Leafe

Enhancing end-of-life communication between emerging adults and their incurably ill parent.



A Master's thesis
By Anne Mostert
December 2025

"Life has to end,
Love doesn't."

-Mitch Albom (2004)

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Master's Thesis

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Design for interaction

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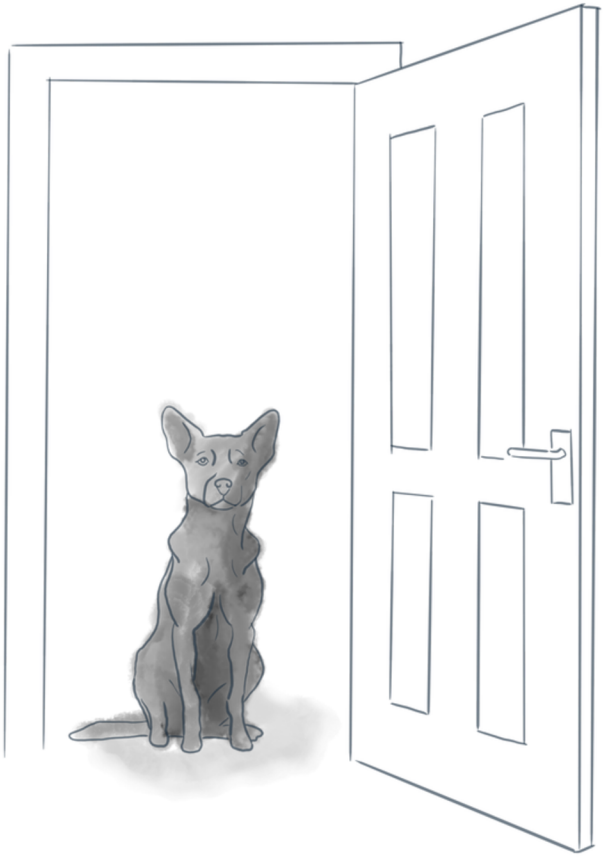
TU Delft

A. Incurable illness

"One day, the doorbell will ring, and a large black dog will be sitting on the sidewalk. He will walk into your house uninvited, check your fridge, and take a seat on the couch next to you. You won't be able to get rid of him, but the trick is to show him his place. For me, it is the mat at the front door. He'll be there, but not so obvious."

"Op een dag wordt er aangebeld, en daar zit een grote zwarte hond op de stoep. Die loopt onuitgenodigd door je huis, kijkt in je koelkast en gaat lekker bij jou op de bank zitten. Je krijgt de hond niet weg, maar de kunst is hem zijn plaats te wijzen. Bij mij is dat op de mat bij de voordeur. Dan is hij er wel altijd, maar niet zo duidelijk aanwezig".

Stated by Rommy. Quote from the book: Tussenland,
Jannie Oskam(2021).



B. Acknowledgements

Dearest reader,

My name is Anne, it is very nice to meet you!
I would like to start by sharing how I came to the theme of my graduation project. I am currently 25 years old, when I was 21, my dad received a diagnosis of incurable cancer. It had returned after nine years, and this time it was incurable. Thus began a challenging three-year journey. My father passed away while I was in the midst of working on this graduation project. I started this project alongside him, and now I have completed it in his honor.

During his illness, I found it difficult at times to communicate with him about his condition and the topic of end-of-life issues. After all, who wants to discuss death? I worried about upsetting him, yet I also felt the need to ask my questions. I wanted to feel "prepared" (though can anyone ever truly be prepared?), to learn more about him, and to support him. Additionally, I wanted to express my own needs and wishes. This led me to wonder: do others experience similar challenges? The answer, of course, is yes; I realized I was not alone in this.

I began researching online, which inspired the theme of my graduation project. I wanted to create something that connects people during this difficult time, allowing them to feel safe and open to communicate their needs and wishes.

Therefore, this thesis is focused on:
Enhancing end-of-life communication between emerging adults and their incurably ill parent.

I could not have done this alone.
First, I want to sincerely thank my supervisors: Marieke Sonneveld and Wim Schermer, thank you for your patience and understanding throughout this process, especially when things took longer than expected. I'm grateful for the time and space you gave me.

Wim, thank you for your trust and encouragement. Your support gave me the freedom to explore and grow, and your advice and reassurance meant a great deal.

Marieke, thank you for your honesty and belief in me, especially during times when I struggled to believe in myself. Your guidance and enthusiasm were truly inspiring.

To everyone who was open to talking with me about this subject, thank you so much. From those who have lost a parent or are caring for a parent with an incurable illness, to the kind experts who shared their knowledge. Psychologists, hospice volunteers, and grief specialists, your openness brought incredible depth to this project and inspired me immensely.

Thank you, Mom, for cheering me on and encouraging me to finish this project, even when it was incredibly hard after losing Dad. You are my biggest supporter, and I'm so grateful for you.

Thank you, little sister, for listening to my rants and giving me pep talks when I needed them most.

To my boyfriend, brothers, my friends, and family, thank you for checking in and seeing how I was doing. Your care meant the world.

And lastly, thank you, Papa. For the conversations, for always motivating me, and for being there, beside me, and from wherever you may be now. Te echo de menos y te quiero mucho.

To everyone reading this now: thank you for taking the time to engage with my thesis. I invite you to join me on this journey of exploration. Enjoy.

Yours sincerely,
Anne



C. Glossary

The following terms are frequently used throughout this graduation project. To ensure clarity and a shared understanding, each term is defined below as it is used within the context of this project.

END-OF-LIFE COMMUNICATION

In this context, end-of-life communication encompasses all communication, both verbal and non-verbal, related to the illness and the awareness that the person's life is coming to an end. This includes practical needs and treatment preferences, final decisions and arrangements, as well as communication about symptoms, mental well-being, challenges, the unknown future, the afterlife, rituals, relationships, bucket lists, memories, and more.

INCURABLY ILL PARENT

The incurably ill parent represents one part of the target group. In this context, the term refers to a parent diagnosed with an incurable illness, excluding conditions that primarily affect cognitive functions, such as dementia. This individual has a child between the ages of 18 and 29.

EMERGING ADULT

The emerging adult forms the other part of the target group. An emerging adult is a person in the life stage between adolescence and young adulthood, typically aged between 18 and 29. This stage is characterised by identity exploration, instability, self-focus, a feeling of being in-between, and a sense of possibilities (Arnett, 2004).

EXPERIENCE EXPERT

The term experience expert refers to research participants who have either lost a parent to an incurable illness, currently have a parent living with an incurable illness, or are a parent experiencing such an illness themselves. These individuals are considered experts by experience.

THEORETICAL EXPERT

The term theoretical expert refers to research participants who possess professional knowledge related to the context of the study. In this project, this includes grief experts, psychologists, palliative caregivers, and hospice volunteers.

D. Summary

By considering the prevalence of incurable illness, the importance of end-of-life communication, and the identified research gap concerning emerging adults coping with an incurably ill parent, the following research question was formulated:

How do emerging adults (ages 18-30) and their incurably ill parents navigate the communication process regarding illness and end-of-life needs and wishes, and what factors influence this process?

In this thesis, a wide range of factors shaping end-of-life communication between emerging adults and their incurably ill parent was identified. Because these factors can vary from person to person, it became clear that any design solution must allow room for personal interpretation.

Several themes within end-of-life communication were also identified. Importantly, the research revealed that, in addition to communicating about wishes, feelings, perspectives, and practical matters, it is vital to communicate about love and connection. Ultimately, love is what it comes down to.

Furthermore multiple barriers to end-of-life communication were found, which lead to coping strategies: avoidance, denial, putting up a façade, and conflict. Motivated by love, emerging adults and their parents aim to protect each other from negative emotions. While well-intentioned, these coping strategies do not always foster connection or effective communication.



Figure 1. Love, Fear, Protection.

The research highlights strategies and means to facilitate end-of-life communication, such as providing guidance, creating awareness, and creating intentional moments for discussion.

The end-of-life process is characterized by three phases: the adaptation phase, the "new normal" phase, and the terminal phase. Among these, the new normal phase presents the most promising opportunities for design.

Based on these insights, the following design goal was formulated:

“To foster connection and create mutual understanding between emerging adults and their terminally ill parent during the new "normal" phase of the end-of-life process at home, by creating space for lightheartedness and open communication about needs and wishes.”

To achieve this goal, six design criteria were set: **explorative, comfortable, lighthearted, connecting, guiding, and evoking curiosity.**

The final concept, called **Leafe**, is an activity designed to facilitate connection between an emerging adult and their terminally ill parent. Together, they create a mosaic artwork while engaging in conversations about end-of-life themes. The box ultimately serves as a keepsake, a place to store photos and mementos, and a tangible reminder of shared memories.

Evaluation of the concept showed that it performs well across the established design criteria. However, further research in real-life contexts is recommended. Additional recommendations include expanding the target group, incorporating a feature to make starting the process less overwhelming, adding options for personalization, developing an effective marketing plan, and improving the production process to make the concept more accessible and cost-effective.





Figure 2. Outcome final concept Leafe

E. How to read this report

This report consists of six main chapters. It begins with an ***Introduction*** to the theme, as well as the research and design process. The second chapter, ***Discover***, presents the key insights gained during the research phase of the project. In the third chapter, ***Define***, a frame for the design is established based on these research insights. Chapter four, ***Develop***, describes the development of the concept, while chapter five, ***Deliver***, presents the final concept. Finally, chapter six, ***Conclude***, reflects on the project and states recommendations for the future.

Each chapter is distinguished by its own main color for easy navigation. Every chapter includes an ***introduction page***, ***scenario pages*** featuring Wout and Iris, ***informational pages***, and a ***concluding page*** summarizing the key insights. Each type of page has its own unique layout (see Figure 3).

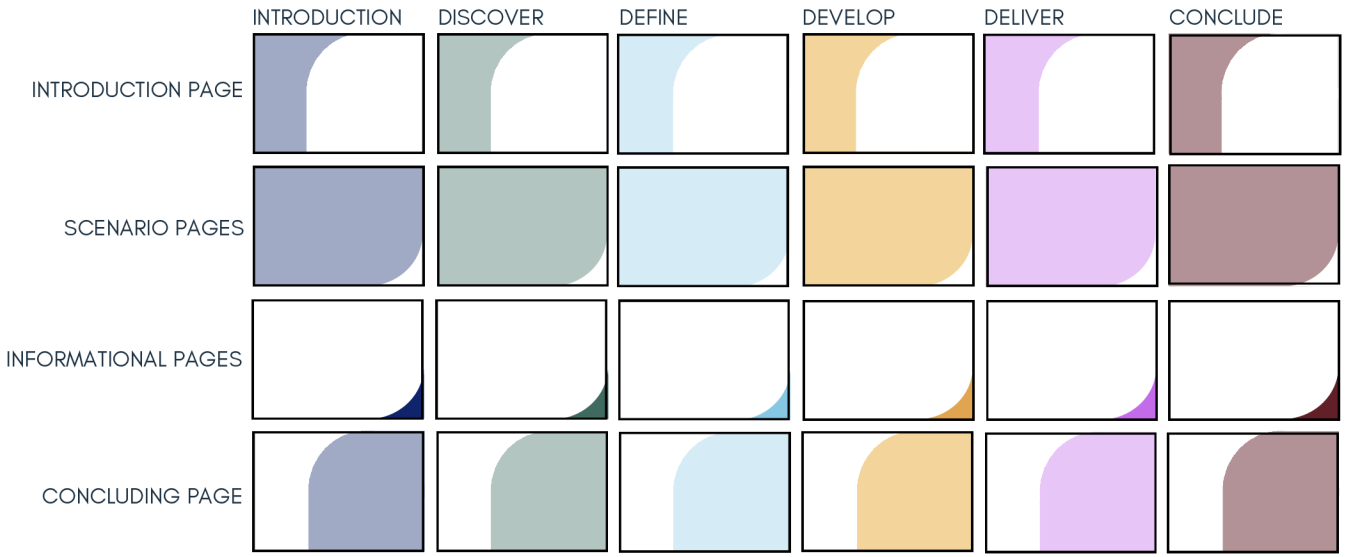


Figure 3. Layout & colour of pages per chapter

ChatGPT (OpenAI, 2025) and magic media (via canva.com) were used to refine text based on tone, grammar and sentence structure, as well as to translate words or sentences from Dutch to English. This thesis is made using canva.com and includes elements provided via the platform. The author retains full responsibility for the content of this report.

