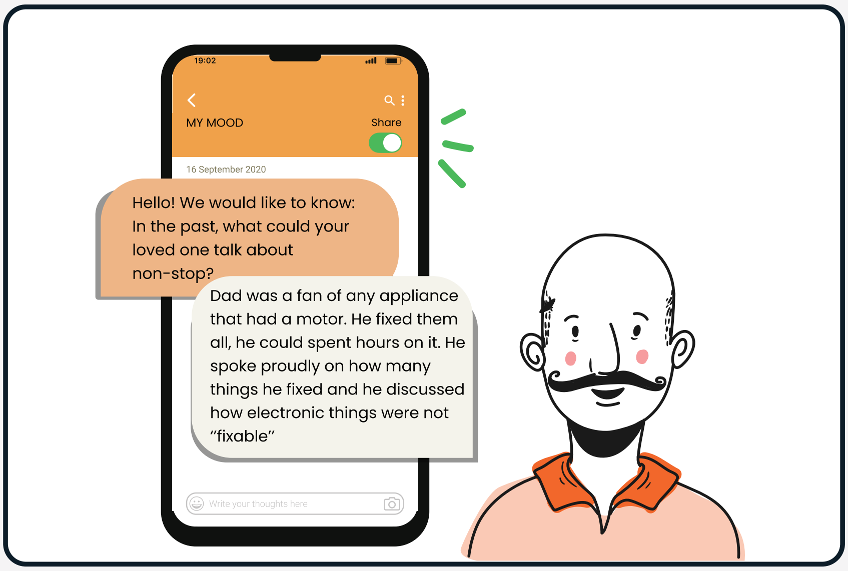
We would like to know..

In the past, what could your [father] talk about non-stop?

Remi asks for a story, this time about themes of interest of residents in nursing houses.

Collaborating with such stories contributes to improving the quality of life of people living with dementia.

12



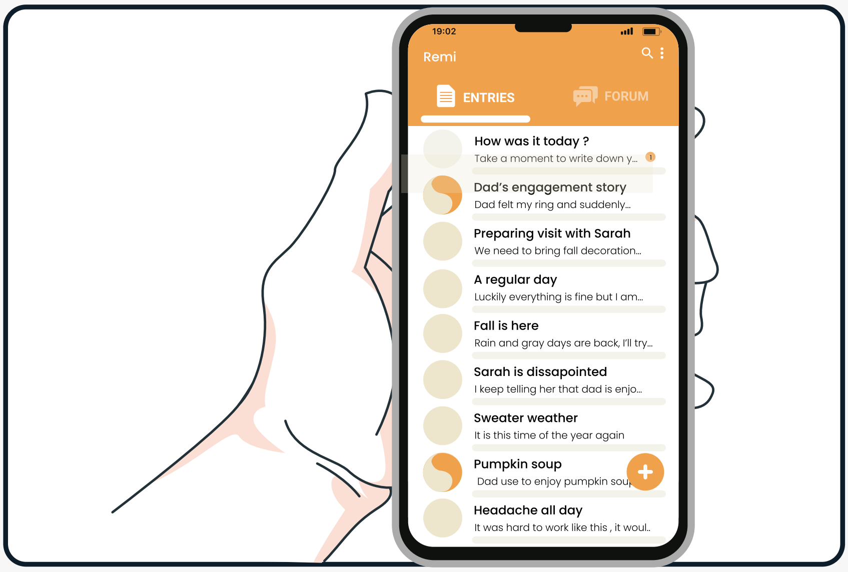
Hello! We would like to know: In the past, what could your loved one talk about non-stop?

Dad was a fan of any appliance that had a motor. He fixed them all, he could spent hours on it. He spoke proudly on how many things he fixed and he discussed how electronic things were not "fixable"

Gus opens Remi and replies, he can decide whether to share that story with Active Cues or not. He chooses to 'share' his storie and feels good to contribute.

It is made sure that shared data is managed confidentially.

13



How was it today ?
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Dad's engagement story
Dad felt my ring and suddenly...

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Fall is here
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Sarah is dissapointed
I keep telling her that dad is enjo...

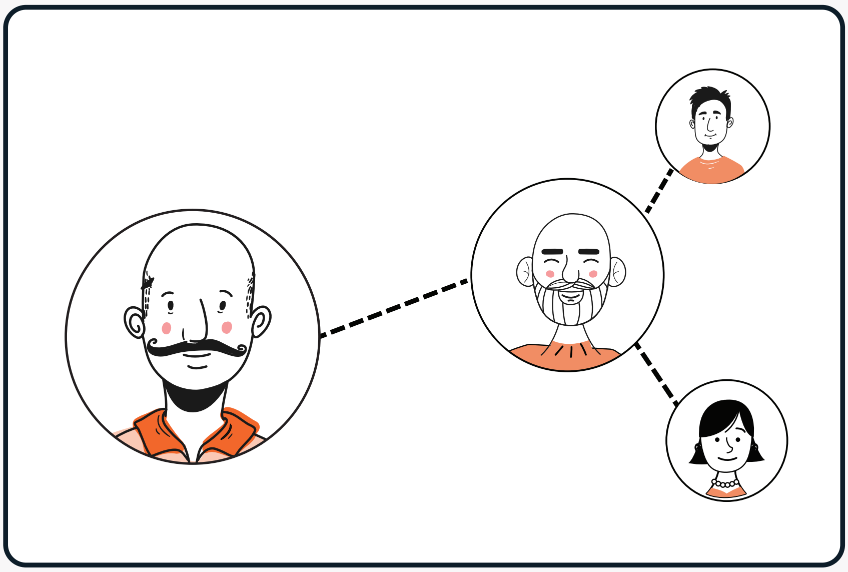
Sweater weather
It is this time of the year again

Pumpkin soup
Dad use to enjoy pumpkin sou

Headache all day
It was hard to work like this , it woul..

After sharing a storie, Gus checks the forum of informal caregivers in the area. He feels a bit concern since his last visit and would like to know what other informal caregivers do when their loved ones are withdrawn.

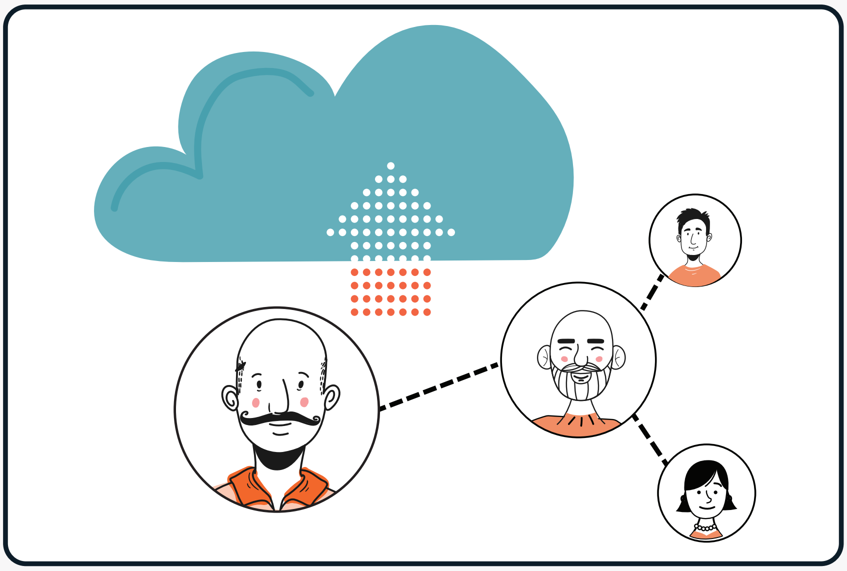
14



Gus meets other informal caregivers. A network that has in common the same nursing home where Vincent lives.

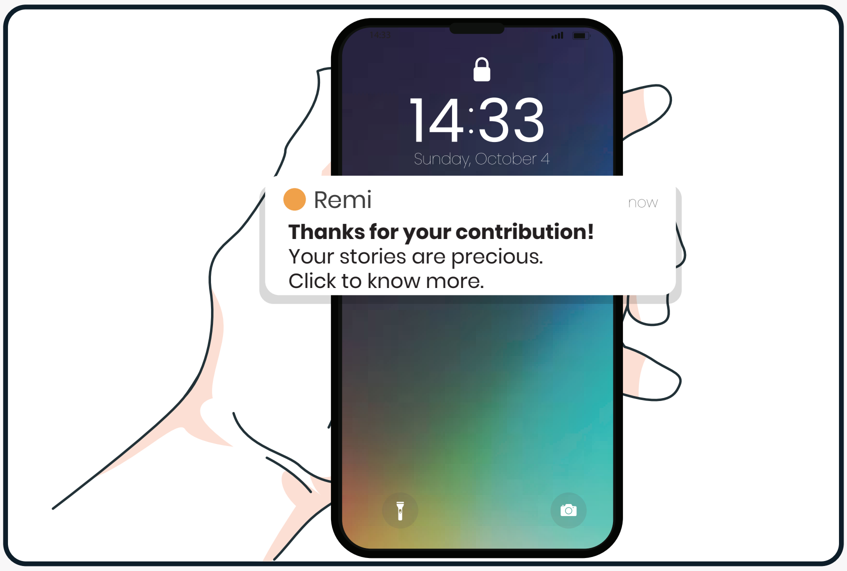
They exchange tips and words of encouragement with each other.

15



This network of informal caregivers share stories via Remi. With these stories, Tina and her team at Active Cues get insights to design even more relevant ToverTafel games for people like Vincent.

16



Thanks for your contribution!
Your stories are precious.
Click to know more.

Now and then, Active Cues informs via Remi their achieved developments to make this collaboration transparent.

17

THE END

Image 7.8
Storyboard of the concept

18

The storyboard was created with images from freepik and thenounproject.

08

Discussion

In this chapter the conclusions of the project are presented followed by the relevance, limitations and recommendations. The chapter closes with a personal reflection on the learnings and experiences during the project. Then I present practical tips for graduates that were passed on to me along with some others that I encountered during my graduation journey.

8.1 Conclusions

Based on the evaluations performed it can be concluded that the design requirements in this project are fulfilled. An interesting finding was that informal caregivers are willing to share their anecdotes and felt part of a bigger purpose by knowing they could collaborate to improve PwD QoL. People that participated in the evaluations started talking about their feelings and reflected on their presence in the dementia journey. All in all, the participants felt positive about the design concept overall.

As for the design goal, *'to gain contextual knowledge about PwD through informal caregivers, for Active Cues to include it in their creative process'*, the objectives are achieved to the extent of the caregiver, taking into consideration that the complexity of the project was reduced to focus on the informal caregiver. Last, for this project's aim, *'to enrich Active Cues creative process',* the concept should be further developed and tested to fully reach the project's aim.

8.2 Relevance

This project touches upon the dementia journey, zooming in, specifically, in the informal caregiver. The latter play a significant role in our society taking care not only of PwD, but also, people with chronic diseases or disabilities.

The healthcare system supports itself enormously on the volunteering of informal caregivers. Often this group of people are overlooked and in terms of design interventions there is much that could be done to improve their overall wellbeing. It is crucial that we as designers pay attention to this group because in order to give care to someone one should be also taken care of and have tools and resources to continue doing this volunteering and generous work.

8.3 Limitations & recommendations

Throughout the whole project there were different limitations that should be considered for the project.
During the generative techniques, classmate Hannah Pak carried out all the interviews in Dutch to make sure participants felt the most comfortable by speaking in their native language. Although my understanding of Dutch is about 75-80% and we both did the analysis of the interviews together, the interpretation of interviews could be affected by this factor.

Another thing to consider is that all the interviews were done to people that *had* parents living with dementia and their parents passed away from 1 - 5 years ago as of the first phase of the project as mentioned in section 3.4 the dementia journey. As a recommendation it will be interesting to go through the same process including not only child-parent relationships but also couples that go through the dementia journey. The same way it is recommended that the journey map is seen through the eyes of someone that went through the whole process. Perhaps the vision of someone that is living the journey (without being out of it) could be different because it does not have yet a holistic view of it all. Therefore, another recommendation is to recreate the journey with people that are passing through it, zooming in the stages found, compare and adjust accordingly.

As described in chapter 7 in the limitation sections of the interaction evaluation done, the timeframe of the test was done in nine days, as such it is recommended to do a long-term pilot to see the answer of informal caregivers.

At last, in both evaluations informal caregivers from the Netherlands and Mexico participated, which created a richer perspective of informal caregivers, however the cultural difference is a limitation. In Mexico people are in a way expected to take care of their family, as community and family are big values, which may lead to overlooking the work that informal caregivers are putting in as this is an expected task. Whereas in the Netherlands people tend to be more individualistic, in my opinion, and taking care of your family might not be necessarily expected, as it is acknowledged the work that involves, so volunteering yourself as an informal caregiver might prompt to be highly recognized and valued.

8.4 Personal reflection

This project's motivation was to learn in-depth about dementia and understand the process that my family has gone through with my grandmother back in Mexico. I wanted to immerse myself in this subject because I see that the elderly are overlooked, and it was of my interest to see the great work that Active Cues does to address this.

The project setup allowed me to hear different stories and perspectives of caregivers, so I learned a lot about PwD and how caregivers approach their job with so much dedication. Sometimes listening to all these stories was not easy to do; at moments, the project's subject felt heavy because I had to manage my own emotions and other people's emotions that sometimes can be too much.

This project has impacted my life, not only because it is my master's graduation project but also because it reframed some aspects of my relationship with my parents. It sparked my interest in their past, their stories, and background, which allowed me to understand them with a more loving and less judgemental view. So I am immensely grateful for that. I recommend that people ask their parents about their past; I assure you will learn a lot from them, and consequently learn about yourself.

On a cultural level, thanks to the fact that I speak Dutch to no small extent, it was sometimes surprising to hear people's stories. The Dutch culture is very open and transparent, so when people tell you they are willing to participate, you will, for sure, hear very personal anecdotes, that from a Mexican perspective, could be impressive. Although we, Mexicans are warm people, generally speaking, we do not tend to be as direct and open about our thoughts and feelings. Being direct could be interpreted as offensive;

therefore, people in Mexico tend to hide their feelings in my experience.

Finally, this project allowed me to know myself better and the way I work the best. Knowing your limits and capabilities is crucial to keep developing yourself.

8.5 Tips for futures graduates

One of the first things I learned from other students is: **start on time looking for a graduation project.** It can feel too early to do it two to three months in advance; however, that can allow you to see more of a variety of projects and start when you are planning to do so. Related to this point the tip is to **contact all the professors you feel you need to,** and do it as often as necessary, don't be afraid to feel 'pushy'; it is your graduation project, so **you are the only one who can make it happen. Persistence does not mean rudeness.** Professors have a busy schedule and sometimes forget or do not have the time to respond. In case they forget, it comes in beneficial to send a reminder email. Otherwise, you might be waiting and waiting, and again, it is your project, so you are the only one who can make it happen.

As for **the theme of the project,** I wouldn't worry too much; **make sure you enjoy and are genuinely interested in the topic** because no matter what, at some point, you will get tired of it, and it comes in handy to like the subject. Also, unless you have concrete career goals, such as pursuing a Ph.D., for example, this can be your chance to explore something you do not necessarily want to follow in the next years, but a theme you truly want to learn about. In the end, you will have a nice project to showcase in your portfolio, but again unless you have particular career goals, then yes, hang on to that specific topic.

About **the planning,** yes, try as much as you can to stick to it. Nonetheless, keep in mind some plans will be thrown overboard, that is normal, and it is okay to feel frustrated and not know what to do; at the end of the day, **planning is also about flexibility.**

As **for communication**, try to keep an **open contact with your mentors,** and once you know, try to **tell what works and what does not work for you.** Also, keep in mind, **sometimes you will get caught in details that** they do not remember at all, they also have their personal and working life, they are not thinking of you 24/7, the same as you will not think of them.

Try to involve your circle of acquaintances and friends in your project. Having **other people's opinions will give you a different and fresh perspective** on your project. Yet it is also wise to **recognize the moment you stop asking for feedback and follow your gut.**

As **for practicalities,** try to **set a routine for yourself,** it doesn't matter if you start at 6 am or 11 am as long as you **start, that is the crucial part.**

Finally, I recommend taking time to **rest, exercise, have fun, and eat properly;** that is also part of the planning. **The graduation project can get tough**, and it is essential, in my opinion, that you **keep your physical and mental health a priority** to push yourself forward.