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Introduction

CHAPTER 1

OVERVIEW

1.1. Theme Introduction
1.2. Project Scope
1.3. Design process
1.4. Meeting Wout & Iris

INTRODUCTION

This chapter serves as an introduction to the project and consists of four sections. First, the theme of the project is presented in section 1.1.. Next, the scope of the project is defined in section 1.2.. Section 1.3. provides an overview of the research and design process, including the methods used throughout the project. Finally, in section 1.4., you will be introduced to Wout and Iris, the fictional main characters featured in the scenario that runs throughout this report.

1.1. Theme Introduction

INCURABLE ILLNESS

In the Netherlands, approximately 105,000 people die each year due to incurable diseases. These illnesses typically involve a progressive decline before death, which is why they are often referred to as expected deaths (IKNL, 2022).

Among the top ten conditions associated with the highest number of years of life lost are several incurable diseases. Lung cancer ranks first, followed by dementia, coronary heart disease, chronic obstructive pulmonary disease (COPD), colon cancer, heart failure, and breast cancer (CBS, 2025 & Plasmans & Hendriks, 2025).

Cancer is perhaps the most widely recognized incurable disease, particularly prevalent among older adults. In the Netherlands, 54% of individuals diagnosed with cancer are over the age of 70. However, this means that 46% are younger, highlighting a significant population of younger individuals living with incurable cancer (Buijs & Hazekamp, 2025 & IKNL, 2025).

In her book Tussenland (The In-Between Land), Jannie Oskam describes being diagnosed with an incurable illness as akin to entering a foreign country, one where you don't speak the language and must learn entirely new ways of living while letting go of the familiar. She likens the experience to a head-on collision that forces individuals to find a delicate balance between acknowledging their mortality and continuing to live meaningfully. This is often a profoundly difficult challenge (2021).

The emotional and psychological impact of such illnesses extends beyond the patient. Partners, children, parents, and siblings are also deeply affected (Van Edom, 2017).

END OF LIFE COMMUNICATION

The term end-of-life communication refers to communication concerning the end of life.

According to Keeley (2017), such communication plays a crucial role in improving medical, psychological, and relational outcomes for individuals facing an incurable illness, as well as for their close relatives.

Van Edom (2017) stresses the importance of talking about your needs and wishes with your relatives in order to leave a good memory. She states that fear does not need to be solved, but sharing your fears can feel as relief. In her book she writes:

> ***"Through giving it words, because spoken, drawn or written, the pain loses its power." -van Edom (2017)***

Despite its importance, end-of-life communication is often experienced as difficult. Numerous factors and barriers influence this process, one of the most prominent being avoidance. Individuals may refrain from discussing death in an effort not to burden one another. According to Keeley (2017), such avoidance can stem from fear, norms, views or beliefs.

This graduation project seeks to identify and understand the barriers that hinder end-of-life communication, with the goal of addressing and alleviating them through design.

EMERGING ADULT AND INCURABLY ILL PARENT

A significant gap identified in the literature is the lack of research focusing on emerging adult children of incurably ill parents. Some studies examine communication involving children or adolescents, such as the paper by Muriel et al., (2019) and Phillips (2014), others (Herbst et al. (2021), Read en Wuest (2007) , Roscoe en Barrison (2018) and Scheinfeld en Lake (2019)) focus on adult children and their elderly parents, on family as a unit (Wallace, 2014) or a family member in general (Allen, 2009, Jung and Matthews (2020) Keating et al. (2013) and Möllerberg et al. (2017)). Emerging adult children seem to occupy a middle ground between these two groups of children and adults.

Children and adolescents might be more dependent on their parents, and the literature often emphasizes their needs (Phillips, 2014). Conversely, in other cases, the ill persons needs are typically prioritized (Möllerberg et al., 2017).

Emerging adult children are likely to fall somewhere in between, balancing a sense of independence with possibly lingering dependence on their parents.



Figure 4. Theme introduction scheme

This dynamic makes emerging adults an interesting and underexplored target group, which will be focussed on in this graduation project.

By combining the significant prevalence of incurable illness, the importance of end-of-life communication, and the identified research gap concerning emerging adults dealing with a parent with incurable illness, the following research question was formulated:

RESEARCH QUESTION

How do emerging adults (ages 18-30) and their incurably ill parents navigate the communication process regarding illness and end-of-life needs and wishes, and what factors influence this process?

Figure 4 shows the target group and main theme: end-of-life communication between emerging adult and their incurably ill parent.

1.2. Project Scope

Before starting the research activities, it is necessary to establish a clear and manageable scope. This section explains the scope of the project.

INSIDE SCOPE

EMERGING ADULTS

The first character in the research is the emerging adult, a person between the ages of 18 and 29 (Arnett, 2004). In the context of this study, this individual has a parent with an incurable illness that will ultimately lead to the parent's passing.

INCURABLY ILL PARENT

The second character in the research is the incurably ill parent, a person who has an *emerging adult child* and has been diagnosed with an *incurable illness*, fully aware that it will eventually lead to their passing.

HOME CONTEXT

The scope of this research is limited to the home environment to keep the context clear and manageable. This setting was chosen because it is familiar and allows the focus to remain solely on the two individuals involved.

END OF LIFE COMMUNICATION

This research focuses on end-of-life communication. In this context, end-of-life communication goes beyond discussing burial wishes. It encompasses all communication related to the illness and the awareness that the person's life is coming to an end. This includes practical needs and treatment preferences, final decisions and arrangements, as well as communication about symptoms, mental well-being, challenges, the unknown future, the afterlife, rituals, relationships, bucket lists, memories, and more.

OUTSIDE SCOPE

OTHER RELATIVES AND FRIENDS

In the context of illness and end-of-life communication, interaction often extends beyond the immediate parent-child relationship to include others such as the other parent, siblings, and close friends. However, including these additional stakeholders would significantly increase the complexity of the research. Therefore, this thesis will specifically focus on the communication between emerging adults and their incurably ill parent.

HEALTHCARE PROFESSIONALS

Individuals with incurable diseases and their children often interact with a range of healthcare professionals, such as doctors, nurses, general practitioners, psychologists, coaches, and palliative care specialists. Although these professionals play a significant role in the overall experience, they are excluded from the main research scope to keep it clear and manageable. However, they are included in the study as experience expert participants, given their valuable experience working within this context.

CONDITIONS IMPACTING COGNITIVE FUNCTION

Conditions that impair cognitive function, such as dementia, will also be excluded from this study. These diseases may impact communication in fundamentally different ways, potentially complicating the research and shifting its focus.

An overview of the scope of the project is presented in figure 5.

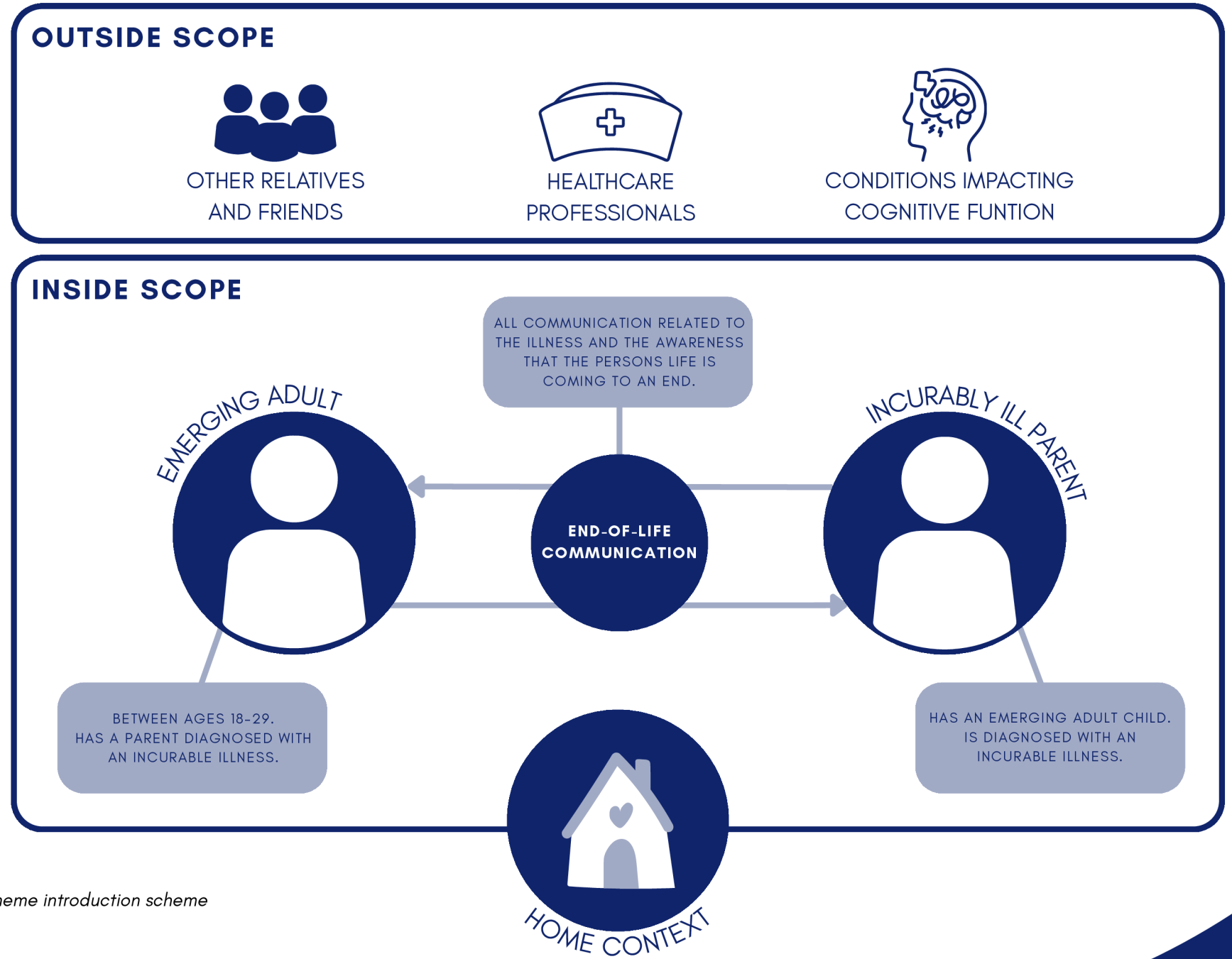


Figure 5. Theme introduction scheme

1.3. Research & Design Process

This section explains the design process chosen for this project.

THE DOUBLE DIAMOND

The design process used in this graduation project can be described by the double diamond model (Design Council, n.d.) . The model portrays two diamonds each representing a diverging and a converging phase in the design process (See figure 6).

DISCOVER

The discover phase is the research phase of the project based on the main research question and subquestions. It explains both activities by analysing literature as well as self-performed research activities like interviews and context-mapping.

DEFINE

This phase is about translating research findings to a design vision and requirements.

DEVELOP

The develop phase is an iterative process in which multiple ideas and concepts will be generated. It will include multiple ideation methods like sketching and co-design sessions.

DELIVER

In the last phase, a concept will be evaluated and improved accordingly. Future recommendations will be discussed.

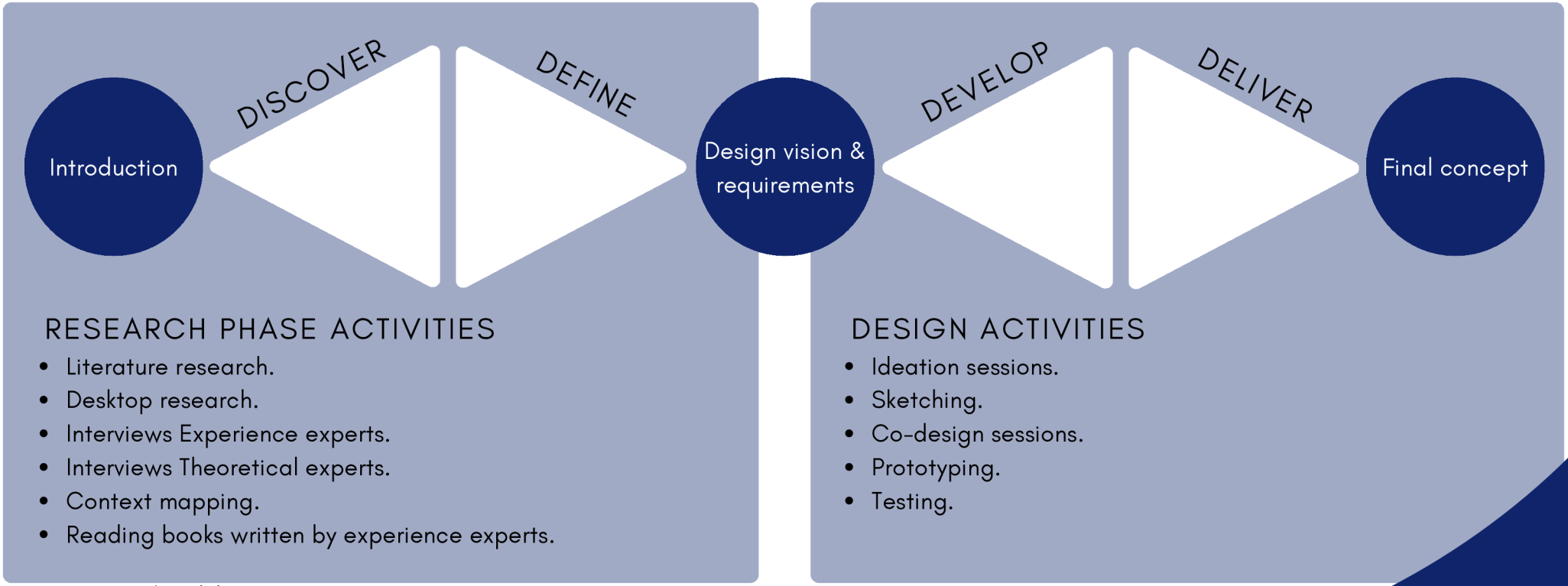
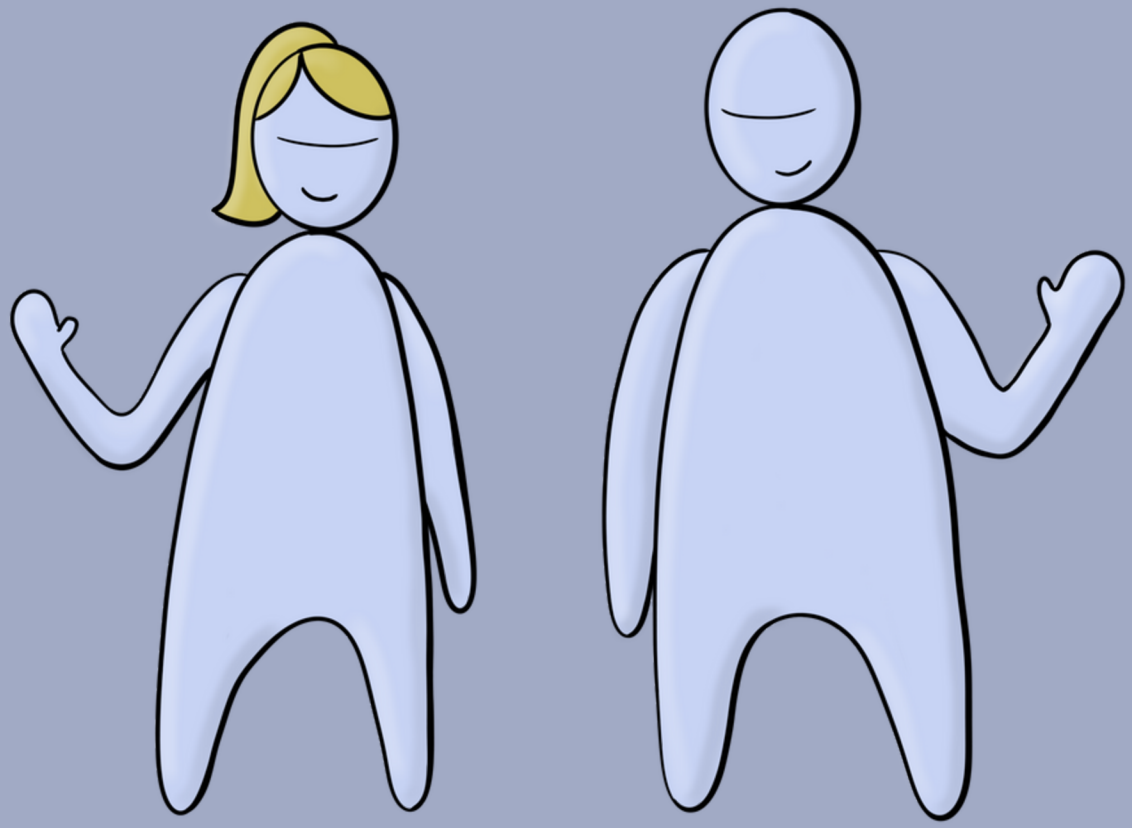
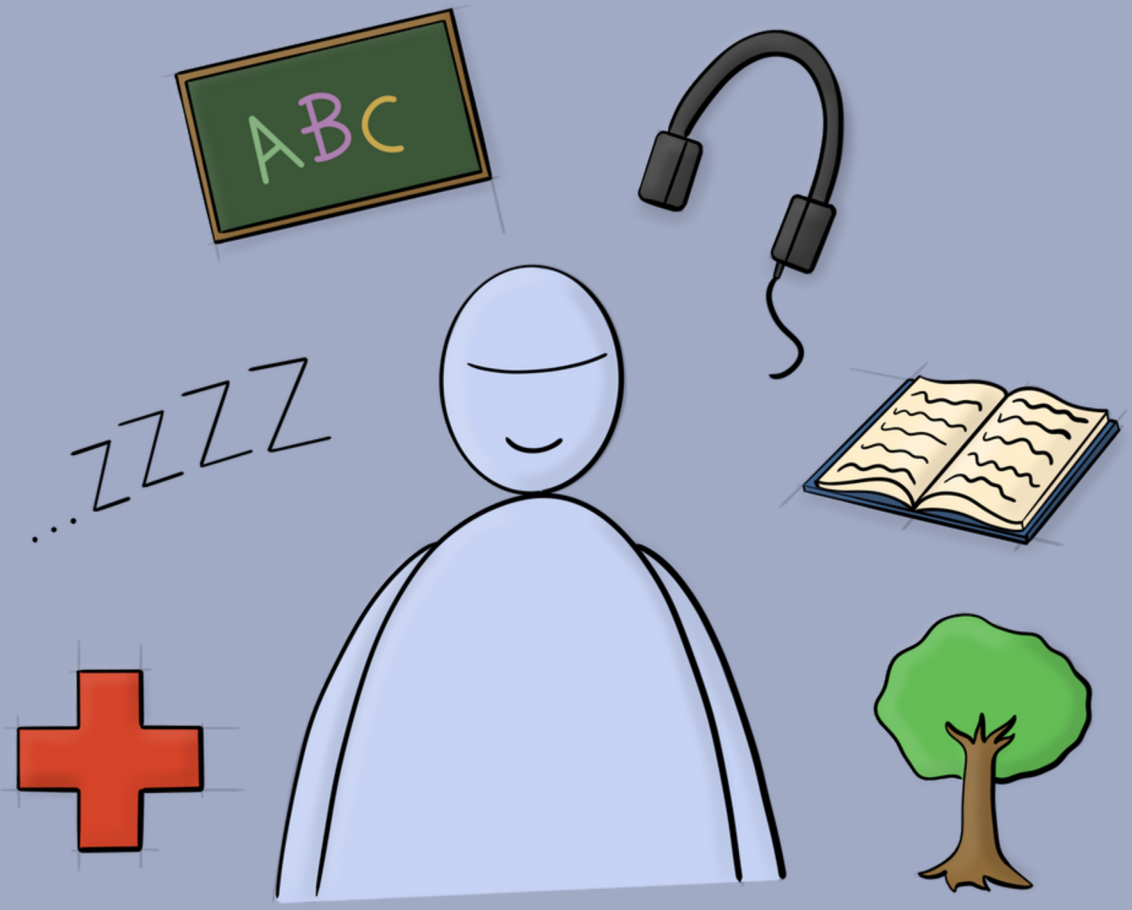


Figure 6. Research and design process.

Meeting Iris & Wout



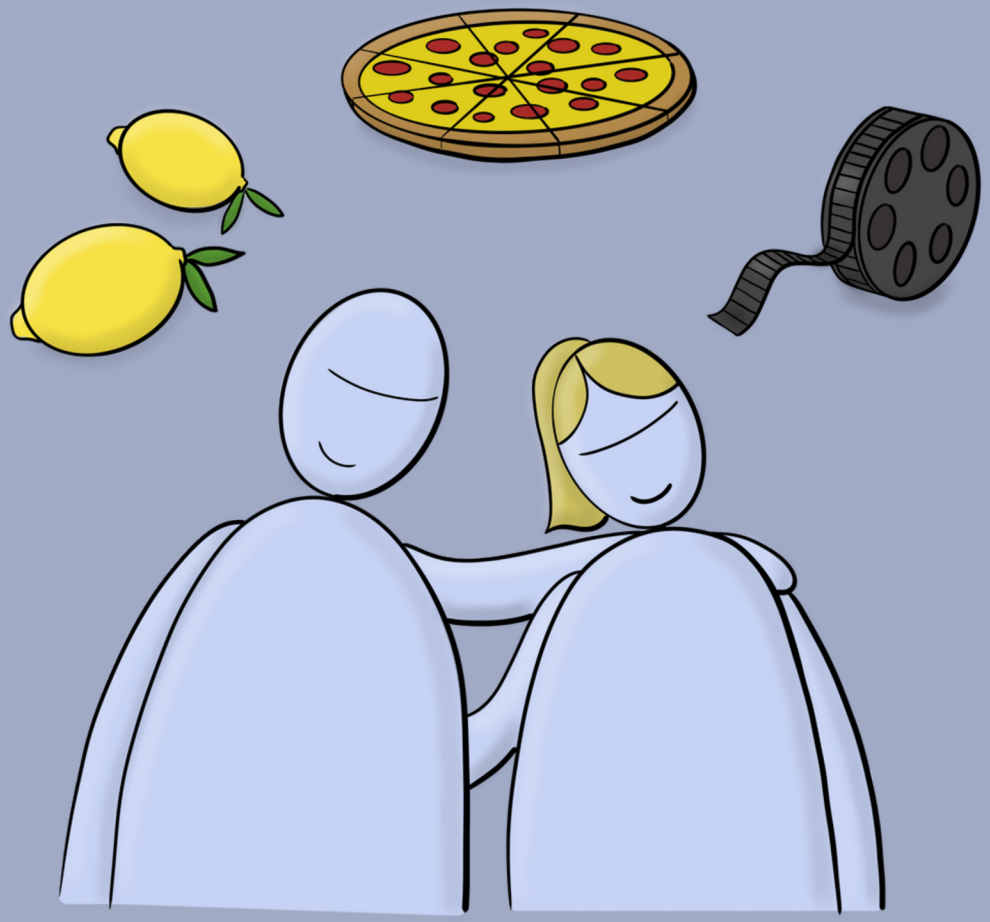
Meet Iris and Wout, a father and daughter.