Good luck!

Ile

09

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9.2 Icons

Paper by scott desmond from the Noun Project
Thought Bubble by Adrien Coquet from the Noun Project
Image by Pavani TLN from the Noun Project
Camera by Alfa Design from the Noun Project

10

Appendices

10.1 Appendices

Appendix A - Initial Project Brief
Appendix B - Sensitizing material - Professional Caregivers
Appendix C - Interview scripts (professional and informal caregivers)
Appendix D - Questionnaire via google forms for Active Cues
Appendix E - Digital Cultural Probe testing setup
Appendix F - Storyboards used during co-creation sessions
Appendix G - Co-creation sessions breakdown
Appendix H - Evaluation Plan
Appendix I - Storyboard for concept review sessions

TU Delft

Procedural Checks - IDE Master Graduation

APPROVAL PROJECT BRIEF

To be filled in by the chair of the supervisory team.

chair Marieke Sonneveld date 23 - 03 - 2020 signature

CHECK STUDY PROGRESS

To be filled in by the SSC E&SA (Shared Service Center, Education & Student Affairs), after approval of the project brief by the Chair. The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total: 30 EC

Of which, taking the conditional requirements into account, can be part of the exam programme 30 EC

List of electives obtained before the third semester without approval of the BoE

● YES all 1st year master courses passed

○ NO missing 1st year master courses are:

name J. J. de Bruin (SPA-IO) date 08 - 04 - 2020 signature J. J. de Bruin Digitally signed by J. J. de Bruin Date: 2020.04.08 16:06:44 +02'00'

FORMAL APPROVAL GRADUATION PROJECT

To be filled in by the Board of Examiners of IDE TU Delft. Please check the supervisory team and study the parts of the brief marked **. Next, please assess, (dis)approve and sign this Project Brief, by using the criteria below.

- Does the project fit within the (MSc)-programme of the student (taking into account, if described, the activities done next to the obligatory MSc specific courses)?
- Is the level of the project challenging enough for a MSc IDE graduating student?
- Is the project expected to be doable within 100 working days/20 weeks ?
- Does the composition of the supervisory team comply with the regulations and fit the assignment ?

Content: ● APPROVED ○ NOT APPROVED

Procedure: ● APPROVED ○ NOT APPROVED

comments

name M. von Morgen date 14 - 04 - 2020 signature

The Last Stages of Dementia: A Toolkit to Create Moments of Joy project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 02 - 03 - 2020

28 - 08 - 2020 end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

Active Cues is a company that creates moments of happiness in residential care by developing games for specific groups such as elderly living with dementia in nursing houses [1]. This company emerged from Hester Le Riche's Ph.D. at TUDelft in where she designed a product called the ToverTafel (Figure 1). One of Active Cues' cornerstones is research for product development with their unique vision: "Everybody has the right to play."

On average, people can live up to eight years with dementia: approximately six years at home and two years in residential care [2]. According to The Global Deterioration Scale for Assessment (GDS) of Primary Degenerative Dementia, there are seven different stages of dementia. And at the start of stage 5, the person living with dementia is no longer able to live without assistance [3].

When the elderly move in a nursing house, their apathy increases, they lose mobility and socialize less [4]. The ToverTafel, an interactive table, addresses these characteristics by stimulating the elderly living with dementia to socialize and move (to get physically active). Although the ToverTafel is a great product that activates the elderly in nursing houses, there is a group of residents that Active Cues has not addressed yet: People living in the last stages of dementia.

People living in the last stages of dementia experience severe cognitive and psychomotor abilities decline, e.g., they lose the ability to walk and sit, which leaves them confined to their bed or room. And, due to these symptoms they are not able to join the ToverTafel anymore. Everybody has the right to live a worthy life until the end; therefore, Active Cues wants to give people in the last stages of dementia the chance to also experience moments of joy.

This project aims to support Active Cues in their current design research process in the scope of designing for moments of joy for residents of nursing houses in the last stages of dementia.

The main limitation of the project will be the frequency in which I can visit the nursing houses, although Active Cues has contact with them, the visits are frequency restricted. For this, proper project management is essential to gain as much depth with the possible amount of visits.

space available for images / figures on next page introduction (continued): space for images

image / figure 1: The Tovertafel in use at a nursing house.

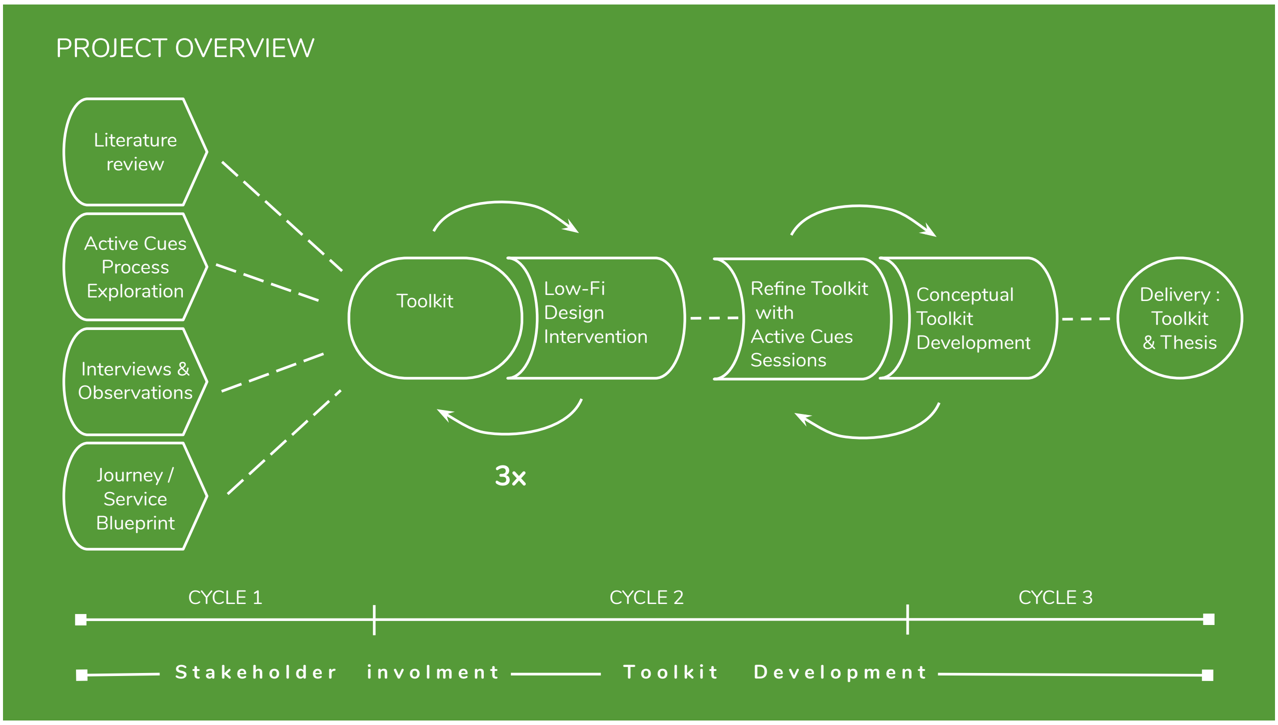


image / figure 2: Project Overview

Initials & Name I Diaz Couder Breceda Student number 4861477

Title of Project The Last Stages of Dementia: A Toolkit to Create Moments of Joy

PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

Currently, Active Cues is looking to design for people in the last stages of dementia; however, they do not have an in-depth insight into this particular user group (people in the last stages of dementia, their family, and caregivers).

In-depth knowledge means:
- Discerning the emotional needs of residents living in the last stages of dementia and the ones around them
- Understanding the spectrum and reach of what a playful experience is for these residents, and,
- The ability to translate this into a service/product/system for this vulnerable group.

This project focuses on this knowledge gap, which is now a limitation for Active Cues to design for people living in the last stages of dementia. Since the project revolves around Active Cues and People Living in the Last Stages of Dementia in nursing houses, the research questions are divided into these two areas:

REGARDING ACTIVE CUES
- How does Active Cues perform design and research now?
- Where do they lack knowledge and tools to design for people living in the last stages of dementia?

REGARDING PEOPLE IN THE LAST STAGES OF DEMENTIA
- What are the emotional needs of people in the last stages of dementia (and the ones around them)?
- What is quality of life in the last stage of dementia?
- And how could design for playfulness address these emotional needs and meaning of quality of life?

ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, ... In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

With a research through design approach, I will explore the emotional needs and meaning of the quality of life for people in the last stages of dementia and the ones around them. In parallel, I will investigate Active Cues' current design research process. Then I will create low-fidelity design interventions that will serve as a tool to generate knowledge [5]. Lastly, this knowledge will be the final deliverable of this project in the form of a toolkit.

The project divides into 3 cycles:

CYCLE 1: Literature review will be done, and then Active Cues current design research process will be investigated . In parallel, observations and interviews will be planned. (in collaboration with Hannah Pak). An analysis of the data and an elderly journey will follow to identify the best moments for the Design interventions.

CYCLE 2: During this cycle, work will be done in parallel: the creation of low-fidelity design interventions, and with the insights generated, the first version of the toolkit will be created. This will be an iterative intertwined process. In this way, I can validate the toolkit before doing the sessions with Active Cues. By the end of cycle 2, I will have a refined concept of the toolkit.

CYCLE 3: This cycle will serve to compile the conclusions, recommendations and limitations; Edit the thesis report and create other required deliverables.

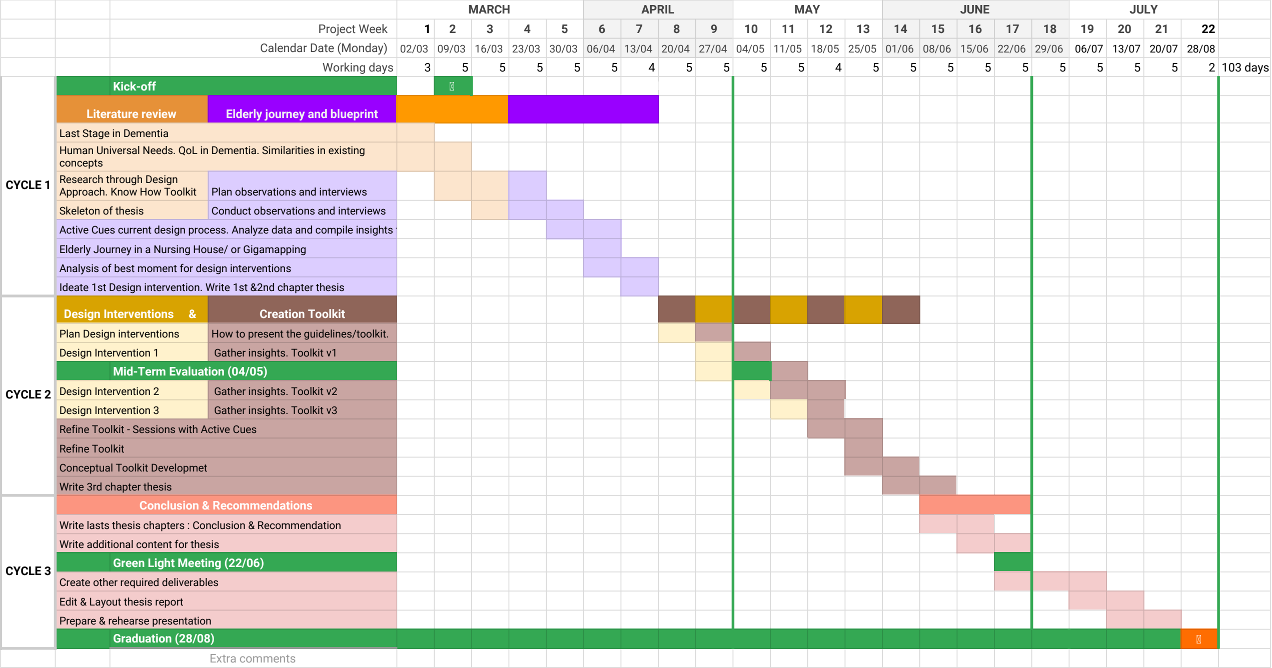
The deliverable of my graduation project will be an insightful toolkit that will serve as a support, guidance, and inspiration for Active Cues in their design research process to start closing the gap to design for happy moments for people in the last stages of dementia.

PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date 2 - 3 - 2020

28 - 8 - 2020 end date



			MARCH					APRIL				MAY				JUNE					JULY				
		Project Week	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	
		Calendar Date (Monday)	02/03	09/03	16/03	23/03	30/03	06/04	13/04	20/04	27/04	04/05	11/05	18/05	25/05	01/06	08/06	15/06	22/06	29/06	06/07	13/07	20/07	28/08	
		Working days	3	5	5	5	5	5	4	5	5	5	5	4	5	5	5	5	5	5	5	5	5	2	103 days
CYCLE 1	Kick-off			■																					
	Literature review	Elderly journey and blueprint	■	■	■	■	■	■	■																
	Last Stage in Dementia		■																						
	Human Universal Needs. QoL in Dementia. Similarities in existing concepts		■	■																					
	Research through Design Approach. Know How Toolkit	Plan observations and interviews		■	■	■																			
	Skeleton of thesis	Conduct observations and interviews			■	■	■																		
	Active Cues current design process. Analyze data and compile insights						■	■																	
	Elderly Journey in a Nursing House/ or Gigamapping							■																	
	Analysis of best moment for design interventions							■	■																
	Ideate 1st Design intervention. Write 1st &2nd chapter thesis								■																
CYCLE 2	Design Interventions &	Creation Toolkit								■	■	■	■	■	■	■									
	Plan Design interventions	How to present the guidelines/toolkit.								■	■														
	Design Intervention 1	Gather insights. Toolkit v1									■	■													
	Mid-Term Evaluation (04/05)										■	■	■												
	Design Intervention 2	Gather insights. Toolkit v2										■	■	■											
	Design Intervention 3	Gather insights. Toolkit v3											■	■											
	Refine Toolkit - Sessions with Active Cues													■	■										
	Refine Toolkit														■										
	Conceptual Toolkit Developmet														■	■									
	Write 3rd chapter thesis															■	■								
CYCLE 3	Conclusion & Recommendations																■	■	■						
	Write lasts thesis chapters : Conclusion & Recommendation																■	■							
	Write additional content for thesis																	■	■						
	Green Light Meeting (22/06)																		■						
	Create other required deliverables																		■	■	■				
	Edit & Layout thesis report																				■	■			
	Prepare & rehearse presentation																					■	■		
	Graduation (28/08)		■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	
		Extra comments																							

Milestone dates:

- KIDK-OFF ·······························> Friday 13th of March, 2020

- MIDTERM EVALUATION ····> Monday 4th of May, 2020

- GREENLIGHT ·························> Monday 22th of June, 2020

··················· Vacation in August ···················

- GRADUATION ·······················> Friday 28th of August 2020

MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, ... Stick to no more than five ambitions.

In a personal matter, my grandmother is going through the last stages of dementia, it's hard to see and understand this condition, so I want to immerse myself in this context as a process for acceptance. Also, I think it is interesting to design to bring joy to people; It gives me satisfaction to know that I can collaborate to make someone's day lighter.

On a skill level, I want to apply the gained knowledge from the masters and keep learning about understanding needs of people in their context, such as in the context mapping course, where I learned that the user is the expert in the subject you're researching. Also, I want to further develop my design research skills (literature review, interviews, observations, gather and analyzing qualitative data).

My ambition is to learn and apply a research through design approach for my graduation project. I want to strengthen my ability to develop design interventions, gather, analyze, and synthesize qualitative data and to improve my competences to turn the insights gained into a tangible deliverable: a toolkit.