Wout is 56 years old. He used to work as a teacher at the local high school but has since retired. A year ago, he was diagnosed with incurable lung cancer. He now spends much of his time at home and is undergoing treatment to extend his life. Although his energy is often low, he enjoys reading books, listening to podcasts, and taking short walks in nature.

Iris is 21 years old and currently in her third year of studying Biology. She lives in a student house with three roommates but goes home to her parents every weekend. Iris enjoys going to parties, working out, and watching movies with friends. Every Saturday, she works at a jewelry store.





Wout and Iris love cooking together on the weekends, especially Italian dishes. They both share a deep love for Italy, a place they've visited on holidays ever since Iris was little. They also enjoy spending time together watching movies and series.

Introduction

SUMMARY

THEME INTRODUCTION

By combining the significant prevalence of incurable illness, the importance of end-of-life communication, and the identified research gap concerning emerging adults dealing with a parent with incurable illness, the following research question was formulated:

How do emerging adults (ages 18-30) and their incurably ill parents navigate the communication process regarding illness and end-of-life needs and wishes, and what factors influence this process?

SCOPE

The scope of this project includes the **emerging adult** (aged 18-29) and the **incurably ill parent** within the **home context**. The project focuses on **end-of-life communication**, encompassing all forms of communication related to the illness and the approaching end of the parent's life. Other relatives, friends, and healthcare professionals are excluded from the scope, as are illnesses that affect cognitive function, in order to avoid unnecessary complexity.

RESEARCH AND DESIGN PROCESS

This project follows the Double Diamond process (British Design Council, 2005), which consists of four phases: **Discover, Define, Develop,** and **Deliver**.

Research activities include literature review, desktop research, interviews with experience experts, interviews with theoretical experts, context mapping, and the analysis of books written by experience experts. Design activities include ideation sessions, sketching, co-design sessions, prototyping, and testing

Discover

CHAPTER 2

OVERVIEW

2.1. Research approach
2.2. **Factors** - How EoL-communication is affected.
2.3. **Themes** - Important themes during incurable illness.
2.4. **Barriers** - The navigation of EoL-communication and understanding what makes it difficult.
2.5. **Facilitators** - How we could connect emerging adults and their parents during the incurable illness process.
2.6. **Timeline** - The end-of-life communication process.
2.7. Communication between Wout & Iris.

INTRODUCTION

This chapter focuses on the research phase of the project. The main research question is addressed by exploring four subquestions, each examined through various research methods described in Section 2.1. Section 2.2. discusses the factors that influence communication, while Section 2.3. outlines the main communication themes. Barriers to communication are elaborated on in Section 2.4.. Section 2.5. introduces potential facilitators that could strengthen the connection between emerging adults and their ill parents. Section 2.6. presents a timeline of the communication process. Lastly in section 2.7., the findings are presented in the scenario of Wout and Iris, showing what the communication could be like.

2.1. Research Approach

This section outlines the research approach adopted for this project. It discusses the main research question and its subquestions, and presents the methods used to address them

RESEARCH QUESTIONS

The main research question is divided into five subquestions, each addressing a key aspect of the topic (see Figure 7). Each question will be explored and answered in a separate section of this chapter.

Given the breadth of five research questions, the focus will be on a select few, while the others will serve as background information.

In particular, emphasis will be placed on Questions 3 and 4. Question 3 highlights the specific struggles faced by the target group, while Question 4 explores ways to overcome these challenges, insights that are especially valuable for the design process. The remaining questions provide additional context and findings that will serve as supporting information.

MAIN RESEARCH QUESTION

How do emerging adults (ages 18-30) and their incurably ill parents navigate the communication process regarding illness and end-of-life needs and wishes, and what factors influence this process?

SUBQUESTIONS

- SubRQ1: What factors can influence end-of-life communication and in what ways?
- SubRQ2: What are important topics in the end-of-life phase?
- **SubRQ3: How do an emerging adult and their incurably ill parent navigate the end-of-life process and what barriers do they experience in communicating about end-of-life needs and wishes?**
- **SubRQ4: How can communication between an emerging adult and their incurably ill parent about end-of-life needs and wishes be facilitated to improve mutual understanding, emotional support, and connection and what innovations to facilitate informal end-of-life communication already exist?**
- Sub-RQ5: How does the emotional navigation of the end-of-life process evolve over time for both the emerging adult and their incurably ill parent?

Figure 7. Research questions

RESEARCH METHODS

This study will employ six research methods to answer the research questions. These methods are illustrated in Figure 8 and described in detail below.

LITERATURE RESEARCH

The research began with an exploration of relevant literature. Specific keywords were used in Google Scholar to find pertinent studies (Keywords: emerging adult, incurably ill parent, family dynamics, communication patterns, end-of-life, needs and preferences, communication, conversations, parent-child roles, discussions, death, palliative care). A backward citation method was applied to discover additional sources in the references of the identified literature. As the literature was reviewed, new themes emerged, which were then used as keywords to uncover further studies.

DESK RESEARCH

The desk research consisted of watching documentaries, listening to podcasts, and exploring websites related to the theme.

INTERVIEWS

A total of ten interviews were conducted. Four interviews were with **emerging adult experience experts**: emerging adults who have a parent with a terminal illness or who have experienced the loss of a parent to such an illness.

The remaining six interviews involved **theoretical experts** (two interviews included two participants resulting in a total of eight participants) including psychologists, grief experts, palliative care workers, and hospice employees. Additional information about the interview setup can be found in Appendix A4.

For the experience experts, fictitious names are used throughout this thesis. For extra information on ethical approach, see appendix A2.

CONTEXT-MAPPING

Following each interview, participants were asked to partake in a context-mapping exercise. They used a set of images and words to create collages, one representing their current situation and another depicting the facilitation of end-of-life communication. More details about the context-mapping exercise are available in Appendix A3. and A4.

READING BOOKS WRITTEN BY EXPERIENCE EXPERTS

To gain insight into the communication experiences of incurably ill parents, several books authored by writers facing incurable illness were analyzed.



Figure 8. Research methods

2.2. Factors - How EoL-communication is affected.

This section aims to answer the following research question:
SubRQ1: What factors can influence end-of-life communication and in what ways?

Several subgroups of factors influencing end-of-life communication were identified. The following subgroups will be discussed in this section: socio-cultural factors, relational factors, personal factors, the dynamic between emerging adulthood and being a patient, as well as physical and mental state.

SOCIOCULTURAL FACTORS

There are several contextual factors that can influence end-of-life communication, as they shape individuals' beliefs and perspectives. The following factors will be discussed: gender, culture, and religion and spirituality.

GENDER

Gender can influence communication between the two parties, particularly in relation to their roles in the illness situation. According to Lundquist (2017) , being a father is often associated with the role of providing for the family, a perception rooted in societal expectations. Losing this role due to illness-related impairments is frequently experienced as a significant challenge.

Similarly, Read en Wuest (2007) highlight that caregiving is traditionally viewed as a woman's role, often placing the responsibility of parent care on daughters. This creates unequal demands and expectations for daughters when caring for their ill parent, potentially impacting their emotions, needs, and wishes in this situation.

In a study by Baider en Bengel (2001) on gender differences in dealing with cancer, specifically focusing on spouses, researchers further emphasized the influence of cultural stereotypes. Women were often found to adopt the nurturing role and were more responsive to the well-being of others. The study also noted that women experiencing chronic illness tend to report higher levels of distress, which may stem from their more self-reflective and compassionate nature.

Grief and loss coach Ellen van Leenen states that gender can influence the way people experience grief and the behaviors that result from it. She explains:

"Men and women often grieve differently. Men start working a lot or going to the gym, are not inclined to share their feelings. While women are more inclined to do so. They show it when they are sad." -Ellen van Leenen (Grief and loss coach)

Therefore, gender can impact communication by shaping perceptions of gender roles, stereotypes, and inherent differences in experience and emotional expression.

CULTURE

Aspects of the end-of-life situation can be heavily influenced by culture, including the decision to care for an ill family member. Pharr et al. (2014) found in a study on various cultures in America that, for some cultural groups, the decision to provide care was not even a question, it was simply regarded as the expected norm.

In contrast, within European-American culture, caregiving was less ingrained as a cultural expectation. The act of caring for a parent was also shaped by cultural values surrounding responsibility. In cultures such as Asian-American, African-American, and Hispanic-American communities, values of respect and honor are highly prioritized. This often means taking care of a family member in a way that aligns with their preferences, with the aim of preserving family harmony. However, this suggests that cultural expectation can lead to individuals placing their own needs and wishes secondary to those of their parents.

Furthermore, in some cultures, discussing death is believed to hasten the end-of-life process, creating taboos around end-of-life conversations. Cultural differences also extend to preferences regarding how information about the illness is delivered, as well as the level of directness in communication (Cain et al., 2018).

Based on her experience in the hospice, Rivka Bakkers-de Jonge says:

"A while ago, we had a man with an islamic background, and that has a significant effect. Because they don't talk about death, they don't want to know that they are in a hospice." -Rivka Bakkers-de Jonge (Hospice volunteer)

The findings indicate that cultural background influences communication preferences and norms.

RELIGION

Patients and caregivers often experience spiritual uncertainty due to the incurable illness. Questions and doubts related to meaning, religion, and spirituality can weigh heavily on their minds, leading to a search for meaning and shaking their beliefs (Ellington et al., 2017).

However, religion can be a positive influence on patients. Mirjam Willemsen (Incurably ill general practitioner) writes the following in her book about a patient:

"She doesn't want to die but accepts her faith. She finds so much strength in faith. For Rosalie, death is not the end, but a transition to a next stage of being. She beliefs that after death, there is no consciousness, until god brings them back to life in paradise. This belief provides her consolation and hope in her illness process." - Willemsen (2024)

Spiritual coping refers to all coping mechanisms related to spirituality, such as praying or meditating. Prouty et al. (2015) suggest that spiritual coping is more of an individual phenomenon. However, higher levels of spiritual coping in individuals are associated with improved family communication.

Religion and spirituality can influence communication through both positive and challenging aspects. On one hand, spiritual uncertainty may cause existential questions and contemplating, on the other hand, faith can serve as a positive predictor for communication, fostering hope and consolation.

RELATIONAL FACTORS

Communication can also be influenced by relational factors like family communication patterns and the parent-child relationship.

FAMILY COMMUNICATION PATTERNS

Family communication patterns are an essential factor in understanding interactions during a terminal illness. According to Koerner en Fitzpatrick (2006), family communication patterns can be categorized along two dimensions:

- 1. Conversation orientation: the degree of openness within the family and the range of topics they are willing to discuss.
- 2. Conformity orientation: the extent to which parents expect their children to conform to their values rather than fostering their independence.

Families can vary widely across these dimensions, resulting in distinct communication dynamics.

Keating et al. (2013) found that family communication patterns do not significantly influence whether difficult conversations are initiated. They argue that the importance of such conversations often outweighs family dynamics. However, their study only examines whether the conversation occurred, not the levels of stress, anxiety or experience of the conversation.

It's of course also about how you are used to interact with each other. If you are used to talking about everything, and that you are allowed to cry and be angry and sad. Then it is easier in such a situation." -Annebet Nolen (Psychosocial therapist)

This quote illustrates how patterns which people are accustomed to can shape the communication process during the end-of-life.

PARENT-CHILD RELATIONSHIP

Research by Phillips (2014) with adolescents suggests that a strong parent-child relationship before diagnosis predicts better adaptation and coping during the illness.

A parent's illness can also sometimes strengthen the relationship. The time pressure associated with a terminal diagnosis often motivates both parties to spend more time together and make the most of their remaining time. For instance, Herbst et al. (2021) report that sharing childhood memories and getting to know one another better during the end-of-life phase fosters greater emotional intimacy.