REFERENCES
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4. H. Anderiesen (2017). Playful Design for Activation: Co-designing serious games for people with moderate to severe dementia to reduce apathy. https://doi.org/10.4233/uuid:ebeef0fa-46fe-4947-86c1-c765a583770a

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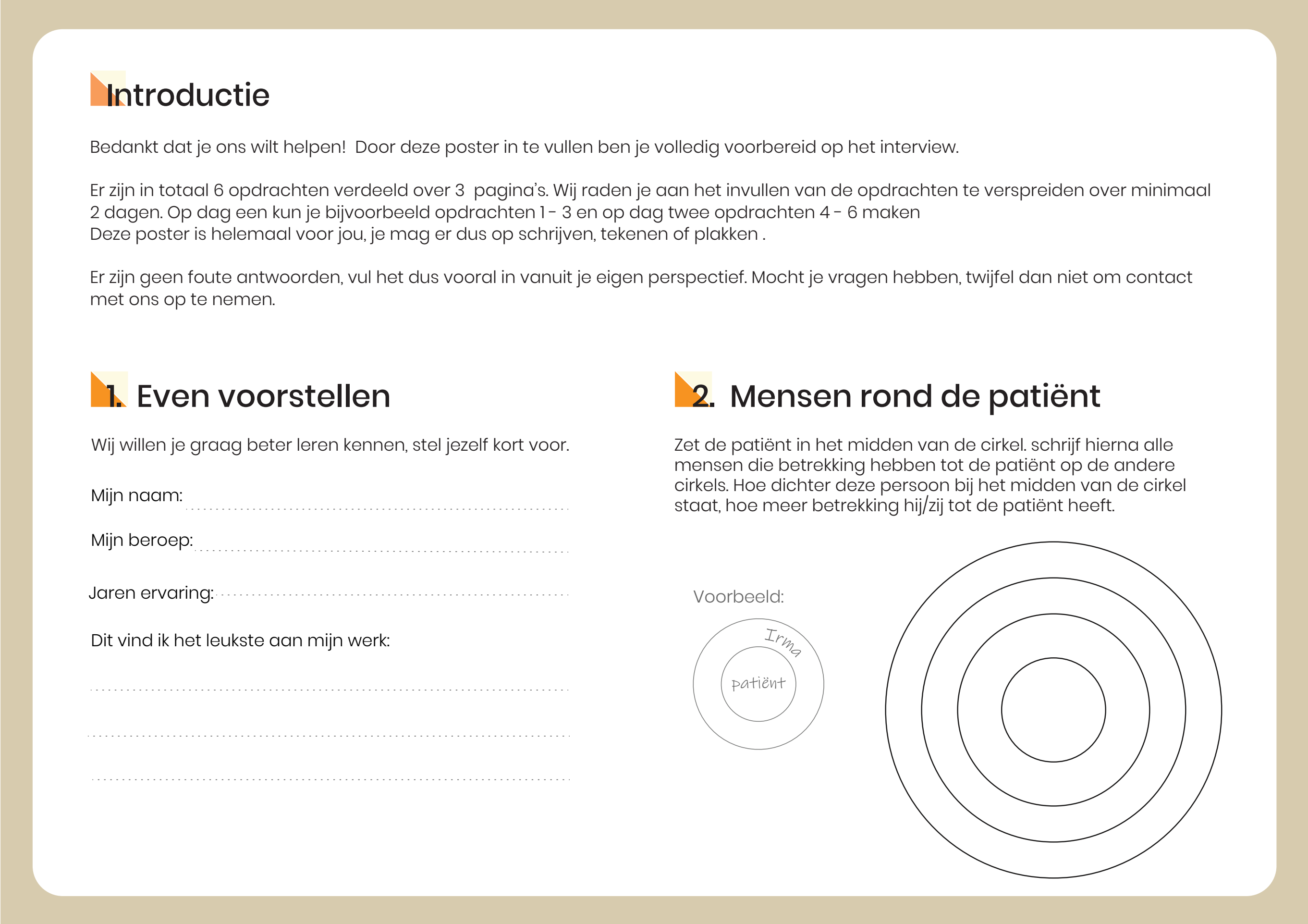
FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

Initials & Name I Diaz Couder Breceda Student number 4861477

Title of Project The Last Stages of Dementia: A Toolkit to Create Moments of Joy

Appendix B - Sensitizing material



Introductie

Bedankt dat je ons wilt helpen! Door deze poster in te vullen ben je volledig voorbereid op het interview.

Er zijn in totaal 6 opdrachten verdeeld over 3 pagina's. Wij raden je aan het invullen van de opdrachten te verspreiden over minimaal 2 dagen. Op dag een kun je bijvoorbeeld opdrachten 1 - 3 en op dag twee opdrachten 4 - 6 maken
Deze poster is helemaal voor jou, je mag er dus op schrijven, tekenen of plakken .

Er zijn geen foute antwoorden, vul het dus vooral in vanuit je eigen perspectief. Mocht je vragen hebben, twijfel dan niet om contact met ons op te nemen.

1. Even voorstellen

Wij willen je graag beter leren kennen, stel jezelf kort voor.

Mijn naam:

Mijn beroep:

Jaren ervaring:

Dit vind ik het leukste aan mijn werk:

2. Mensen rond de patiënt

Zet de patiënt in het midden van de cirkel. schrijf hierna alle mensen die betrekking hebben tot de patiënt op de andere cirkels. Hoe dichter deze persoon bij het midden van de cirkel staat, hoe meer betrekking hij/zij tot de patiënt heeft.

Voorbeeld:

3. Mijn leven als een verzorger

Schrijf en teken op de tijdlijn hoe een dag in jouw leven als verzorger er uit ziet.

Voorbeeld:

4. Moment waarderen: Positief en uitdagend

Kijk terug naar de tijdlijn. Noteer een ✧ bij ieder positief moment en een ⚐ bij ieder uitdagend moment in de tijdlijn.

5. Beredeneren

Kies de twee meest positieve en meest uitdagende momenten die in de vorige oefening zijn aangegeven. Leg uit waarom deze momenten zo fijn of uitdagend waren.

Positief

1

2

Uitdagend

1

2

6. Mijn ervaringen

Terugkijkend naar je eigen ervaringen:
Wat is een of twee memorabelen ervaring in de gehele tijd dat je in deze sector werkt?

Wat zou je graag geweten willen hebben toen je met dit werk begon?

Bedankt voor je medewerking en tot bij het interview!

Interview informal caregiver (family member):

0. Inleiden
Hoi ....
Wat fijn dat je tijd kon maken om een interview met ons te doen. Ik ben Hannah en dit is mijn mede student Ileana. Wij studeren beide design for interaction aan de TU Delft en zijn momenteel bezig met ons afstudeerproject omtrent geluksmomenten voor mensen in de laatste, bedlegerige fase van dementie.

Dit interview is onderdeel van ons onderzoek om de emotionele behoeften en de kwaliteit van leven in kaart te brengen.

Voor we aan het interview beginnen willen we je nog een aantal dingen vertellen.
Wij zijn geen experts op het gebied van Mensen met dementie, wij zien jou als de expert van je eigen ervaringen op dit gebied. Wij zijn benieuwd wat jouw ervaringen zijn. Er zijn dus geen foute of goede antwoorden.
Zoals beschreven staat in het toestemmingsformulier zal alle informatie die je ons geeft tijdens dit interview anoniem verwerkt worden.
De resultaten van het onderzoek zullen worden gedeeld in de TUDelft repository, wij en anderen willen van jouw ervaringen leren om hiermee andere mensen met dementie te kunnen helpen.
Ga je akkoord met deze voorwaarden en heb je het toestemmingsformulier ondertekend?
Dan zullen we nu beginnen met het opnemen van het interview.

Is het gelukt om de poster in te vullen? En heb je hem momenteel bij de hand.

Heb je verder nog vragen voor we aan het interview beginnen?

We zullen het interview afnemen aan de hand van de poster. We beginnen bij de eerste opdracht.

1. Voorstellen
Kun je ons vertellen wat je bij de eerste opdracht hebt ingevuld, om jezelf voor te stellen?
Naam
Ouder
Activiteit: waarom was/is dit je favoriete activiteit?

Kun je ons vertellen hoe het verzorgingstehuis waar je ouder woonde er uit zag?
Aantal mensen die er werken
Aantal bewoners
Leefomstandigheden/ ruimten

2. Mensen rond mijn ouders
Wie is het meest belangrijk geweest voor jouw ouder?
Wat heeft die persoon voor jouw ouder betekent?
Is er een persoon die weinig betrekking heeft (gehad) tot jouw ouder, maar wel een bijzondere relatie heeft (gehad) tot jouw ouder?

3. Het traject van mijn ouder
Kun je ons vertellen hoe je de tijdlijn hebt ingevuld.
Wat was de voornaamste reden om jouw ouder in het verzorgingstehuis te plaatsen?
Hoe lang heeft jouw ouder in het verzorgingstehuis gewoond?
Wat waren de voornaamste momenten in de tijd in het verzorgingstehuis?
Heeft jouw ouder een fase van bedlegerigheid meegemaakt?
Was er een speciale gebeurtenis waardoor jouw ouder op bed kwam te liggen?
Hoe was de transitie van nog mobiel te zijn, naar bedlegerig zijn?
Hoe communiceer(de) je met je ouder? Is daar een verandering in opgetreden nadat je ouder bedlegerig werd?
Waar reageerde jouw ouder positief op?
Waar reageerde jouw ouder geïrriteerd op?

5. Beredeneren
Welke 2 positieve momenten heb je uitgekozen?
Waarom waren deze momenten het meest positief?
Wat denk je dat de belangrijkste factor was voor dit positieve moment?
Welke 2 uitdagende momenten heb je uitgekozen?
Geen → en wat gebeurde er dan tijdens slechte dagen?
Waarom waren deze momenten het meest uitdagend?
Wat denk je dat de belangrijkste factor was voor dit uitdagende moment?
Wat had volgens jou dit uitdagende moment kunnen verlichten?

6. Mijn ervaringen
Wat was je meest favoriete ervaring?
Wat maakte dit je meest favoriete moment?
Wat zou je andere families in dezelfde situatie aanraden?
Waarom raadt je dit andere families aan?
Had je dit advies graag zelf gehad?

Interview Professional Caregiver:

0. Inleiden
Hoi ....
Wat fijn dat je tijd kon maken om een interview met ons te doen. Ik ben Hannah en dit is mijn mede student Ileana. Wij studeren beide design for interaction aan de TU Delft en zijn momenteel bezig met ons afstudeerproject omtrent geluksmomenten voor mensen in de laatste, bedlegerige fase van dementie.

Voor we aan het interview beginnen willen we je nog een aantal dingen vertellen.
Wij zien onszelf niet als experts op het gebied van Mensen met dementie, voor ons ben jij de expert van jouw ervaringen op dit gebied. Wij zijn benieuwd wat jouw ervaringen zijn. Er zijn dus geen foute of goede antwoorden.
Zoals beschreven staat in het toestemmingsformulier zal alle informatie die je ons geeft tijdens dit interview anoniem verwerkt worden.
De resultaten van het onderzoek zullen worden gedeeld in de TUDelft repository.

Heb je verder nog vragen voor we aan het interview beginnen?

Wij willen het interview doen aan de hand van de poster die je voor ons hebt ingevuld.

1. Voorstellen
Kun je ons vertellen wat je bij de eerste opdracht hebt ingevuld, om jezelf voor te stellen?
Naam
Beroep
Jaren ervaring
Leukste aan werk

Kun je ons vertellen hoe het verzorgingstehuis waar je werkt uit ziet?
Aantal mensen die er werken?
Aantal patiënten
Leefomstandigheden/ ruimten

2. Mensen rond de bewoner
Wie is het meest belangrijk voor de bewoner?
Wat betekent die persoon voor de bewoner?
Is er een persoon die weinig betrekking heeft op de bewoner, maar wel een belangrijke bijdrage levert aan de gemoedstoestand van de bewoner?

3. Mijn leven als een verzorger
Waarom heb je besloten om in een verzorgingstehuis te gaan werken?
Op welk moment begint jouw tijdlijn?
Hoe ziet de verzorging van een bewoner uit? Wat voor zorg hebben ze nodig?
Wat zou je nooit doen tijdens de verzorging van een bewoner?
Wat is je meest waardevolle activiteit?
Wat was de voornaamste reden om mensen in het verzorgingstehuis te plaatsen?

Bedlegerigheids fase
Kun je omschrijven hoe het voor iemand is om op bed te liggen in de laatste fase?
Hoe ziet hun dag er uit?

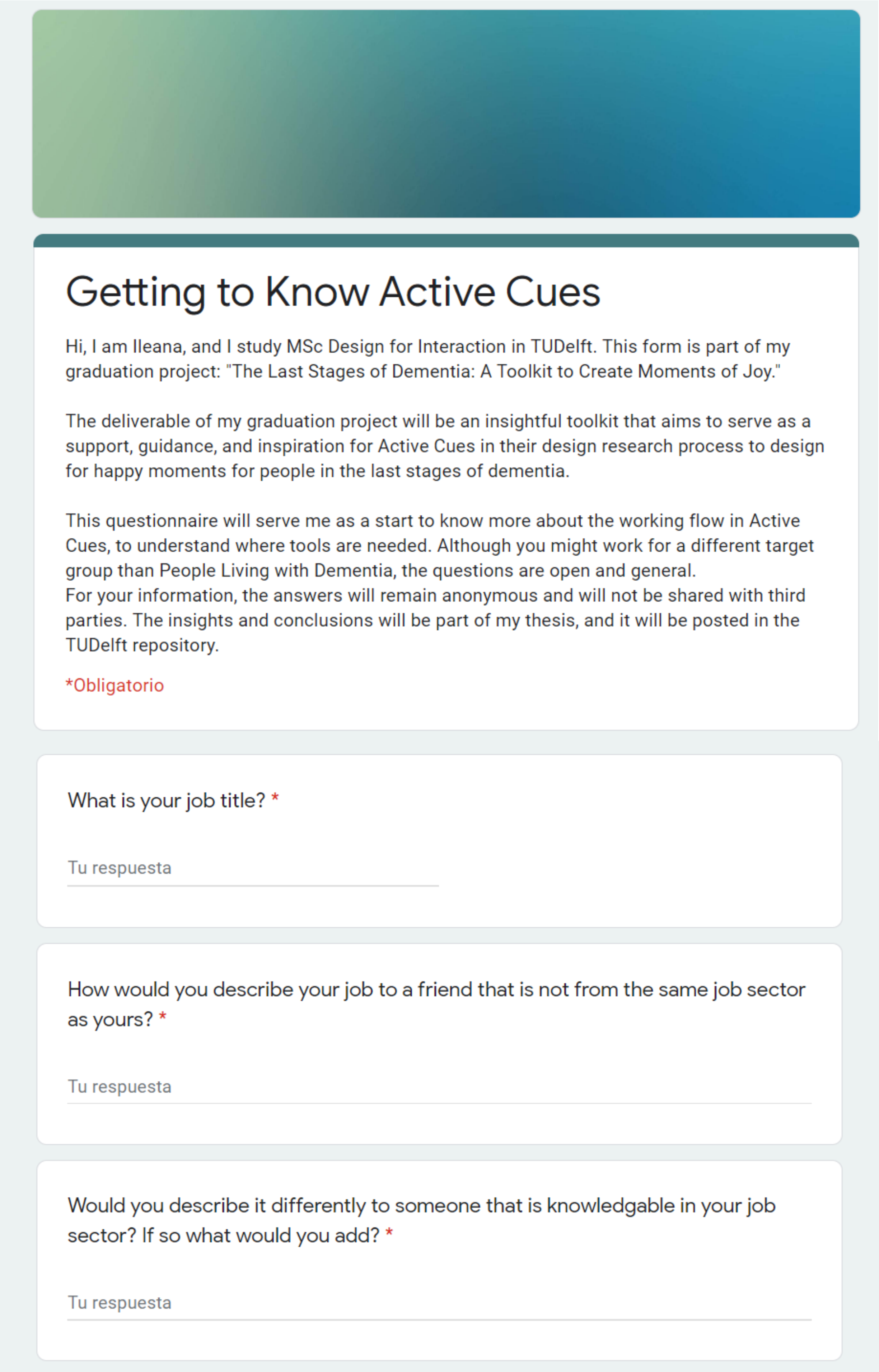
Wat is de hoogtepunt van hun dag?
Wat voor activiteiten doe je om de bewoner heen?
Hoe communiceer(de) je met een bewoner?
Waar reageert een bewoner positief op?
Waar reageert een bewoner geïrriteerd op?

Hoe gaan jullie momenteel met de corona maatregelen om?