On the other hand, the parent-child relationship is highly susceptible to change under the circumstances. Scheinfeld en Lake (2019) explains how children often transition from being dependents to becoming caregivers, a process that can be stressful, traumatic, and emotionally taxing. Similarly, Herbst et al. (2021) describe how having a terminally ill parent feels contrary to the natural order, requiring parents to relinquish their traditional role as the stronger party and accept assistance from their child. Complications can also arise when the parent and child have differing needs for closeness or distance. These mismatched expectations can result in challenges in meeting both physical and emotional care needs.

Changes in the relationship were also observed by experience expert Madelief. This suggests that shifts in the parent-child relationship can influence end-of-life communication.

"When my mom got sick, the division of roles changed. It is not like parents and child anymore. My parents did try to be our parents and take on that role. But it did change, also when my mom got worse. Then my dad took the caring role and we helped when we were home. You just interact with each other differently. -Madelief

PATIENT AT THE CENTRE

In end-of-life communication, the parent is often at the centre. In a research by Möllerberg et al. (2017) about interaction patterns when a family member deals with incurable cancer, it was found that the ill persons needs are typically prioritized and the ill person has more power over how the family interacts with each other. Other family members will put their own needs and wishes aside in order to make the best out of the last period.

"My mother, in this case, was at the centre". - Camiel

"Communication is often about my dad. Maybe because I don't talk about it myself, but we don't talk about what it all means to me." -Floris

PERSONAL FACTORS

PERSONALITY AND COMMUNICATION STYLE

A study with undergraduate students found that four dimensions of personality: extraversion, neuroticism, agreeableness, and openness to experience, affect communication competence (Hassan et al., 2019). This suggests that an individual's personality can influence how effectively they communicate.

Individuals also have their own communication style, a personal and characteristic way of expressing themselves. These styles can influence how people interact and convey information. Communication style can be described using six behavioral dimensions: expressiveness, preciseness, verbal aggressiveness, questioningness, emotionality, and impression manipulativeness. Furthermore, research has shown that communication style is associated with personality (De Vries et al., 2011).

Since everyone has a unique personality and communication style, communication is shaped in a wide variety of ways. This highlights the importance of considering individual differences when designing interventions or tools for end-of-life communication: every user is different.

"t will be different in each situation, one person is not like another."-Geraldine van Pelt (former palliative care worker)

LIFE GOES ON VS A SMALLER WORLD

LIFE GOES ON

Emerging adulthood is characterised by identity exploration, instability, self-focus, a feeling of being in-between, and a sense of possibilities (Arnett, 2004).

This developmental stage can be significantly affected when an emerging adult is dealing with an ill parent. Whereas this period is typically devoted to exploring oneself and new opportunities, time and energy must now also be invested in caregiving responsibilities. Emerging adults often move between two contrasting experiences: feeling more adult than their peers due to caregiving responsibilities, yet simultaneously feeling as if they are not where they are "supposed" to be in their development. On one hand, caregiving can accelerate maturity and learning; on the other, it can limit growth in other important areas of life (Tong et al., 2024).

The emerging adult must navigate the tension between a life that continues to move forward and a life that feels suspended in time due to the incurable illness, a challenge that can be difficult to balance.

This challenge can become even greater when the emerging adult no longer lives with their parent(s):

"I think I was not fully aware of what that change did to me. I was so busy with my new and fun life, that I did not understand everything once I got home. -Camiel

SMALLER WORLD

Another factor identified is that the patient's world often gradually becomes smaller. Due to their illness, they engage in fewer activities and see fewer people. Sometimes, people turn to social media to maintain contact with others.

"That someone's world is becoming smaller. That is very hard, and it feels strange to experience. Seeing someone become able to do less, and how to cope with that." - Camiel

Your world becomes smaller, literally and figuratively. Structure of life disappears. You no longer go to work everyday, your hobbies fade, there are time-consuming hospital visits, cycling is only possible on good days, you will leave a party early. Your schedule is getting empty. Sometimes, the only contact left with the outside world is social media, facebook or a blog. -Van Edom (2017)

CONFLICTING NEEDS

The life of the emerging adult continues to move forward and may even expand during this developmental stage, whereas the parent's life is gradually becoming smaller. This contrast can be challenging, as their needs may differ significantly. In her book, Willemsen writes the following about patient Ans:

Both her sons are going aboad for several months for an intership. That was already planned and they still want to go. Ans understands that everones life goes on, but for her it is extra hard. She feels useless and feels like she is losing her self-worth. She realizes her life will end. - Willemsen (2024)

PHYSICAL STATE

SYMPTOMS, PAIN AND FATIGUE

A limitation to end-of-life communication for the incurably ill parent is impairment caused by the illness. As Planalp and Trost (2008) state in their research with hospice volunteers, physical and mental impairments can act as barriers to effective communication, for example, when speech abilities or cognitive processes are affected.

When someone is so ill they are not able to speak anymore, or when they went through a personality change. - Annebet Nolen (Psychosocial therapist)

Treatments and incurable illnesses often involve pain. Pain is known to capture attention and override cognitive functions. Pain can interrupt task performance (Moore et al., 2011). This suggests that pain may likewise disrupt communication, as it draws attention away from the task at hand: communicating.

Fatigue can also significantly influence communication. Research on people with multiple sclerosis shows that fatigue can lead to communication-related symptoms such as slurred speech, difficulty finding words, challenges with language processing, and memory problems (Blaney & Lowe-Strong, 2008).

"Then they are too exhausted to talk. They cannot avoid telling others that they are tired." -Gerda (Palliative Care worker)

Overall, the findings indicate that a person's physical state and symptoms can have a substantial impact on their ability to communicate.

MENTAL STATE

EMOTIONS

For both the emerging adult and the incurably ill parent, a wide range of emotions was identified in the research. This period is emotionally complex: at some moments there is room for hope, love, and gratitude, while at other moments the situation can feel overwhelming and confronting, evoking sadness, frustration, insecurity, or anxiety.

Emerging adults may feel powerless or frustrated because they cannot help their parent in the way they wish to. They may also feel curious and have questions about their parent's condition, yet at the same time be afraid of burdening them. Many emerging adults feel pressured to handle everything "the right way".

Parents experience many of the same emotions, but one feeling that stood out in the research was guilt, guilt for causing sadness or other difficult emotions for their child, even though they did not choose to become ill

As van Edom (2017) states in her book:

"All emotions can occur during the grieving process, both positive and negative. Even ones you did not experience before." -van Edom (2017)

The choices we make are often guided by the emotions we expect to feel afterward, a process known as affective forecasting. However, humans are generally not very accurate at predicting their future emotional states and tend to overestimate the intensity those emotions (Wilson & Gilbert, 2005).

This inaccuracy may play a role in end-of-life communication: people often fear the emotions such conversations may evoke or worry about burdening their loved one. As a result, they may avoid discussing end-of-life themes, potentially due to these flawed affective forecasts.

"That you feel scared that when he is finally feeling well, you initiate a conversation about it and he has to think about it again. That is not what you want. You'll be scared to say it." -Leander

Furthermore, research by Song et al. (2017) shows that emotions can interfere with cognitive control, leading to cognitive conflict. Emotional interference and cognitive control share underlying neurophysiological mechanisms, meaning that strong emotions can diminish an individual's ability to carry out tasks effectively. This suggests that emotions may affect communication by impacting cognitive control.

LIFE ON TWO TRAILS

Oskam (2021) describes living with an incurable illness as walking along two parallel trails: one representing the illness and one representing life.

> ***"Following the trail of illness is a hard task. I have to take time for it over and over again. Then I get to be sad. Then I want to tell about my grief avout losing my health and the future I dreamt of." (Oskam, 2021)***

This metaphor suggests that communication about the illness and end-of-life themes tends to occur when someone is on the “illness trail.” When they are on the “life trail,” however, it may not feel like the right moment to engage in such conversations. These alternating trails, and thus how the parent is feeling at a given moment, can therefore influence whether end-of-life communication takes place.

IMPLICATIONS FOR DESIGN

There are many factors that influence the end-of-life communication process, and these can vary greatly from person to person. Therefore, it became clear that any design solution must be flexible and allow room for personal interpretation.

FACTORS IN THE END-OF-LIFE COMMUNICATION SCHEME

The factors and subfactors for both the emerging adult and the incurably ill parent are presented in the end-of-life communication scheme shown in figure 9.

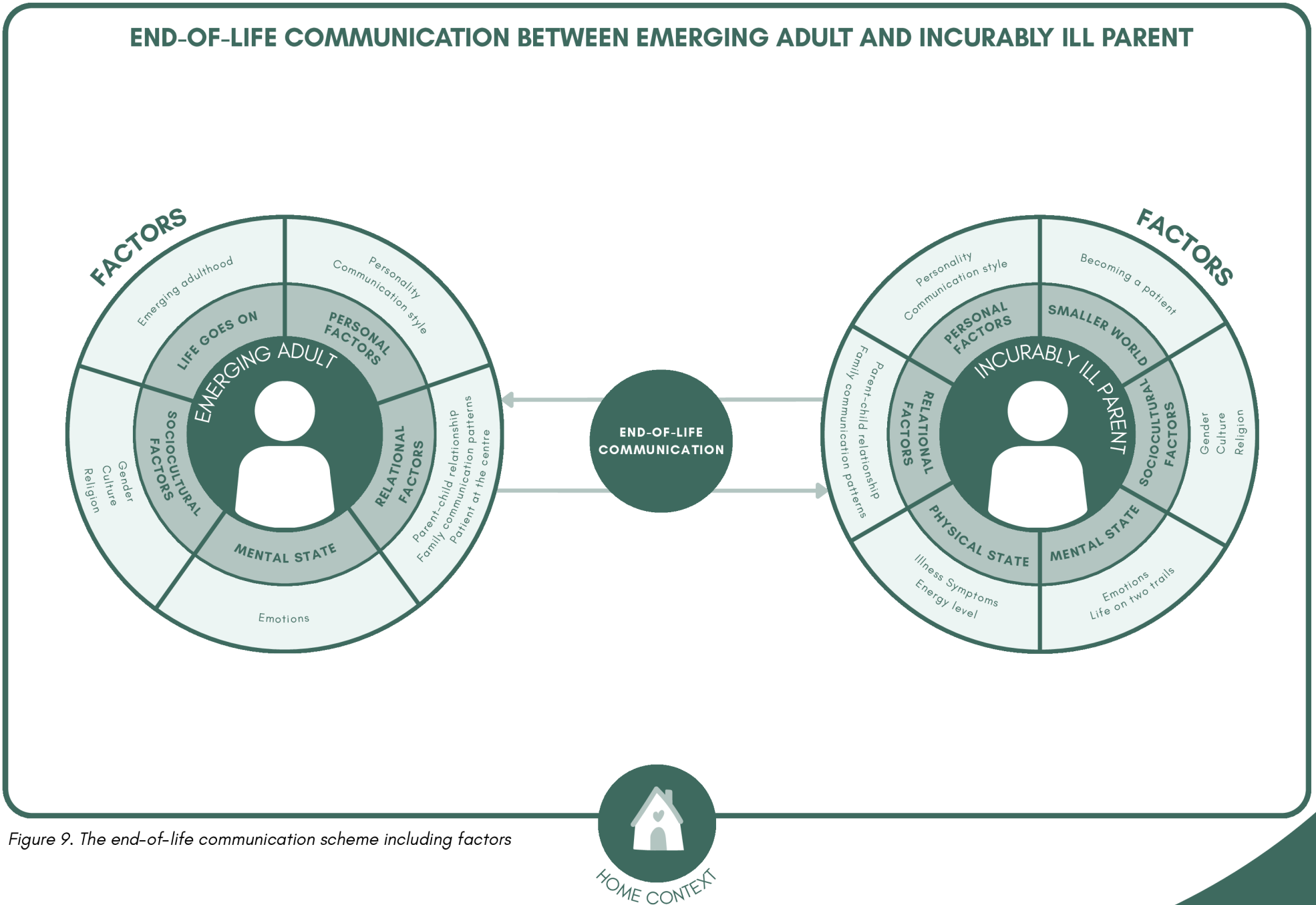


Figure 9. The end-of-life communication scheme including factors

2.3. Themes - Important themes during incurable illness

This section aims to answer the following research question:
SubRQ2: What are important themes in the end-of-life phase?