5. Beredeneren
Welke 2 positieve momenten heb je uitgekozen?
Waarom waren deze momenten het meest positief?
Wat denk je dat de belangrijkste factor was voor dit positieve moment?
Welke 2 uitdagende momenten heb je uitgekozen?
Waarom waren deze momenten het meest uitdagend?
Wat denk je dat de belangrijkste factor was voor dit uitdagende moment?
Wat had volgens jou dit uitdagende moment kunnen verlichten?

6. Mijn ervaringen
Wat is jouw meest memorabele ervaring in de gehele tijd dat je in deze sector werkt?
Wat maakte dit je meest memorabele ervaring?
Wat zou je graag geweten willen hebben toen je met dit werk begon?
Waarom had je dit graag willen weten?
Zou je dit als advies geven aan mensen die nu beginnen met werken in deze sector?

Appendix D - Questionnaire via google forms for Active Cues



Getting to Know Active Cues

Hi, I am Ileana, and I study MSc Design for Interaction in TUDelft. This form is part of my graduation project: "The Last Stages of Dementia: A Toolkit to Create Moments of Joy."

The deliverable of my graduation project will be an insightful toolkit that aims to serve as a support, guidance, and inspiration for Active Cues in their design research process to design for happy moments for people in the last stages of dementia.

This questionnaire will serve me as a start to know more about the working flow in Active Cues, to understand where tools are needed. Although you might work for a different target group than People Living with Dementia, the questions are open and general.
For your information, the answers will remain anonymous and will not be shared with third parties. The insights and conclusions will be part of my thesis, and it will be posted in the TUDelft repository.

*Obligatorio

What is your job title? *

Tu respuesta

How would you describe your job to a friend that is not from the same job sector as yours? *

Tu respuesta

Would you describe it differently to someone that is knowledgable in your job sector? If so what would you add? *

Tu respuesta

What do you like about your job the most? *

Tu respuesta

If you could change something about your work, what would it be? *

Tu respuesta

With how many people do you work closely with? *

Tu respuesta

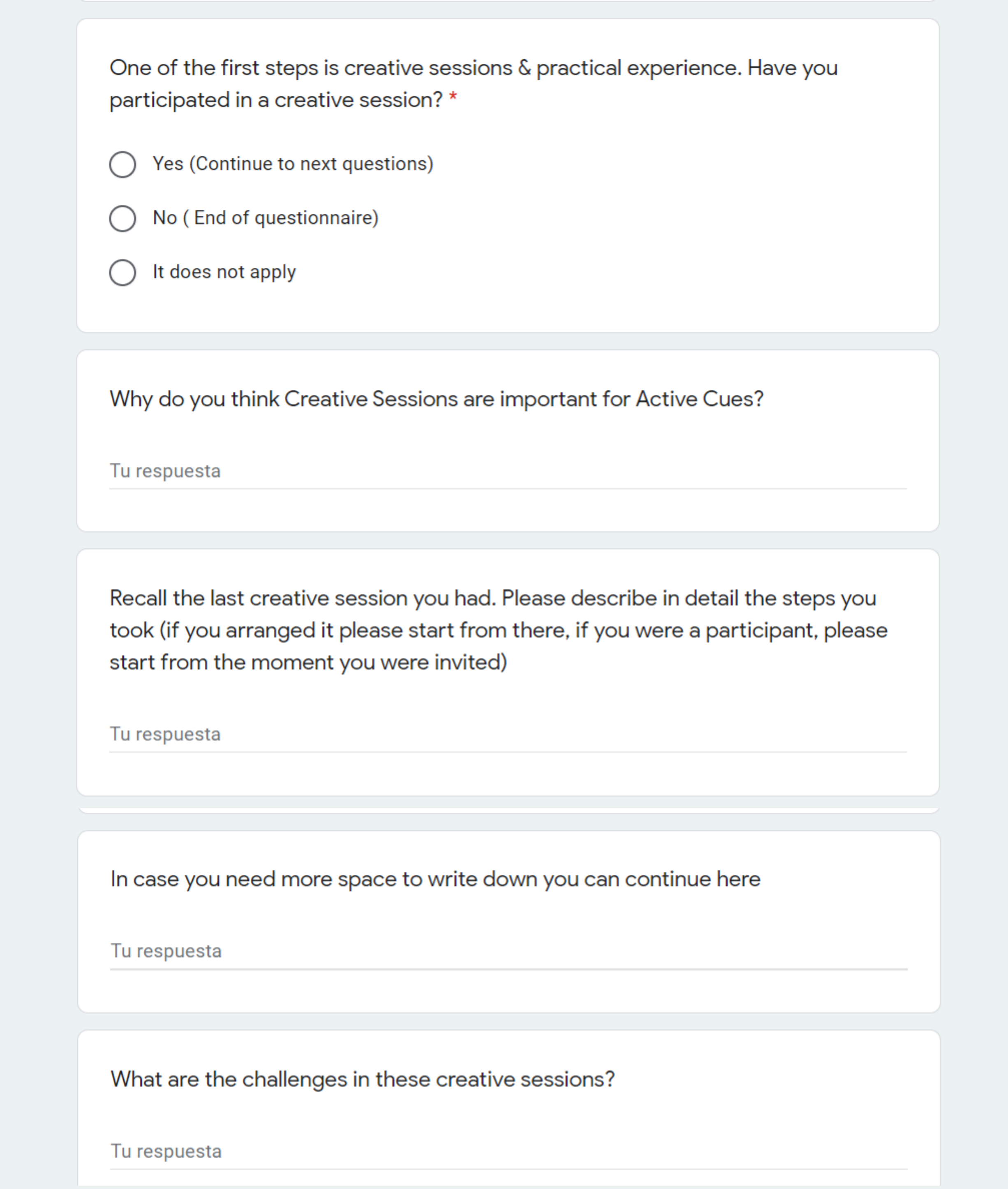
How do their job compliment yours? *

Tu respuesta

Game development in co-design

This image below visualizes the process of game development in co-design

Game development in co-design



One of the first steps is creative sessions & practical experience. Have you participated in a creative session? *

○ Yes (Continue to next questions)

○ No (End of questionnaire)

○ It does not apply

Why do you think Creative Sessions are important for Active Cues?

Tu respuesta

Recall the last creative session you had. Please describe in detail the steps you took (if you arranged it please start from there, if you were a participant, please start from the moment you were invited)

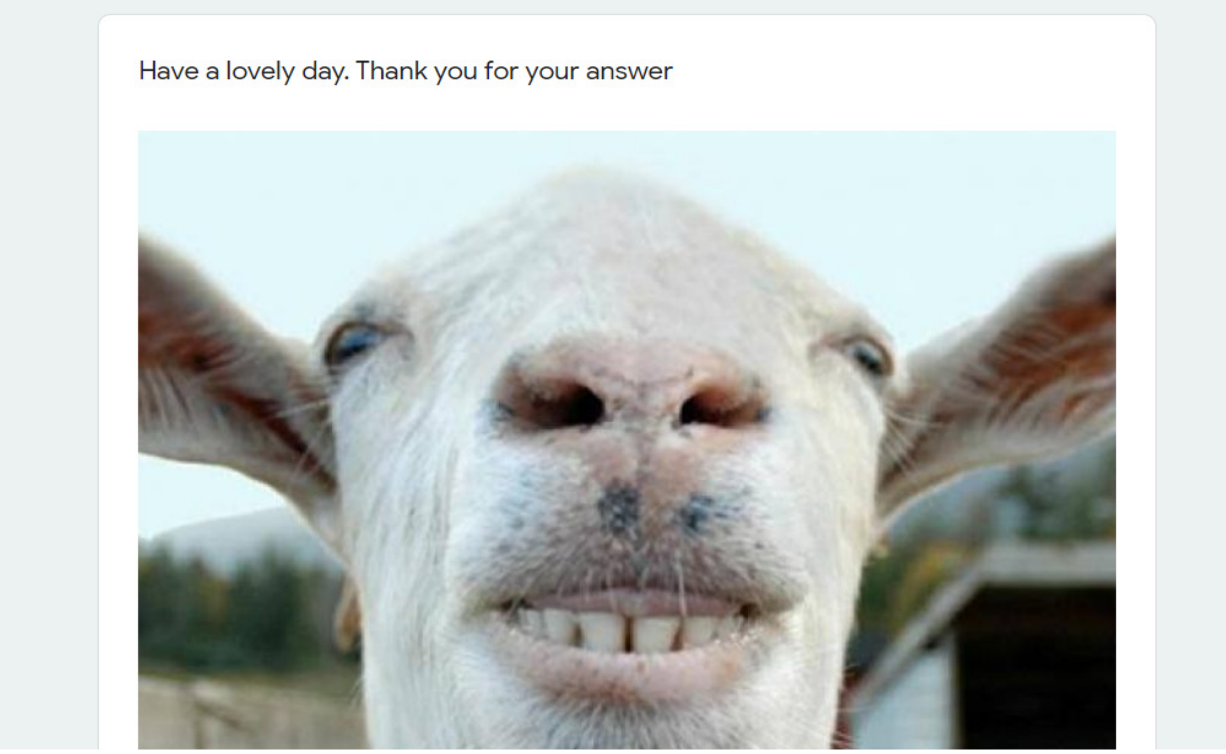
Tu respuesta

In case you need more space to write down you can continue here

Tu respuesta

What are the challenges in these creative sessions?

Tu respuesta



Have a lovely day. Thank you for your answer

Appendix E - Digital cultural Probe testing setup

TEST PLAN

Research questions

Willingness to collaborate

1. Are participants comfortable to collaborate?
1.1 What makes them comfortable/uncomfortable?
2. Are participants enthusiastic about the collaboration?
-2.1 What makes them enthusiastic or apathetic?

Expectations and Concerns

3. What motivates participants to collaborate?
3.1 What demotivates participants?
4. Do participants have expectations from Active Cues? and what do they expect?

Clarity

5. Do participants understand how collaboration works?
6. Are the provided instructions in the platform clear?

Previous to the user test
Send an email with:
Thanking and explaining what is the test about
Time and Zoom link
Send a consent form

During test

Introduction

“Thank you for helping me to continue with my graduation project, I really appreciate it. I am working together with Active Cues, a company that create moments of happiness in residential care. They have a product called the TovertaTafel. With this test, I want to start assessing the idea that I am developing and that I will explain shortly. For you to know the test will take around 45 min and I will ask you to have your cell phone handy because we will use it during the test.
Do you have any questions up until now?

…did you have the time to check the consent form?
You can send a picture to my email later (if they haven’t)

I will start recording

Context

So before we start with the test I want to give you some context about the project. As I men-

tioned before this project is in collaboration with Active Cues. They design for people with dementia and have a product called the ToverTafel.
This company involve their users, in this case PwD while designing. The way to co-design with PwD is with the help of professional caregivers from the nursing houses.

After the analysis of my project what I am proposing to the company is to also involve family members to collaborate while they design, because family members are also caregivers.

And the way I am proposing to involve family members is through an online platform.

So the test consists of three parts:

- First you will receive a text with a link
- Then you will take part in a collaboration survey
- Third part is a short interview to know how things went

During the whole test, please try to think out loud so I can follow your thought process. If you have questions, you can ask them at any time"

Text
Remember to have your phone handy because we will need it for the test

Send the link via whatsapp- Register: https://tinyurl.com/y7n9q4m5
Please go to the link I sent you via whatsapp

Collaboration survey
"You would receive this SMS whenever Active Cues has a new research theme

* Participant goes through the collaboration survey *

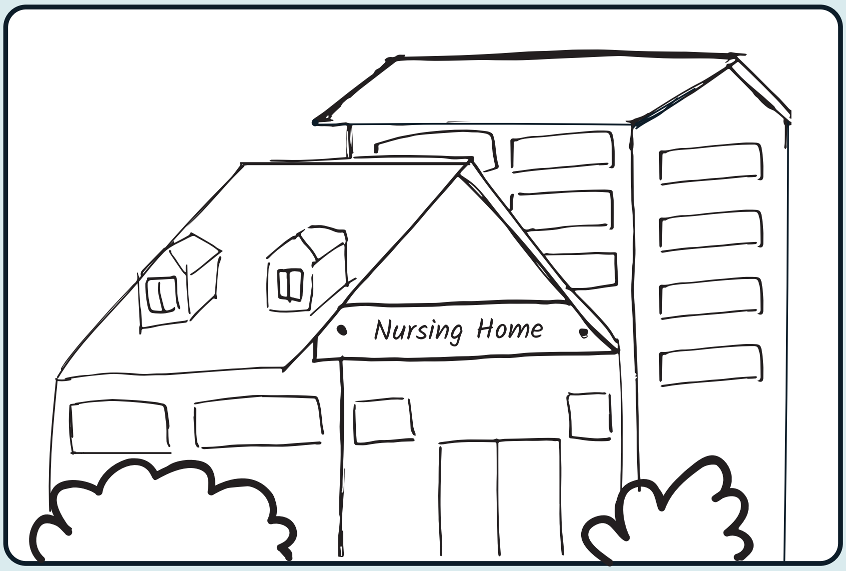
We are done with the second part and we will move forward to the last part now with the test and the next part is for you to assess how things went

Overall experience
Now I would like you to assess how everything went

What is your first impression of this format of collaboration?
What do you think about the length of the collaboration survey?
Would you be willing to participate in such collaboration?
Why?
From 1 to 5 how comfortable were you in the survey collaboration
Why?
From 1 to 5 how clear were the provided instructions
What was clear/unclear?
In the scenario that this company is partnered with the nursing house in which your loved one lived and you were to collaborate, what expectations would you have from this company?

Appendix F - Storyboards used for co-creation sessions

Challenging scenario



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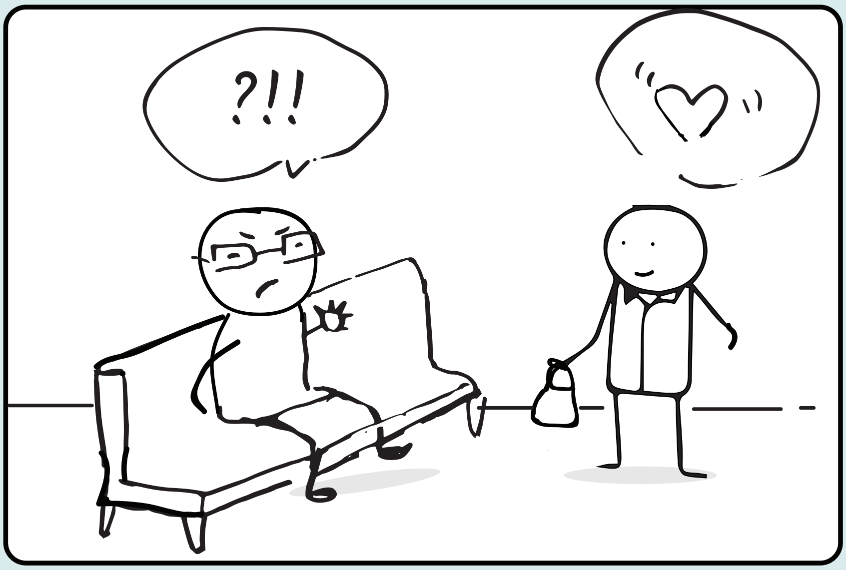

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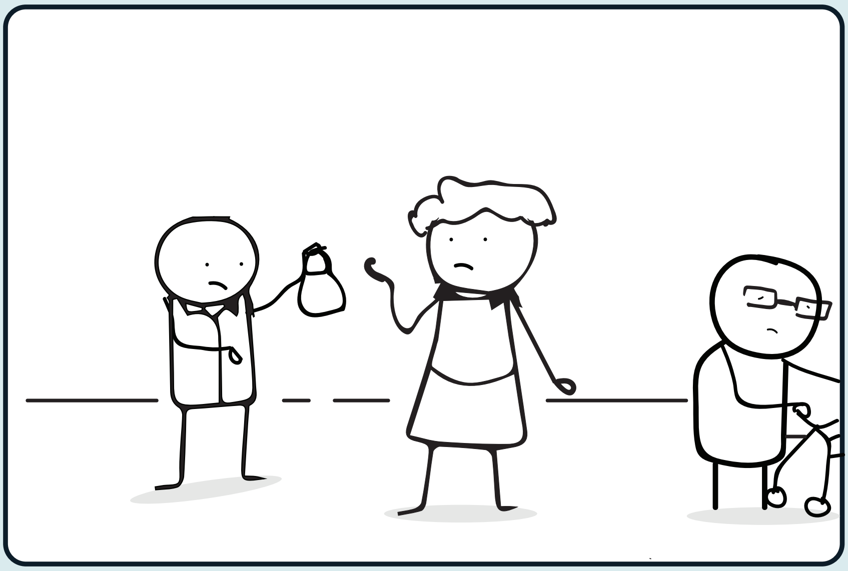