FOUR OVERARCHING PILLARS

The four overarching themes used in this project are derived from the pillars of palliative care as described in the Nationaal Programma Palliatieve Zorg II (n.d.): psychological, social, physical, and spiritual (See figure 10). According to this framework, providing care for patients with incurable illnesses requires attention to all of the patient's wishes and needs across these four dimensions. It also emphasizes the importance of involving relatives to ensure holistic and compassionate care. Although the framework was originally developed for palliative care, it effectively captures the central themes that arise during this phase of life. Therefore, these pillars will serve as the foundation for this study.

PSYCHOLOGICAL

The psychological pillar focuses on mental and emotional well-being. Relevant themes include feelings and coping strategies.

SOCIAL

The social pillar concerns a person's relationships and connection to the world around them. This includes practical aspects such as finances, work, and housing, as well as interpersonal relationships, for example, concerns about loved ones.

PHYSICAL

The physical pillar encompasses themes related to the body and medical care, including treatment, pain management, medication, symptoms, and wishes for the final phase of life.

SPIRITUAL

The spiritual pillar addresses the individual's search for meaning and purpose. It includes existential questions, personal beliefs, and connection.

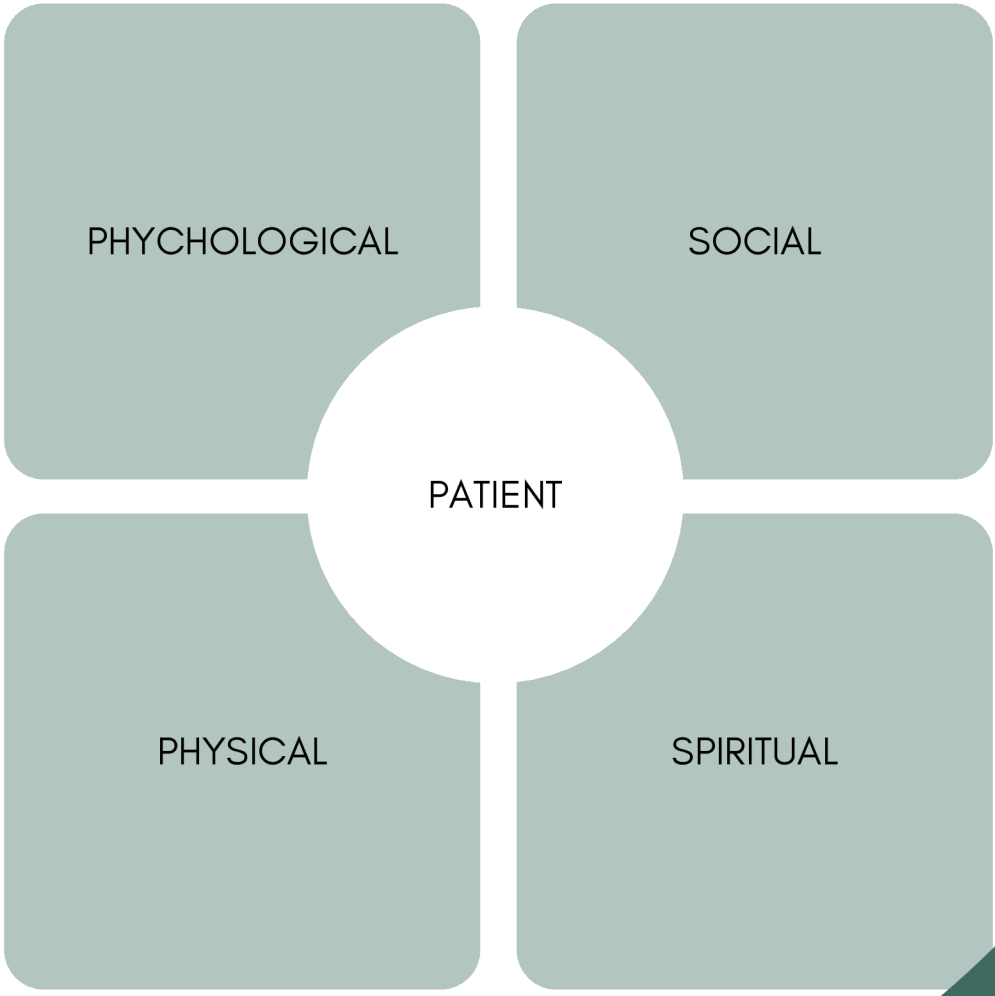


Figure 10. Four pillars of palliative care
(Nationaal Programma Palliatieve Zorg II , n.d.)

PAST, PRESENT & FUTURE

The four pillars are overarching and broad, making it essential to identify subthemes to clarify what each pillar encompasses. During the analysis process, it became evident that the themes could be organized into three temporal categories: Past, Present, and Future. Combining the four pillars with these three time frames resulted in twelve subgroups, within which additional subthemes emerged. Some of the subgroups were supported by findings from the interviews and books written by experience experts. Others were created. (Psychological/past, psychological/present, psychological/future, spiritual/past, spiritual/present).

Figure 12 presents an overview of these subgroups and their corresponding subthemes identified & created during the analysis. Each subgroup is accompanied by a guiding question to further clarify its focus. The physical subgroups are displayed in a lighter colour, as these themes primarily relate to the incurably ill parent. The remaining themes hold relevance for both the emerging adult and the incurably ill parent. Furthermore, the themes are added to the end-of-life communication scheme (See figure 13).

MAIN THEME: LOVE AND CONNECTION

What became evident throughout the research is that, in addition to communicating about wishes, feelings, perspectives, and practical matters, it is equally vital to communicate about love and connection, across the past, present, and future. Ultimately, Love is what it all comes down to. As illustrated in Figure 11, for the experience experts, love and family remain at the very centre.

"Love, the question: Do you love me? That one is the most important. It comes in different shapes. But that is what it's all about. Do you love me? Did you love me? And do I love you?" - Astrid (Hospice worker and creative therapist)



Figure 11. Context mapping exercise by experience expert: Floris (About acceptance, love and family.)

IMPLICATIONS FOR DESIGN

In terms of design, the identified themes can serve as inspiration and guide which topics should be included. Moreover, it is crucial that the design addresses the entire spectrum of themes, with particular emphasis on love and connection, as these have been highlighted as the most important elements.

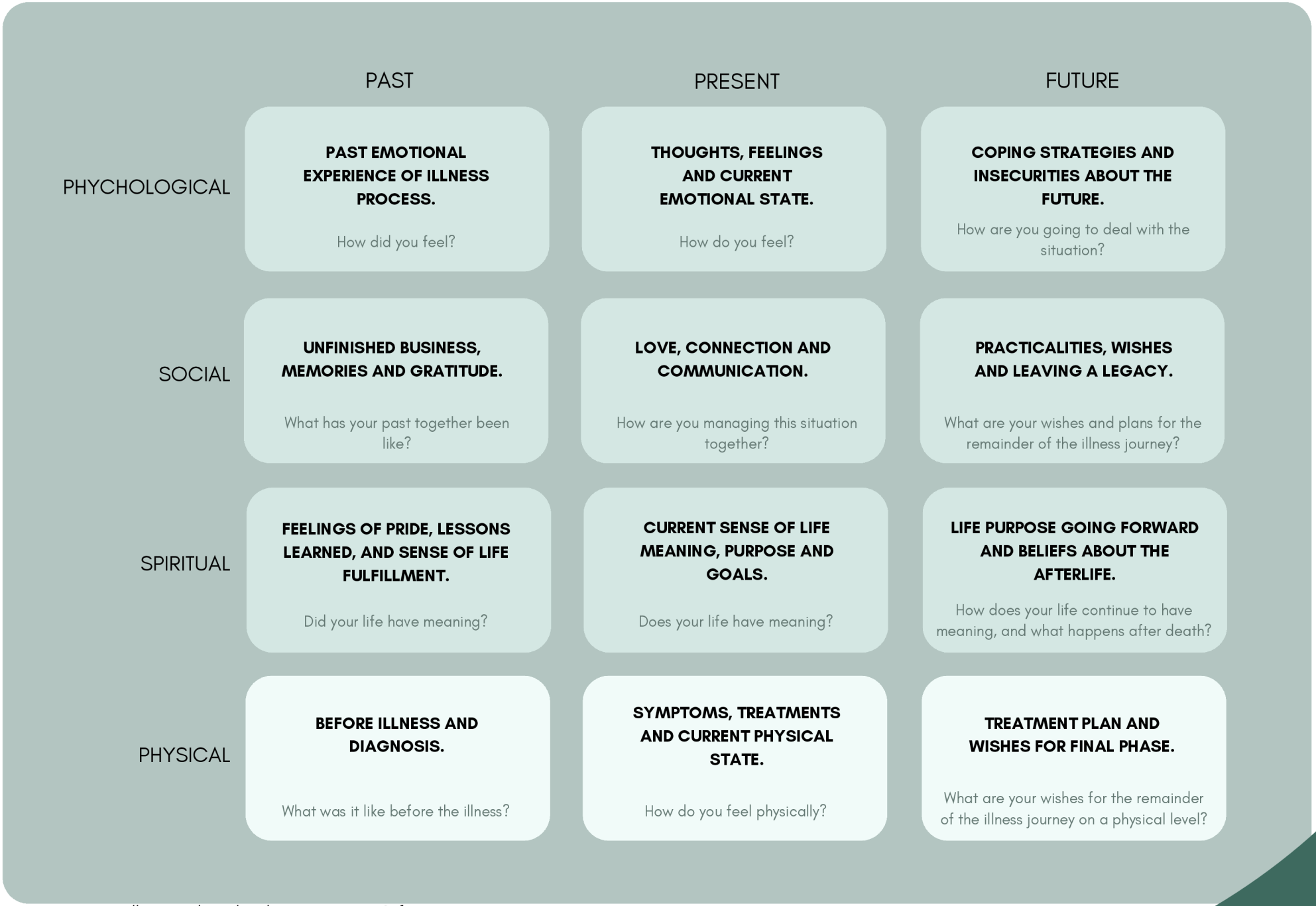


Figure 12. Four pillars combined with past, present & future.