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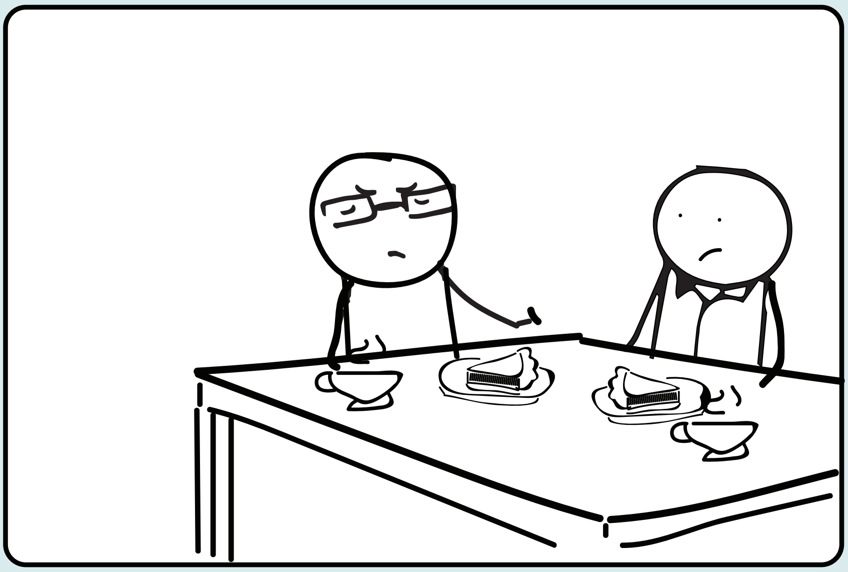

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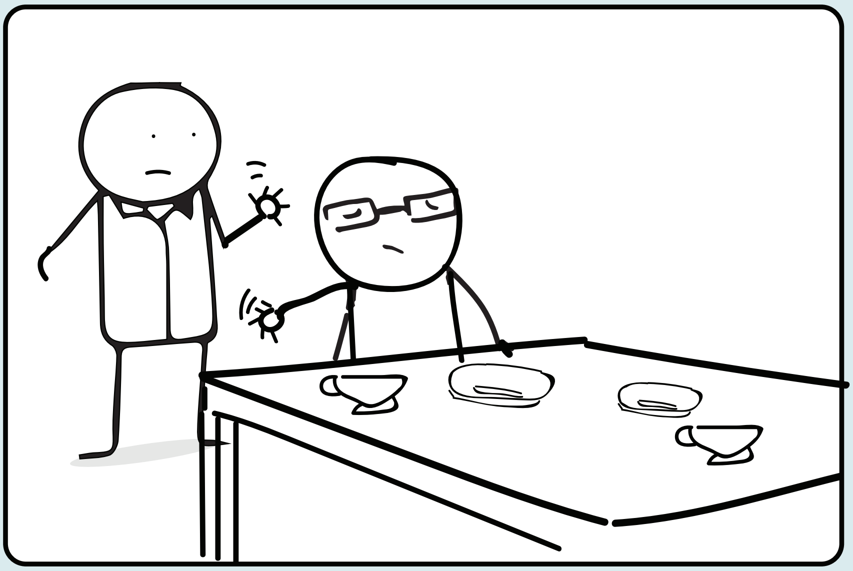

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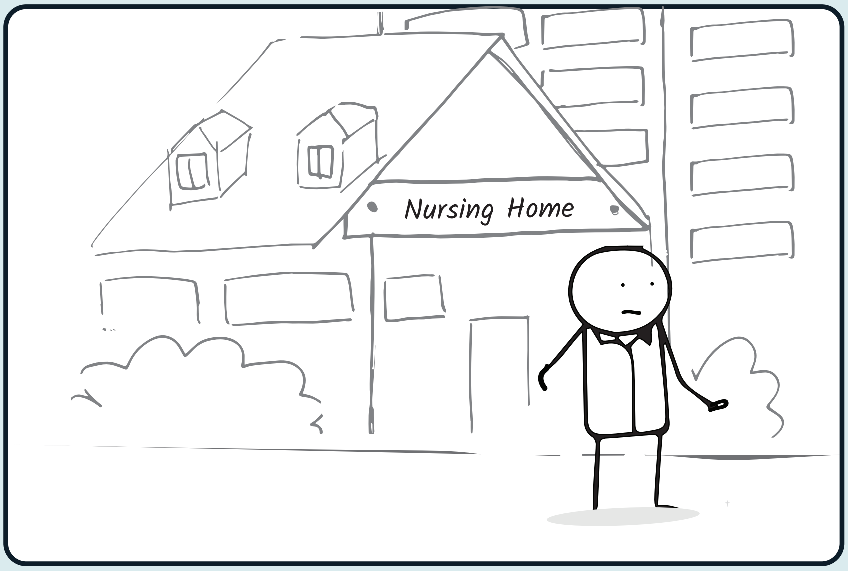

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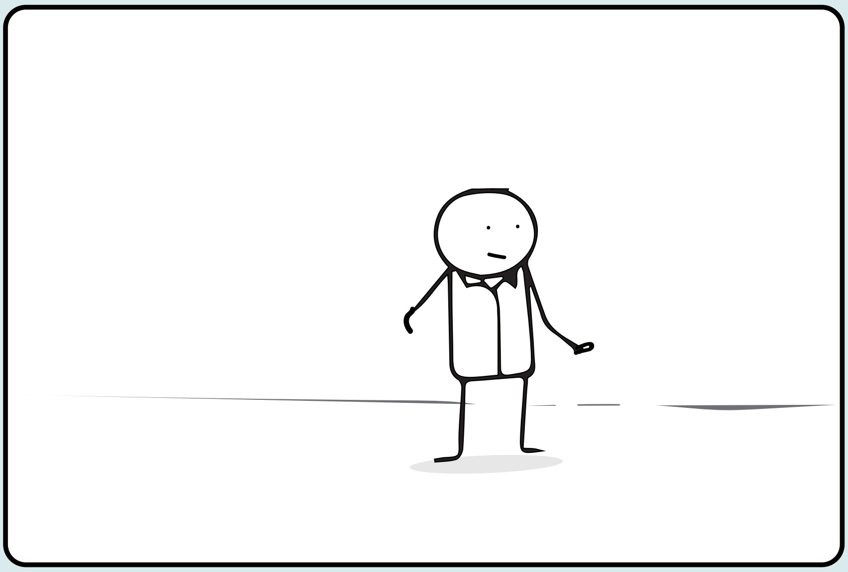

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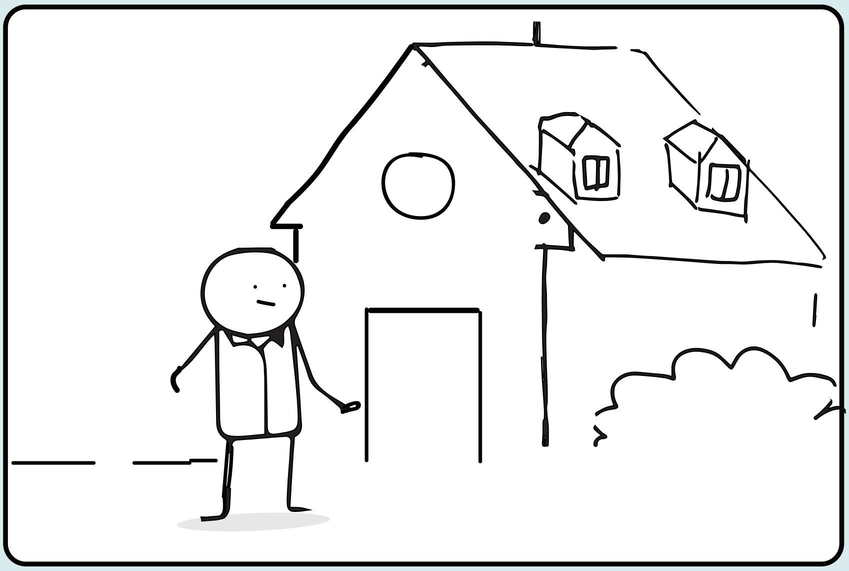

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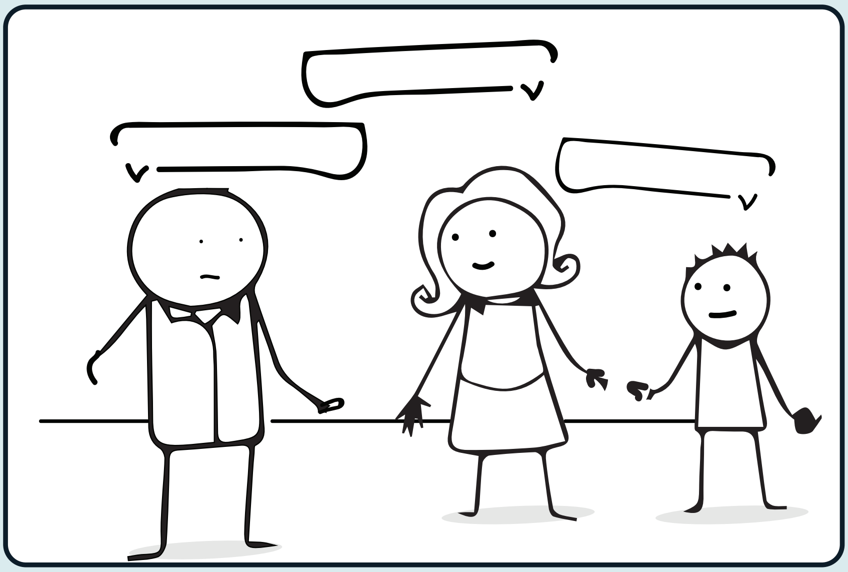

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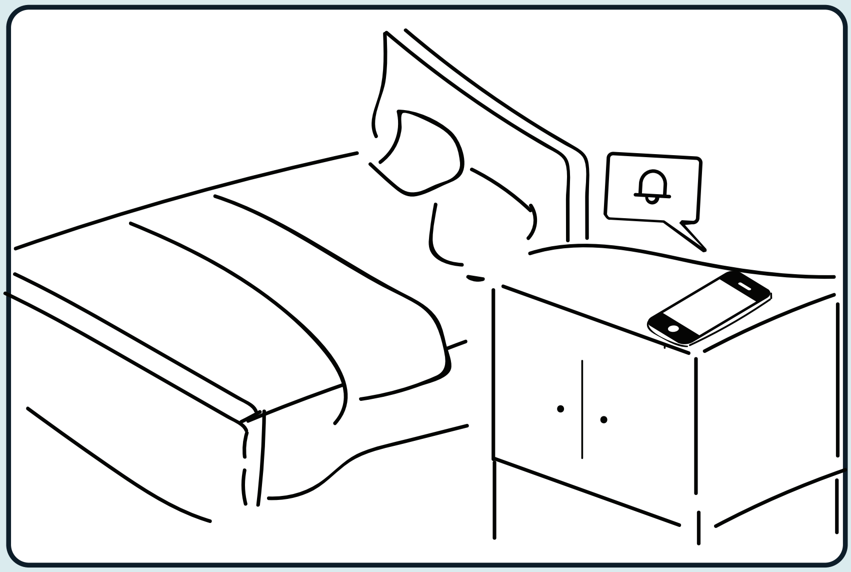

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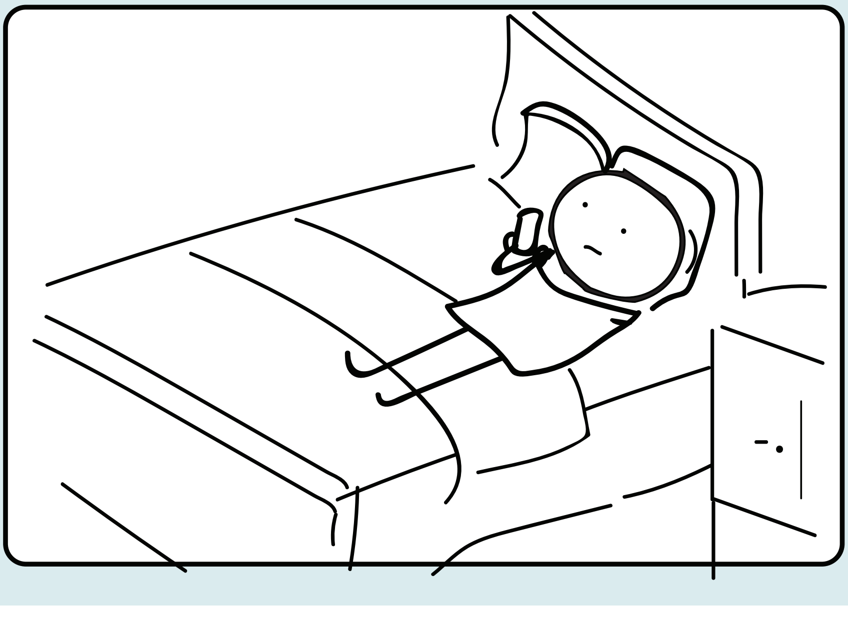

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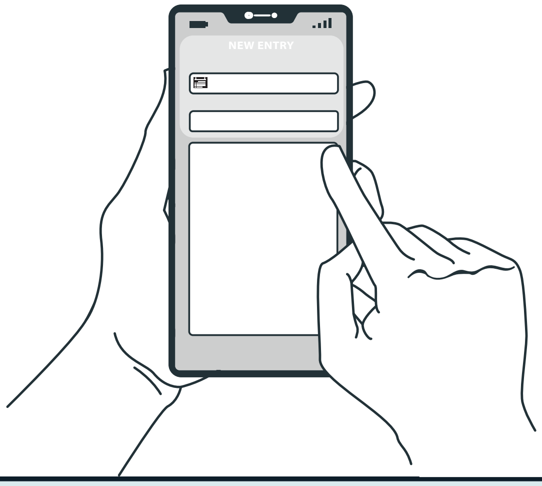

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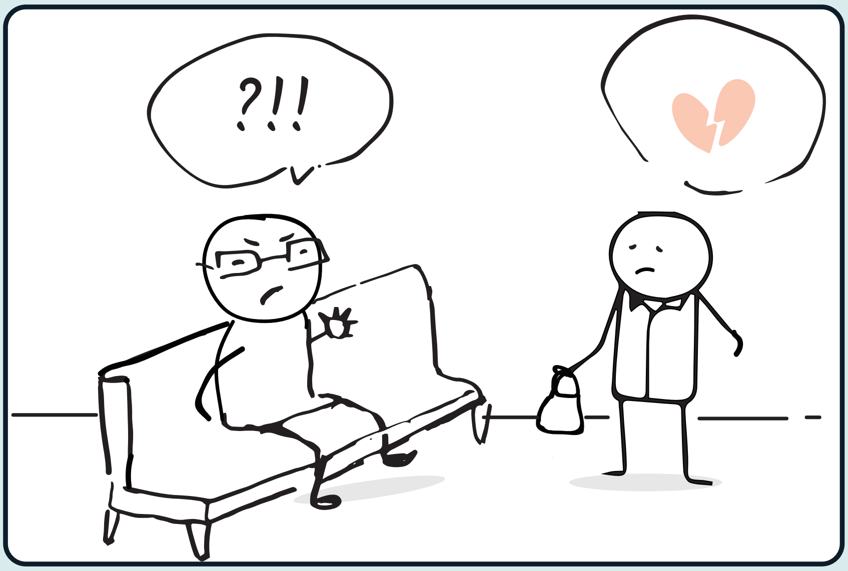

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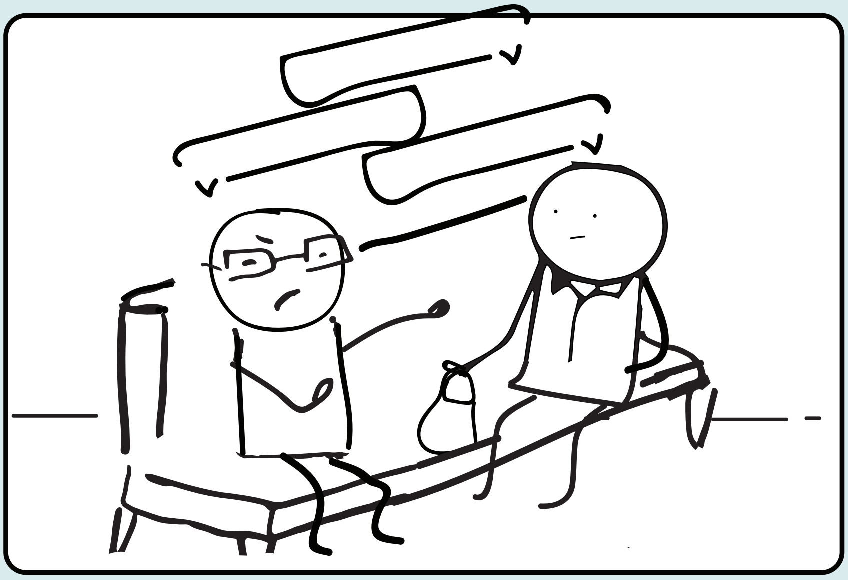

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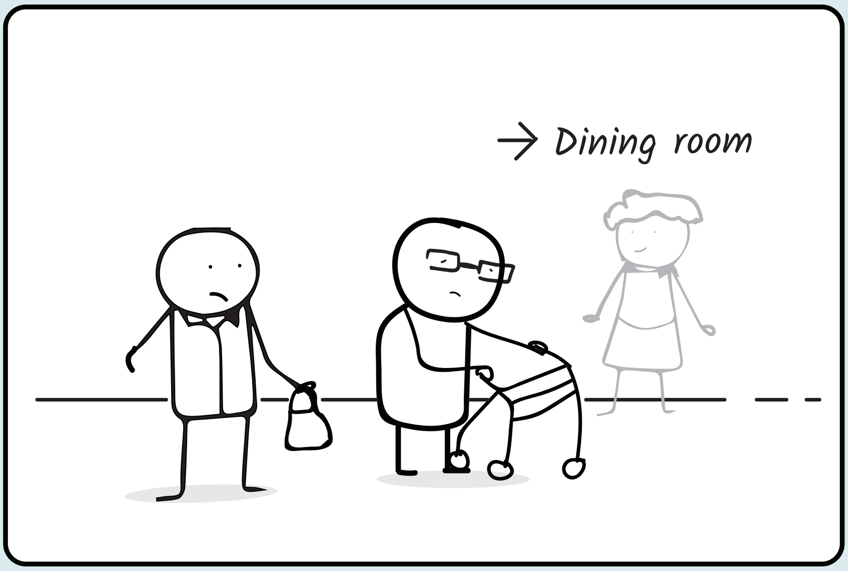

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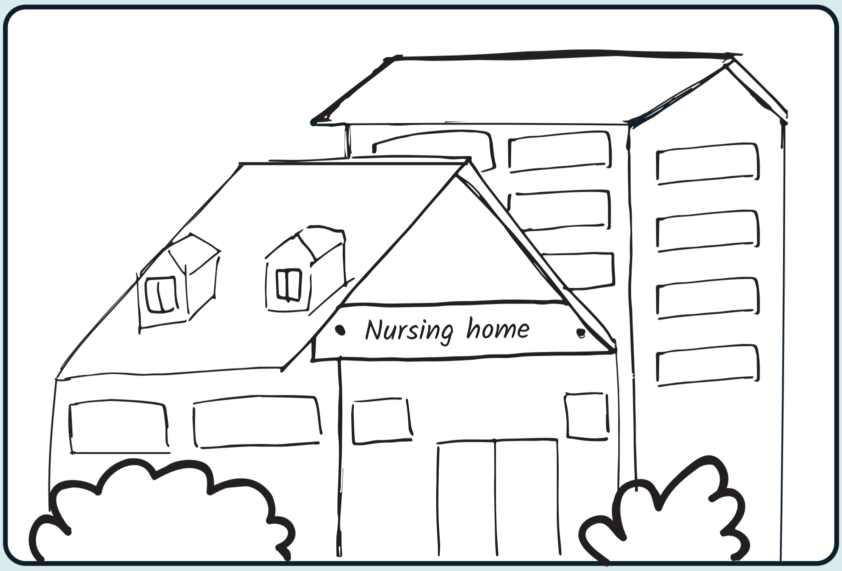
Positive scenario



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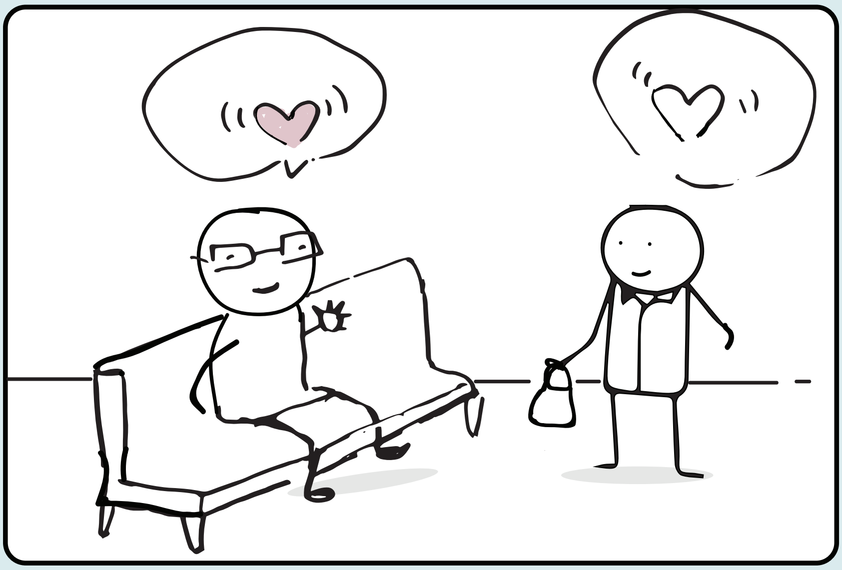

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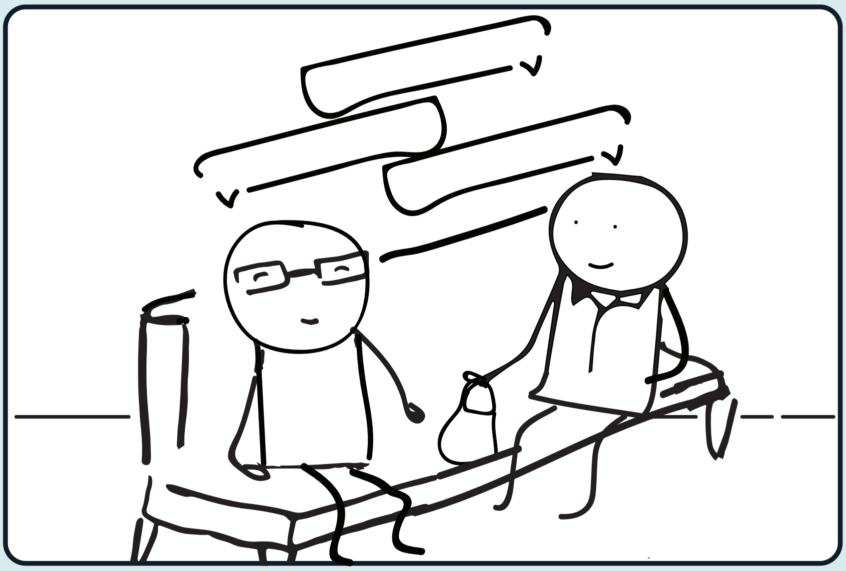

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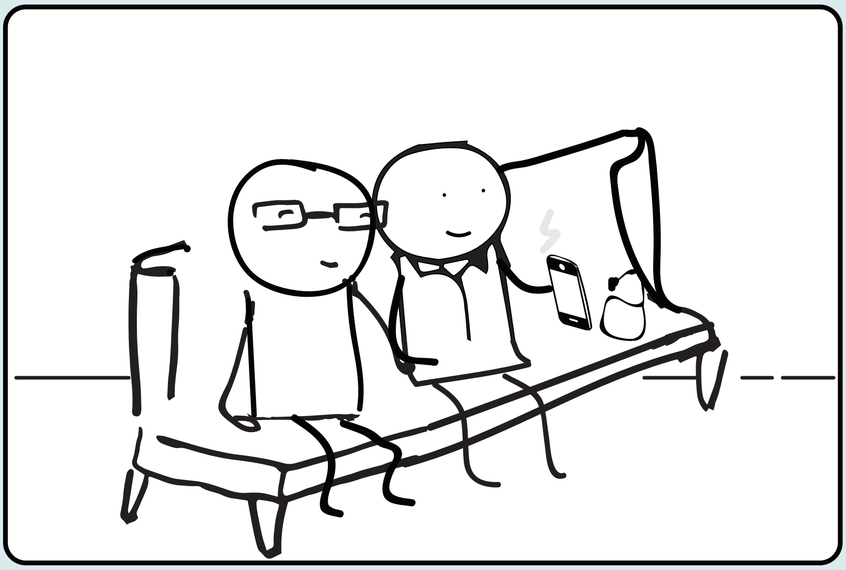

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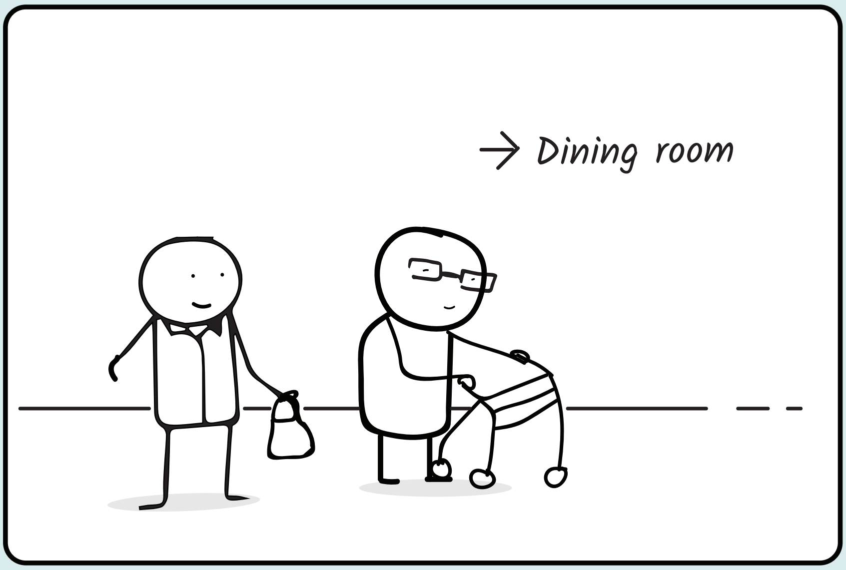

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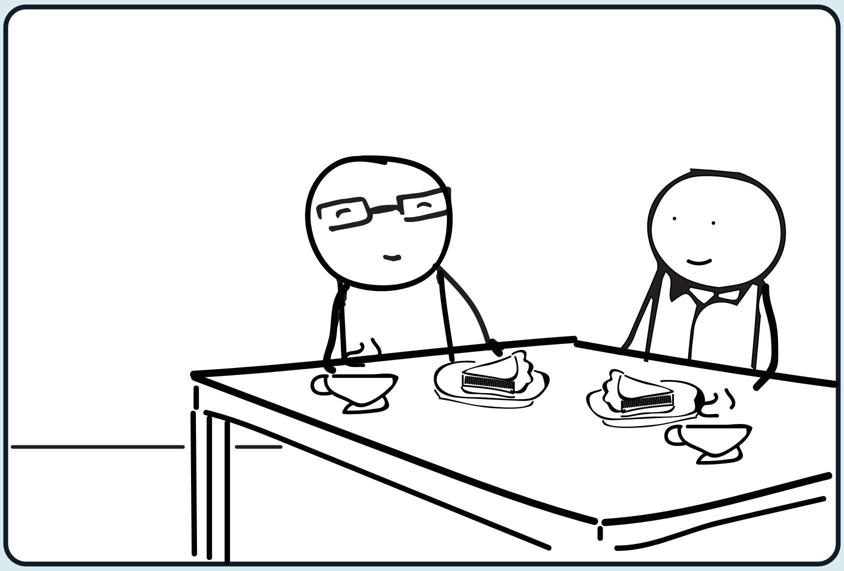

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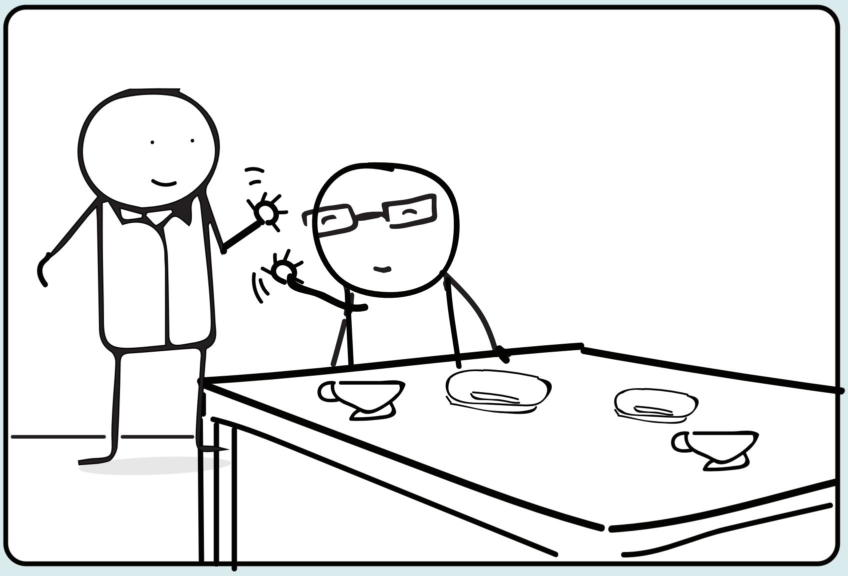

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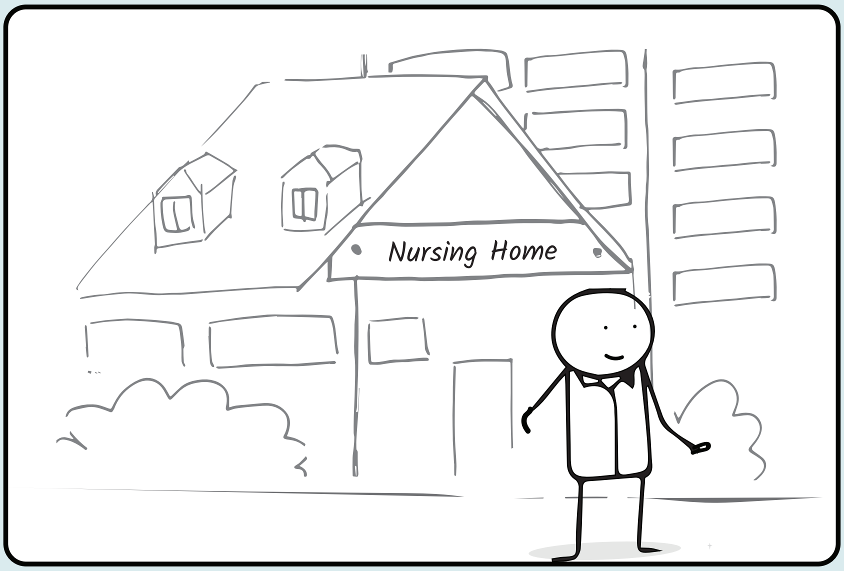