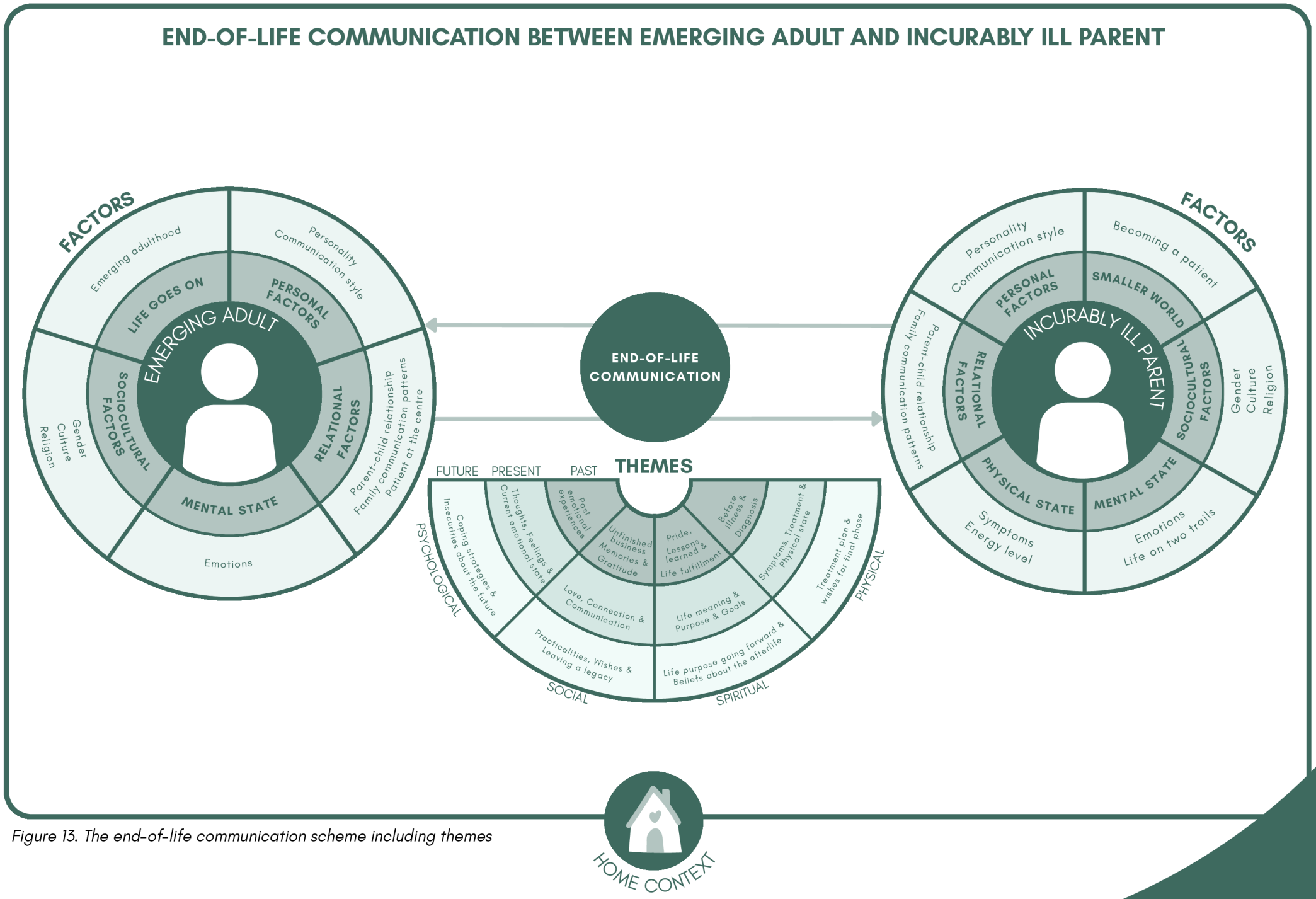


Figure 13. The end-of-life communication scheme including themes

2.4. Barriers -

The navigation of EoL-communication and understanding what makes it difficult.

This section aims to answer the following research question:
SubRQ3: How do an emerging adult and their incurably ill parent navigate the end-of-life process and what barriers do they experience in communicating about end-of-life needs and wishes?

This question is addressed in two sections. First, the barriers are identified and explained, followed by an explanation of the behaviors that arise as a result of these barriers.

BARRIERS

Barriers are factors that make end-of-life communication difficult and lead emerging adults and their incurably ill parent to adopt various coping behaviours. This section explains the barriers identified in this research.

A NEW SITUATION

To begin with, the situation is unfamiliar. It can feel overwhelming, and people are not accustomed to dealing with circumstances like these. As a result, they must find ways to adapt.

"The illness is something big that comes into the picture. A new way of interacting arises. Something is added and everyone has to deal with it." -Annebet Nolen (Psychosocial therapist)

THE PARENT ROLE

Views on parent-child roles can also create barriers to end-of-life communication. Some parents feel they must allow their children to "remain children," which leads them to believe they should not burden them with difficult information.

"Parents want their children to remain children as much as possible. Even when they are adults. They find it hard to see their children having worries or being sad." -Ellen van Leenen (Grief and loss coach)

BEING ON DIFFERENT PAGES

People not being on the same page can also be a barrier to communication. Everyone has their own needs, and when these do not align, friction can arise.

"Everyone has different needs, one person wants to talk about it at a certain moment whereas the other prefers a different moment." -Gerda (Palliative Care worker)

"Everyone deals with loss in their own way, even in families. One deals with anger, while the other turns to denial. Another deals with a lot of sadness. It can be hard to find each other while grieving differently."-van Edom (2017)

TABOO

For some people, talking about death remains a taboo. This can stem from cultural beliefs and can significantly impact communication.

"In her culture, there is little communication about illness and dying. They believe it can attract negative energy or even lead to early death" -Willemsen (2024)

HARD TO INITIATE

Another barrier is that initiating end-of-life communication can be difficult. Uncertainty about whether the other person is open to such conversations can create doubt and hesitation.

"I struggle starting a conversation like that. You never know if the other person wants to as well. That is quite a risk." -Leander

MAKING ASSUMPTIONS

A barrier related to initiative is the tendency to make assumptions. People may believe they already know the other person's views, thoughts, or feelings. This can hinder communication, for example, when someone assumes the other person does not want to talk or presumes how they will react.

"Asking each other questions, without making assumptions. That is also hard. We often make assumptions. Like: the other will think this or feel this and say this and this." - Astrid (Hospice worker and creative therapist)

NO RIGHT MOMENT

People often wait for the "right moment" to start a conversation. However, waiting for a moment that may never come can lead to doubt and hesitation.

"I will be looking for the right occasion to do so. I will be doubting a lot. How do I do it? What do I say and when? I think there is so much doubt you end op not starting the conversation." -Leander

LACK OF AWARENESS

Awareness can also play a role in end-of-life communication. The situation can feel overwhelming, and people may not be fully aware of their own needs, wishes, or questions, making it difficult to express them.

"I think that when she was ill, I did not realise what I wanted to ask her." -Madelief

"It is mostly awareness I think. That is how I look back on it. I can't really remember that period well. It was good, that's not it and it was nice to be there for my mom. But is was all a bit of a blurr." -Camiel

THE PATIENT AT THE CENTRE

Another barrier is that the patient is often at the centre of attention and has more influence over the communication process. While it is natural for them to decide when to talk, this can sometimes result in the child's needs being overlooked.

"Communication is shaped a lot by how the person who is approaching the end of life feels. -Marjo (Hospice caregiver)

FEAR

Fear appears to be the main barrier underlying many other barriers and the resulting behaviours. People may fear burdening the other person, fear reactions and emotions, or fear making mistakes. Motivated by love, they want to "do things right" and protect each other. These concerns can significantly influence how people approach end-of-life communication.

"Fear is the biggest problem. That is what gets in the way most. Fear. From both sides. Fear for sorrow, fear fore emotions. Fear that those emotions will be so big, so overwhelming that you will break down." -Astrid (Hospice worker and creative therapist)

"I don't want to make it any harder for him than it already is. If I tell him that it is also hard for me, it's not fair to him I think. It is my problem, and not something he should be dealing with." -Floris

COPING STRATEGIES

The barriers mentioned often give rise to behaviours that can hinder effective end-of-life communication. This research identified three key coping strategies: avoidance/denial, façade and conflict, which are described below. These behaviours can be similar in nature and may overlap.

AVOIDANCE/DENIAL

The barriers can result in avoidance, where one or both parties choose not to communicate about end-of-life matters, including their needs and wishes, altogether in order to protect each other. Coelho et al. (2019) state that family caregivers, while experiencing anticipatory grief themselves, often choose to inhibit their own feelings in order to avoid burdening the ill person.

"The therapist caused my eyes to open. I told her that I just don't talk about my cancer in order not to burden the other. Then she said: "Do you really think, that if you don't talk about it, your children are not thinking about it?"" - Oskam (2021)

Some people struggle to accept that they or their loved one are approaching the end of life. This difficulty can lead to denial. In some cases, individuals may genuinely believe that avoiding the topic makes the reality feel less true and will communicate accordingly.

"I think it is a way of coping. Like sticking your head in the sand. If I don't talk about it, it doesn't exist." -Janita (Palliative care worker)

FAÇADE

Façade is a coping mechanism similar to denial, but instead of rejecting reality, people choose to present a positive front and focus solely on optimism. Scheinfeld and Lake (2019) describe how adult children often feel compelled to remain positive, concentrating on fun and happy memories. They attribute this behaviour to hope, hope that the parent will recover or is not experiencing significant pain. Oskam provides an example in her book, describing the experience of an interviewee.

"That is what the children did as well : "Dad, it is going to be okay." "No, it is not" I will say." -Oskam(2021)

This can be difficult for the parent. Conversely, when the parent adopts a façade, it can be equally challenging for the child. This is illustrated by Ellen van Leenen, who describes her own experience with her father when she was younger.

"The other way around is hard for the child as well. I experienced it myself with my father. I would call him to ask how he was doing, and he would say: 1000%. And I would think: you are lying, I don't believe it." -Ellen van Leenen (Grief and loss coach)

CONFLICT

When people are not on the same page, conflict may arise. They may argue, blame one another, or even shut each other out entirely.

"You risk getting into a fight over it." -Janita (Palliative care worker)

Geraldine van Pelt also explains that it is often easier to lose control and direct frustration toward family members than toward professionals. She has experienced this in her own work and states:

"It is easer to let yourself go with someone that has been with you for 20 years than someone who has been visiting since two weeks." -Geraldine van Pelt (Former palliative care worker)

PROTECTION AND IMPLICATIONS FOR DESIGN

As described, there are many barriers and a variety of behaviours that emerging adults and their incurably ill parent use as coping strategies. **Ultimately, however, the primary goal appears to be preventing themselves and their loved ones from experiencing negative emotions.** Motivated by love, they often experience fear and doubt, they worry about burdening the other and fear confronting intense emotions, both their own and those of their loved one. This leads to people attempting to protect themselves and each other (See figure 14). While their aim is to protect, the strategies they use for protection do not always foster connection or effective communication, for example by avoiding communication alltogether.



Figure 14. Protection

Therefore, when designing interventions, it is important to help the target group overcome these barriers and encourage behaviours that promote genuine connection, while ensuring they feel safe.

BARRIERS IN THE END-OF-LIFE COMMUNICATION SCHEME

The barriers and coping strategies have been incorporated into the end-of-life communication scheme (see Figure 15). These barriers and associated behaviors can impact end-of-life communication, and are therefore represented accordingly within the scheme.