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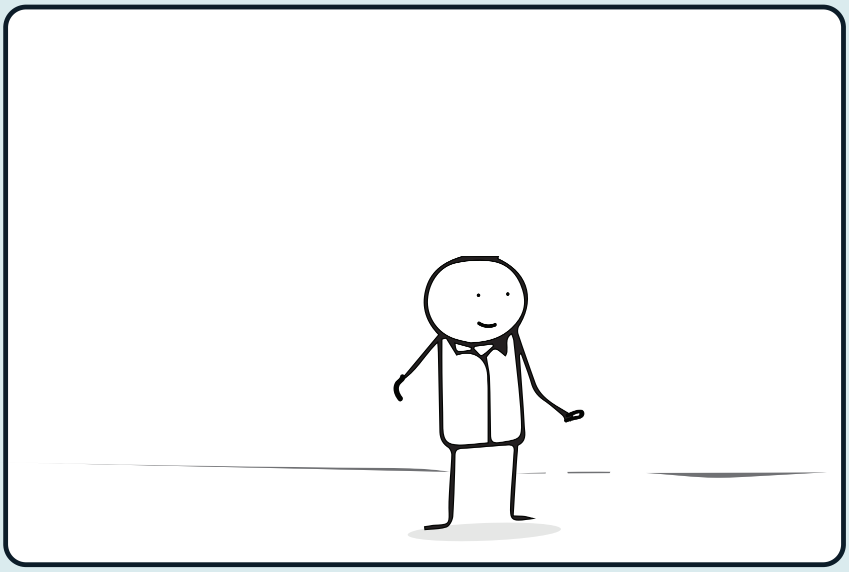

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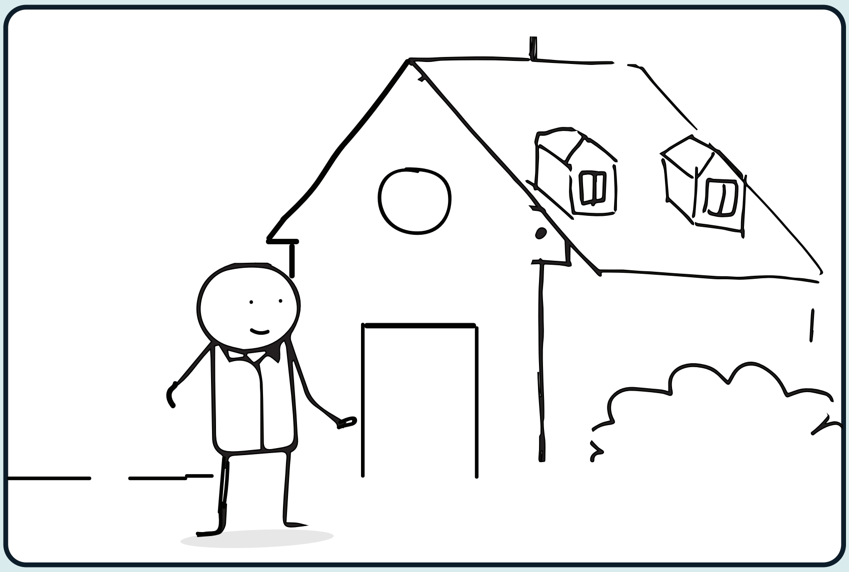

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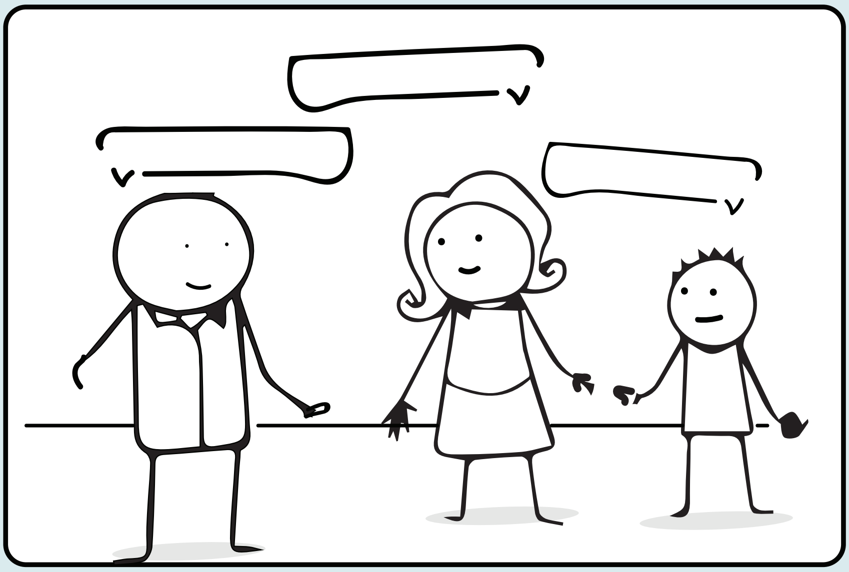

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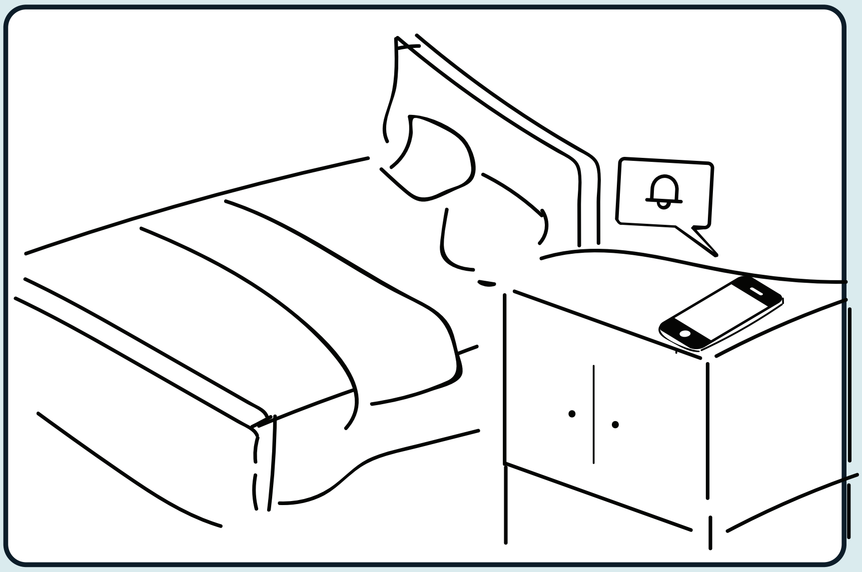

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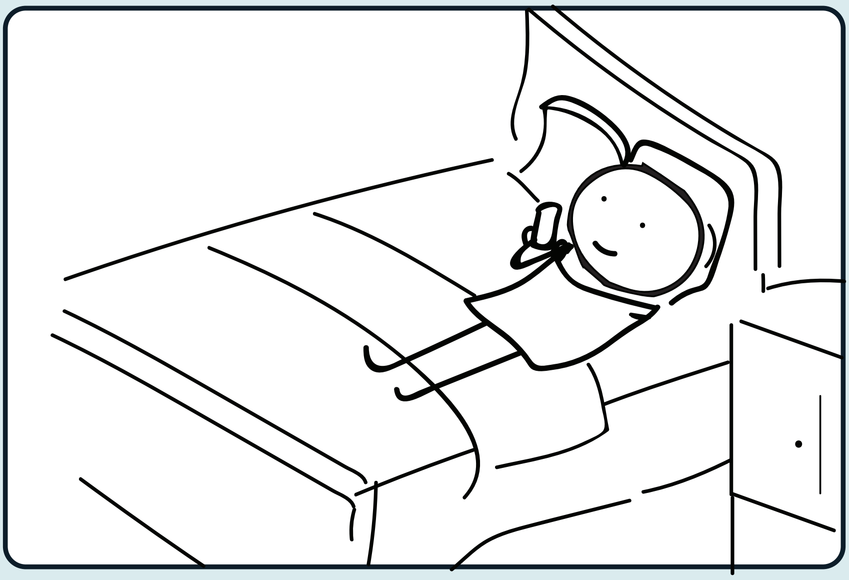

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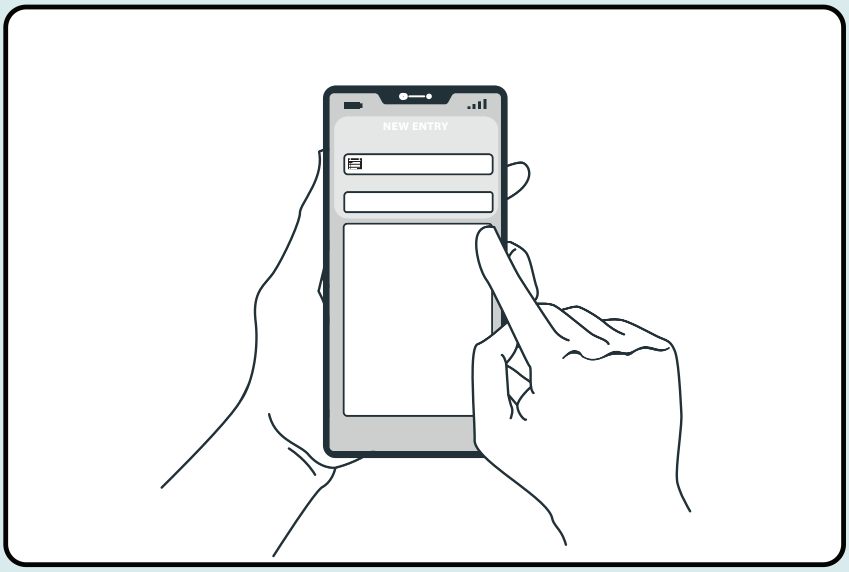

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Appendix G - Co-creation session breakdown

Session breakdown

The session consist of three parts:

- Collage making
- Storyboard imagining use of app
- Showing sketched screens

Collage making

Goal: Get app qualities and values to experience
Duration 20 min

We will make a collage, one the participant and one myself with the question:

- Which characteristics have someone that accompanies you in good and bad moments?

Think of how they look, how they make you feel and how they act

We will explain each other the collages to understand the values behind

Storyboard. Imagining use

Goal: Uncovering imagined functions
Duration 40 min

The storyboards have characters' thoughts, expressions and dialogue. But the storyline is empty. People will be asked to fill the storyline and describe what is happening and how they imagine the app works.

The storyboard shows 2 scenarios of use:

- One is a positive situation after visiting your loved one in the nursing house, a bright day.
- The second situation is a challenging one, a not-so-good day after visiting your loved one.

Then I ask to go back to the spoken characteristics of the collage. We review them together.
Then I ask:
How do you imagine the journal app could work with these characteristics?

Showing first screens

Goal: Get direct input on first screen ideas
Duration 30 min

Main features:
new journal entry
- Besides writing what do you imagine in the app?

Getting a notification or nudge after visiting the nursing house
- Would you like to be able to set the time the notification appears?

Sharing notes with AC
- How could you imagine sharing notes with AC

Appendix H - Evaluation Plan

Goals of the concept

The goals of the concept are e to provide a space for informal caregivers to decompress, reflect about one's feelings and connect with others.

Evaluation Criteria and Questions

A number of sub-goals have been identified based on the design goal and design requirements of the concept, along with evaluation research questions for each.

Clarity
- What do participants think about the concept?
- Would they use such a service?
- Do participants see the relevance of the concept?

Prudent
- Do users feel intimidated by the reminders?
- Do reminders encourage users to journal?
- Do users feel free to share their thoughts?

Reflection
- Did using the concept bring up to observe their feelings ?
- Do users share stories without a notification?

Light hearted interaction
- Does the concept provide a pleasant interaction?
- Do users enjoy writing their notes, stories and thoughts?

Method

Two different tests:
1. Interaction with the reminders and
2. Storyboard review sessions

Interaction test

Since the concept is inspired by having conversations with yourself and the UI simulates a chat-like app, the tests will be carried out via whatsapp. First it is explained by video-calling individually with each of the informal caregivers the goals of the testing and the concept along with the app screens:
"The app would be facilitated by Active Cues to the informal caregivers of nursing houses that have a tovertafel. It has two functions:
It provides is a space for informal caregivers to decompress, reflect about one's feelings and connect with others by journaling, and
To generate valuable insights for Active Cues."

Later it will be asked when they visit their loved one to be able to act as the notifications to remind people to journal and to also share stories of their loved one.

It was also told that they could share a story that came up to their mind if they felt like doing so.

After the informal caregiver visits their parent in aprox 2-3 times in 9 days the following question will be asked: How was the visit to your parent today?

During one of the days that the informal caregiver is not visiting their parent the question: In the past, what could your loved one talk about non-stop?

After the test a semi-structured interview is carried out with the following research questions:
- How was the experience overall?
- How did you feel with the reminder?
- What did you like the most? Why?
- What did you like the least? Why?

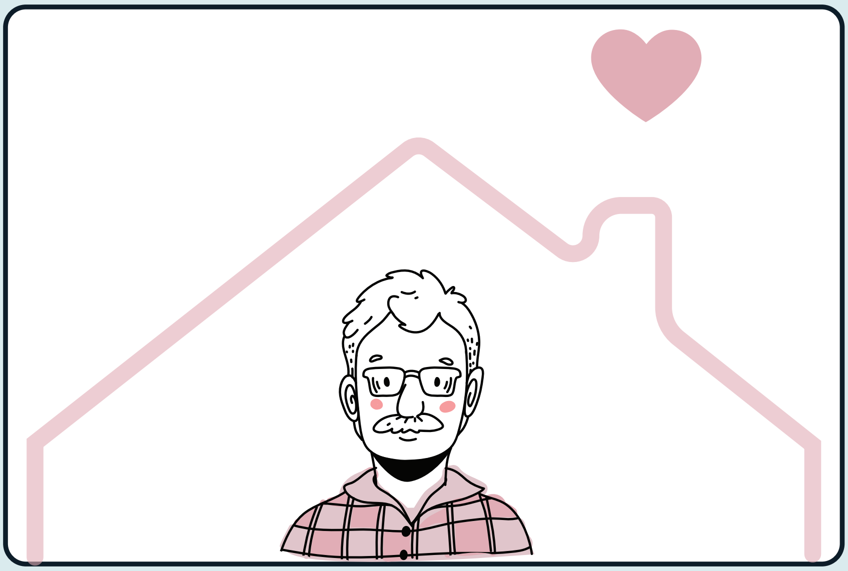
2. Storyboard review sessions

First the storyboard will be send to each of the participants for them to see it at their own pace. Then, a video call will be set to discuss the storyboard further through semi-structured interviews.

Script for interview after seeing storyboard

- Can you tell me what you see in the storyboard?
- Was everything clear?
- Would you use such service? Why?
- How would you feel if you were Gus?
- Have you been in this situation?

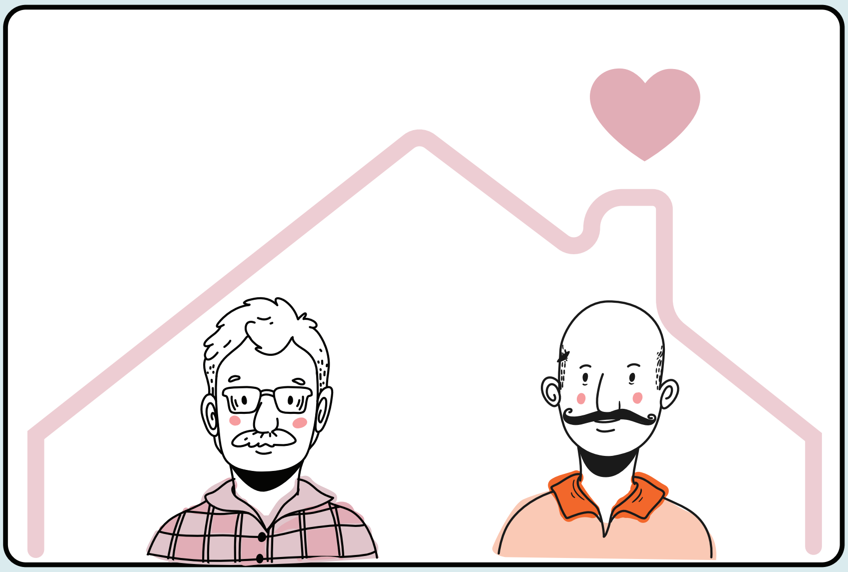
Appendix I - Storyboard for concept review sessions



Meet Vincent

He has dementia, and he moved three months ago to the nursing house: ExtendCare

1

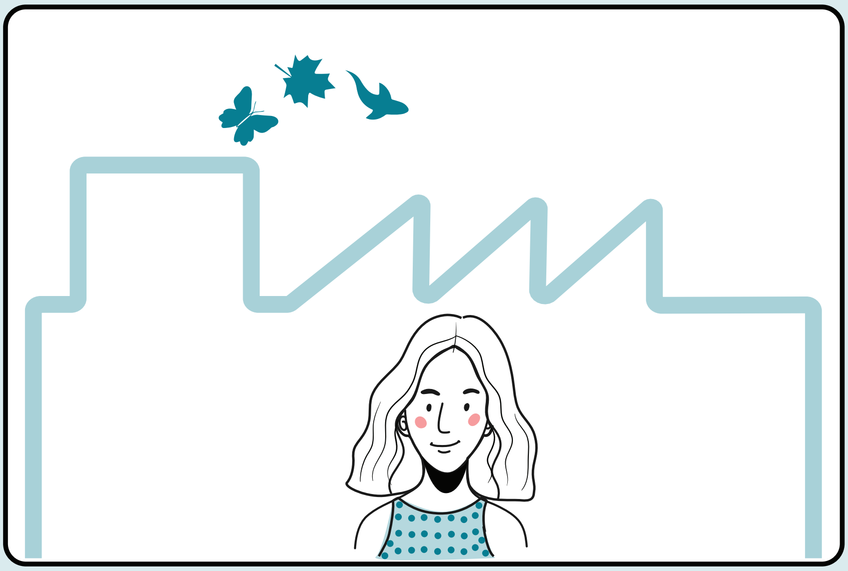


Meet Gus

He is the son of Vincent and also his informal caregiver.

Gus visits his dad once a week

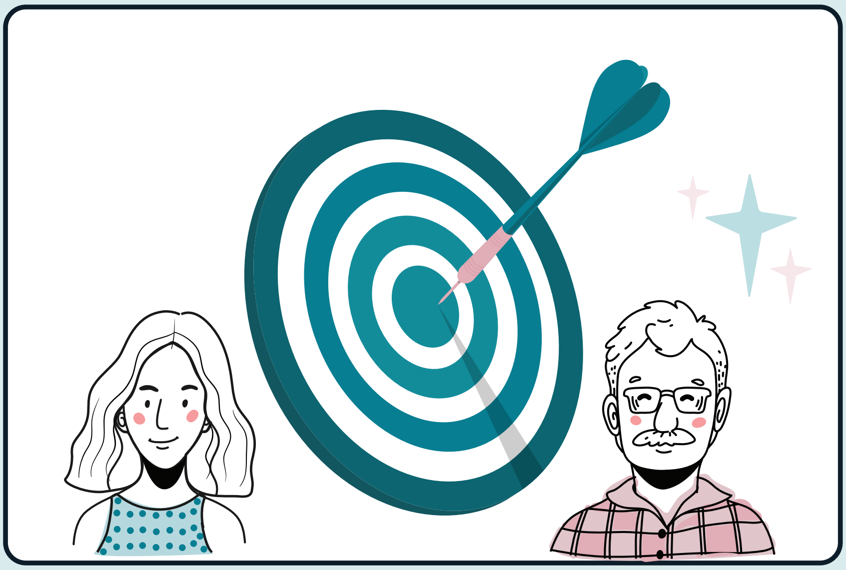
2



Meet Tina

She works at Active Cues, an organization that creates moments of happiness in residential care.

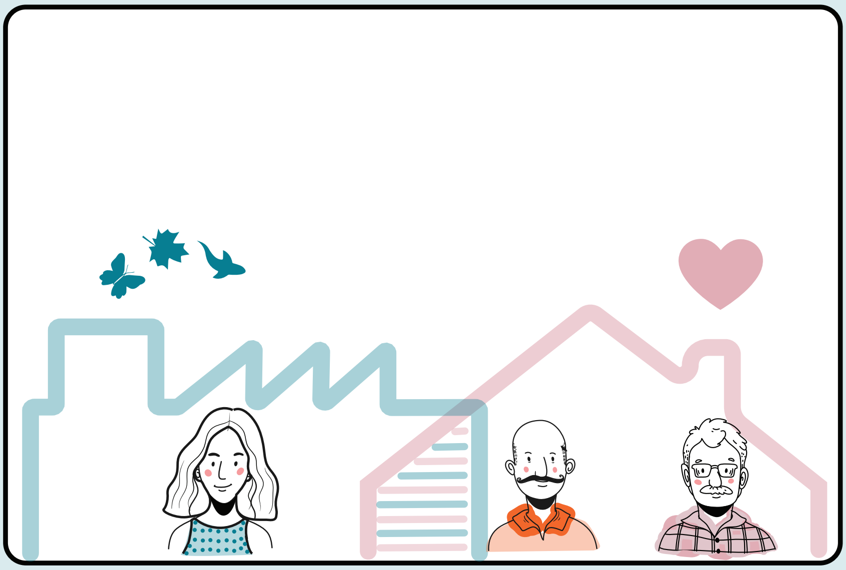
3



Active Cues ultimate goal is to improve the quality of life of people wiht dementia..

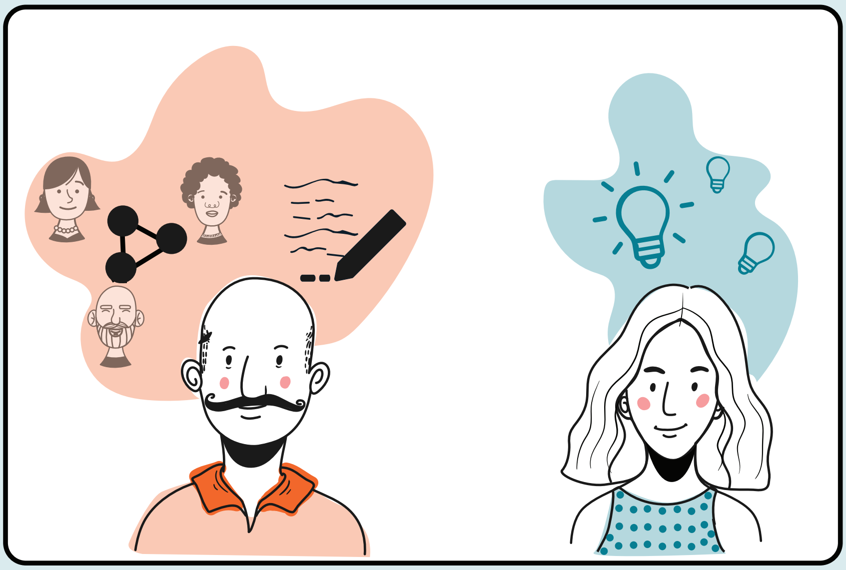
They do so by designing user-centered games for the ToverTafel -an interactive audiovisual experience that triggers people with dementia to move, play and socialize -

4



Active Cues offers a digital service, Praati, for informal caregivers like Gus.

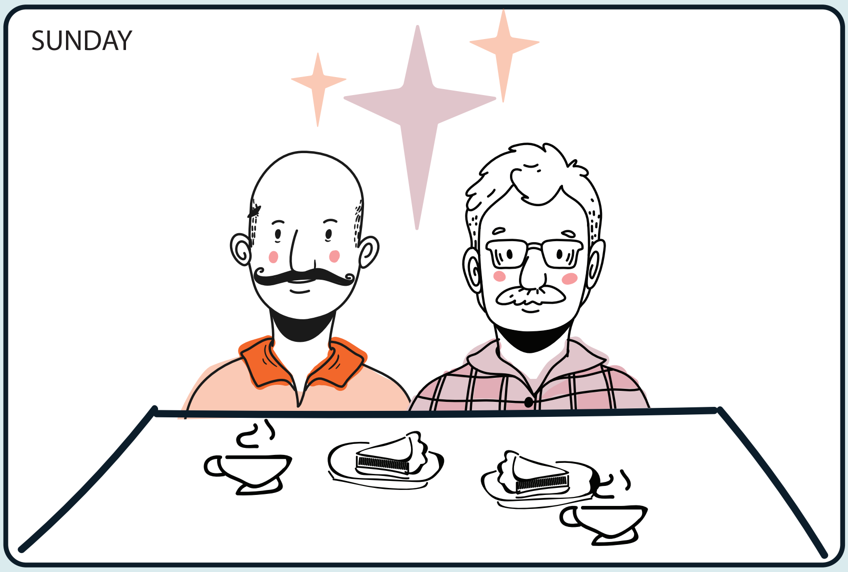
5



Praati aims to provide informal caregivers a space to decompress, reflect on their feelings by journaling, and connect with other informal caregivers.

The data resulting from these actions contains valuable insights for Active Cues.

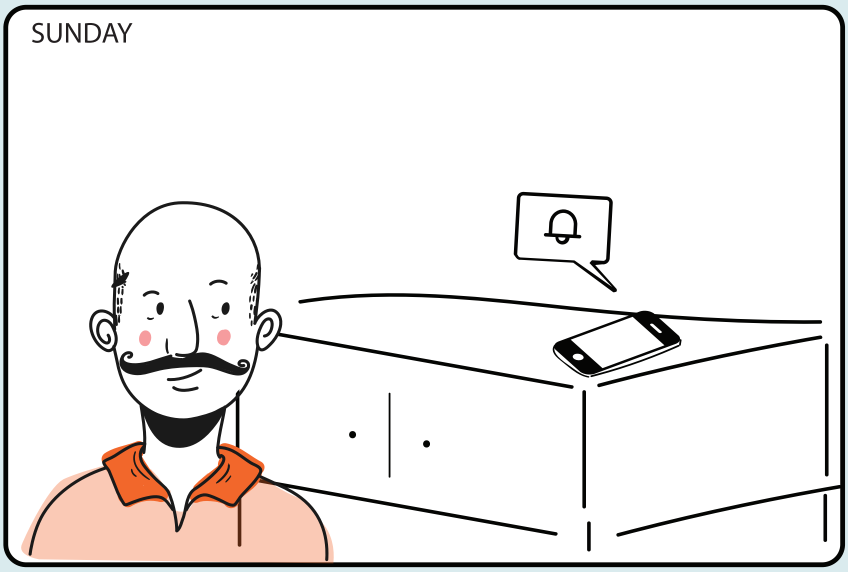
6



Today is Sunday, and Gus visits Vincent.

They both enjoy coffee together at the nursing house.

7



After the visit, Gus comes back home.

Once at home, he receives a notification.

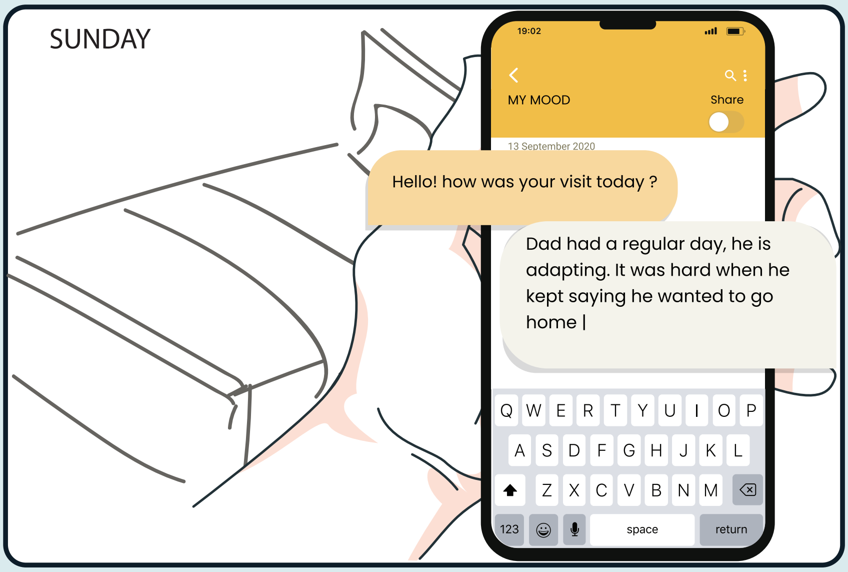
8

How was your visit today?

Take a moment to write down your thoughts

Gus sees the notification and waits until night time to open it to journal.

9



Hello! how was your visit today ?

Dad had a regular day, he is adapting. It was hard when he kept saying he wanted to go home |

Before going to bed, Gus retakes his phone. He writes down his thoughts.

He feels relieved to put his thoughts and feelings into words.

After that, he enjoys a good night.

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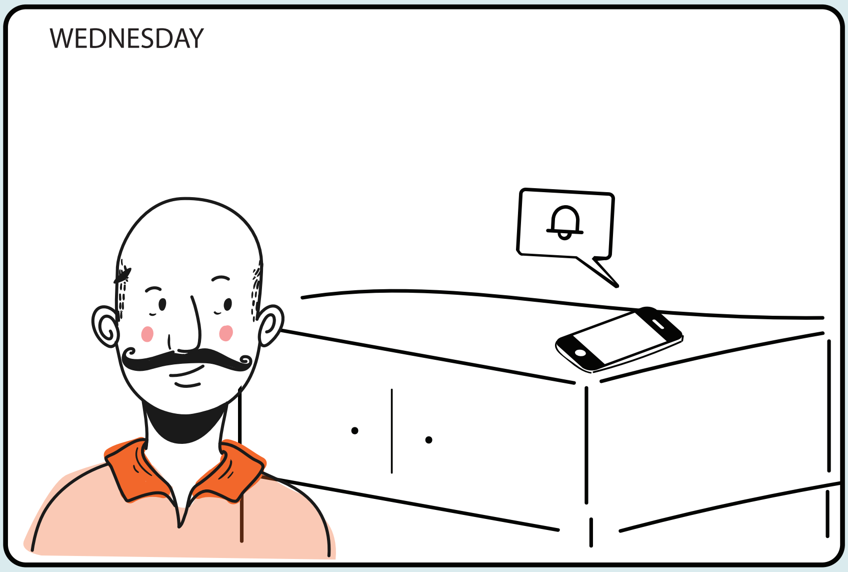

The week goes by, it is Wednesday, and Gus receives a notification from Praati.

11

We would like to know..

In the past, what could your [father] talk about non-stop?

Praati is requesting to share a story, this time about themes of interest of residents in nursing houses.

Collaborating with such stories contributes to improving the quality of life of people living with dementia.

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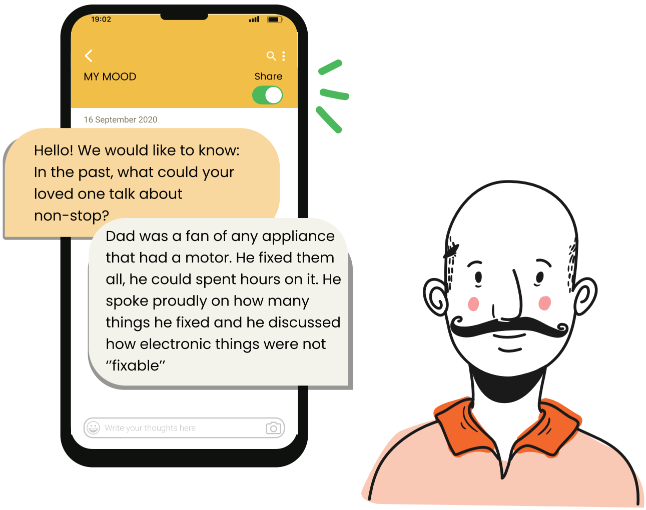

Hello! We would like to know: In the past, what could your loved one talk about non-stop?

Dad was a fan of any appliance that had a motor. He fixed them all, he could spent hours on it. He spoke proudly on how many things he fixed and he discussed how electronic things were not "fixable"

Gus opens Praati and shares a story about his dad.

He decides to click share.

It is made sure that shared data is treated confidentially.

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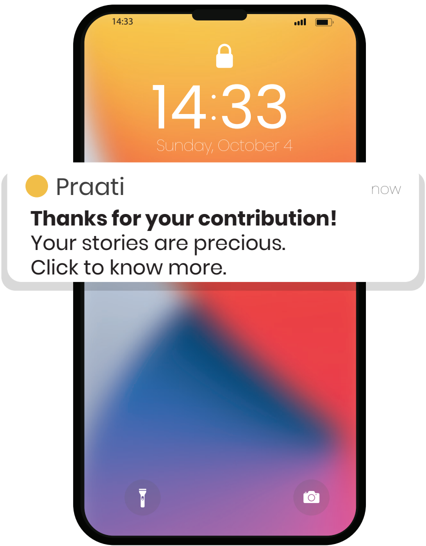

Praati

Thanks for your contribution!
Your stories are precious.
Click to know more.

Now and then, Active Cues informs via Praati their achieved developments to make this collaboration transparent.

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THE END

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The storyboard was created with images from freepik and thenounproject.