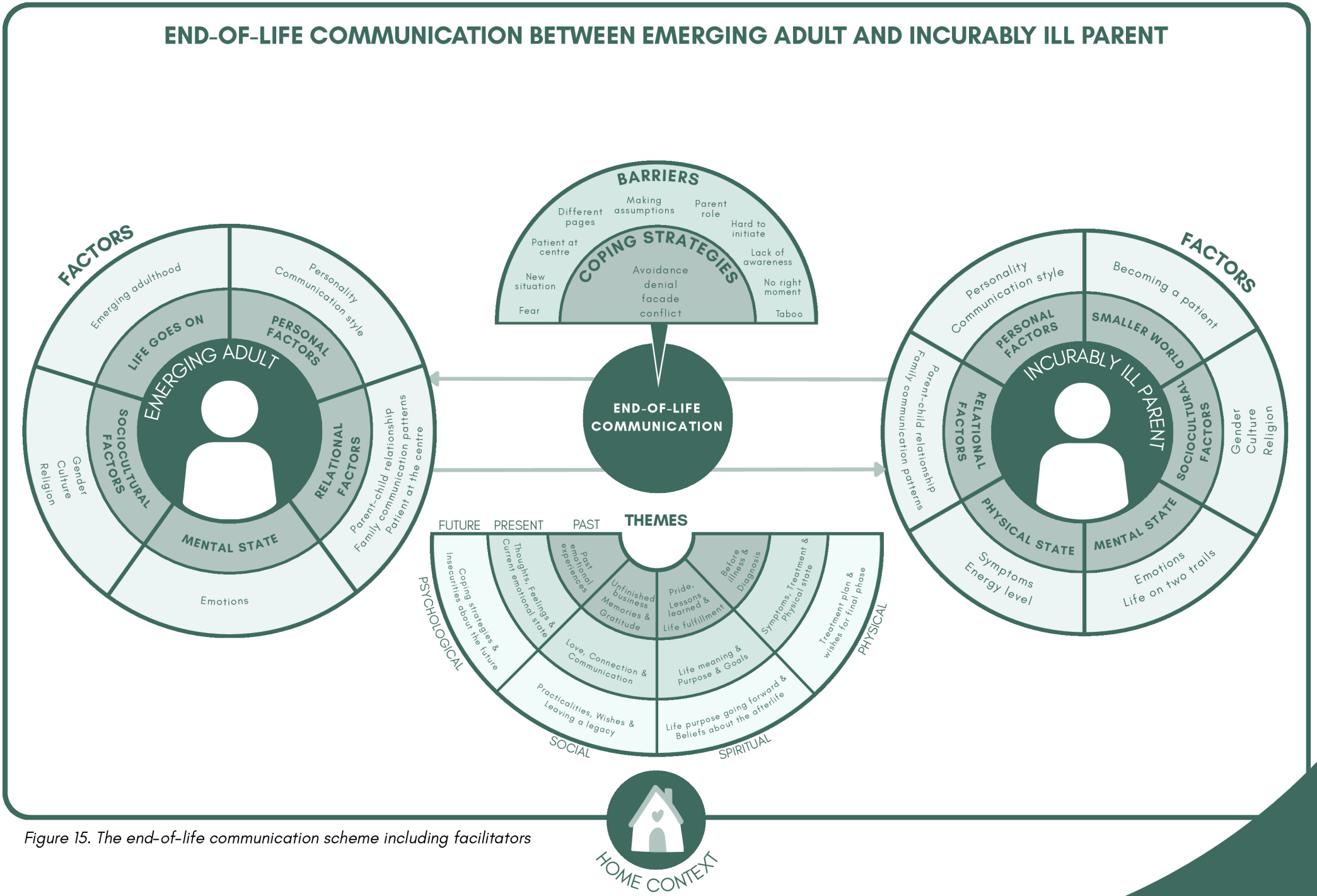


Figure 15. The end-of-life communication scheme including facilitators

2.5. Facilitators -
How we could connect emerging adults and their parents during the incurable illness process.

This section focusses on the following research question:
SubRQ4: How can communication between an emerging adult and their incurably ill parent about end-of-life needs and wishes be facilitated to improve mutual understanding, emotional support, and connection and what innovations to facilitate informal end-of-life communication already exist?

This question will be answered in two sections: strategies facilitating E-o-L-communication and means for facilitating E-o-L-communication.

STRATEGIES FOR FACILITATING E-O-L COMMUNICATION

There were multiple communication strategies identified in the research. These strategies can be used to improve or facilitate end-of-life communication. A list is shown in figure 16 and they will be explained seperately below.

STRATEGIES FACILITATING E-O-L COMMUNICATION

- Guidance
- Creating a moment
- Invitation and initiation
- Creating awareness
- Positive perspectives
- Exploration
- Encouraging open communication.

Figure 16. Stategies for facilitating end-of-life communication

GUIDANCE

There is a need for guidance in end-of-life communication. The situation is unfamiliar, and people may be uncertain about how to navigate it. Offering guidance, therefore, has the potential to serve as an effective facilitation strategy.

"Something like guidelines for hard conversations. Not just sitting down with a piece of paper but some communication tools." -Floris

CREATING A MOMENT

To facilitate end-of-life communication, it can be important to create a dedicated moment that has a clear beginning and end.

"How could you say the things you want and that it will be received? How can you create a moment? You could go cycling or for a drive, and that there is a beginning and an end to the conversation, that you'll say, when we arrive home, we will eat cake." -Annebet Nolen (Psychosocial therapist)

INVITATION AND INITIATION

Initiating end-of-life communication can be challenging due to fear or uncertainty; however, it is crucial to start these conversations. Facilitation can be achieved by providing an invitation to start the discussion, thereby making the initiation process less daunting.

"The invitation is so important: could you tell me about it?." - Astrid (Hospice worker and creative therapist)

"Something informal to start the conversation. A sort of reason to start the conversation. That you don't have to initiate yourself." - Leander

CREATING AWARENESS

The end-of-life process can be overwhelming, and some individuals may not be fully aware of their own wishes and needs. Encouraging a moment of reflection could help increase this awareness and support more effective communication of their preferences and desires.

"I had no idea what was happening and what my views on it were, what I wanted to get out of it." - Camiel

"I think you have to encourage reflection. I think it would have helped me. That it sinks in more." - Camiel

POSITIVE PERSPECTIVES

End-of-life communication is about perspective. While such conversations can be challenging, they can also be deeply meaningful and valuable. Encouraging a positive perspective may therefore serve as a facilitation strategy in end-of-life communication.

"I always explain to people, that even though getting a diagnosis is awful, it offers an opportunity for a meaningful period of saying goodbye and connection. That you especially need to have meaningful conversations together, speak about things you want to talk about and that it can be a gift." -Janita (Palliative care worker)

EXPLORATION

Exploring new strategies or methods of communication can be valuable, as it allows individuals to discover approaches that work best for them. Encouraging such exploration can therefore serve as a helpful aspect when designing interventions for end-of-life communication.

"It asks for some creativity, not like drawing, but dealing with it in a creative manner. To try something that might be a bit weird or different." - Astrid (Hospice worker and creative therapist)

ENCOURAGING OPEN COMMUNICATION

In facilitating end-of-life communication, it is important to encourage openness. This involves encouraging asking follow-up questions, being honest, allowing thoughts and emotions to simply exist, listening attentively, speaking from one's own experiences, and revisiting previous topics or conversations when necessary.

"Sometimes you really have to keep asking questions to get to the core." - Geraldine van Pelt (Former palliative care worker)

MEANS FOR FACILITATING E-O-L COMMUNICATION

There were multiple means for communication identified in the research. These means can be used to improve, facilitate or inspire end-of-life communication. A list is shown in figure 17 and they will be explained seperately below.

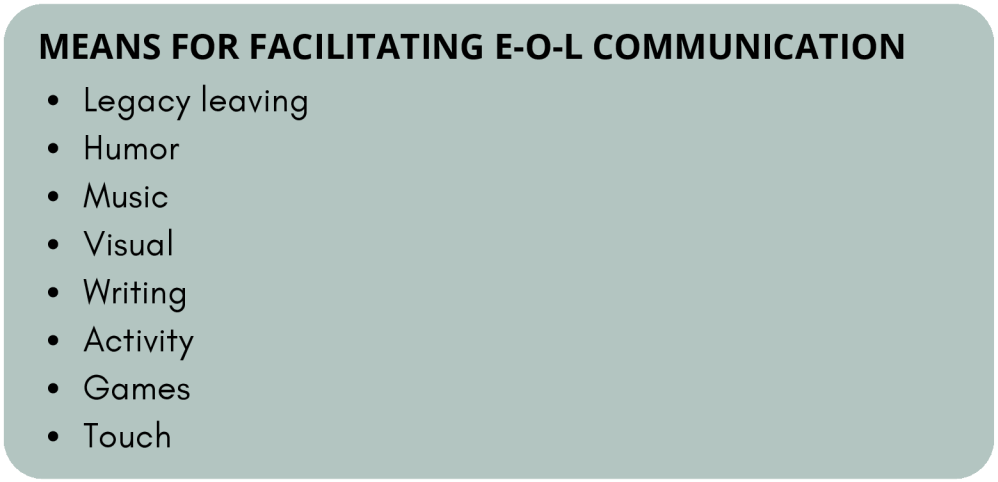


Figure 17. Means for facilitating end-of-life communication

LEGACY LEAVING

In a study by Muriel et al. (2019), it was found that legacy leaving can have a positive effect on bereaved children. Legacies can take various forms, such as personal possessions, photographs, videos, or written communication. Having something tangible left behind by a parent fosters a continuing sense of connection and serves as an important reassurance of the parent's pride and love.

A striking example of this is shared by Dave in the podcast Dealen met de Dood (Di Corrado, 2024). His father passed away after a short period of illness and had written him a letter before his death. Dave has not yet opened the letter, but he finds comfort simply in its existence. He describes keeping it as "having just one more conversation with my dad" and "having one more I love you left."

Legacy leaving holds value not only for those who remain behind but also for the terminally ill individuals who create the legacy. In a study by Allen (2009), a project involving legacy creation among family members encouraged participants to develop personal legacies. This process was found to strengthen individuals' sense of meaning and pride, positively influencing their overall quality of life.

Beyond tangible legacies, legacies can also take the form of advice and life lessons, referred to as an ethical testament. Such a testament may include reflections on significant life events, learned lessons, values, personal stories, advice, and expressions of love and gratitude (Van der Toorn, 2025).

HUMOR

Humor is often used as a coping mechanism to deflect discomfort and alleviate tension during conversations about end-of-life matters among family and friends (South and Elton (2017)). This study however does not include participants facing imminent death. Demjén (2016) examines the use of humour among cancer patients in online settings. In this context, humour can be empowering for patients. They often externalize their illness and use personification, treating cancer as if it were a "person" they can be angry with or blame. This suggests humor can be employed to alleviate tension making communication less heavy.

Theoretical experts also reinforce the importance of humor in EoL-communication:

"You don't have to scream of laughter, but a little bit of humor can help a lot." - Ellen van Leenen (Grief and loss coach)

"Sometimes you try as a nurse, because good moments are so important. If you can make a joke at the right time to put things into perspective. That can be very helpful, it's not just the heavy conversations." - Geraldine van Pelt (Former palliative care worker)

However, humor is a highly personal and sensitive matter, and it can sometimes lead to discomfort. Therefore, while humor can be a valuable tool in communication, it should be used with sensitivity.

"He makes a joke sometimes, but that often rubs me the wrong way. I don't like the jokes. I think he doesn't know what else to do. I just don't respond." -Floris

MUSIC

Music has the power to relax, connect, and evoke emotions, which can have valuable effects during the end-of-life process. Like for experience expert Madelief and her family.

"We sometimes turned on music and randomly dance together, we had a lot of fun doing so." -Madelief

Theoretical experts support this finding by stating:

Music can be so relaxing and connecting. - Annebet Nolen (Psychosocial therapist)

"Sometimes, music brings up emotions and feelings. Than there will be sadness. And it just exists, and we can deal with it. Comfort someone. That more layers underneath sadness emerge or that through sadness, tension is released. - Astrid (Hospice worker and creative therapist)

VISUAL

Visuals and images can evoke themes and emotions and serve as a starting point for conversations.

"You can choose a visual, and talk about it. What do you see? And then a conversation emerges." - Astrid (Hospice worker and creative therapist)

ACTIVITY

An activity can make discussing difficult topics easier, allowing communication without direct eye contact, which can feel less confronting.

"Because I think for younger people, doing an activity makes talking easier. I often go for a walk, then you don't have to make eye contact. -Ellen van Leenen (Grief and loss coach)

WRITING

Writing offers a means of communication that is less direct and potentially less confronting. Additionally, it can support the retention of important information, especially in situations where emotions may be overwhelming (Van Edom, 2017).

Sometimes it helps to write things down. Some people are better at writing than talking. - Gerda (Palliative Care worker)

Writing notes can be nice. You don't have to make eye-contact or be in direct contact. - Annebet Nolen (Psychosocial therapist)

GAMES

Owsley et al. (2015) state that a game, as a fun and structured activity, can create a safe and engaging atmosphere, helping to overcome barriers to discussing end-of-life topics. Therefore, games can serve as promising facilitators for end-of-life communication.

TOUCH

Physical touch can serve as a facilitating factor in communication, as it can feel reassuring.

"I believe touch, the tactile, is extremely important. That you feel each others hand or skin touching, that you establish that's still there." -Marjo (Hospice caregiver)

EXISTING INNOVATIONS AND INSPIRATION

A range of existing innovations provide inspiration for this project in several ways. Many of the analysed examples integrate elements previously identified as key facilitators. For instance, some use game-based components to spark conversations about difficult topics, while others focus on legacy-building, offer guidance, or create intentional moments for communication. These existing innovations not only inspire the project but also demonstrate that the identified facilitating factors are already being successfully applied in practice.

The innovations analysed for this project can be found in Appendix A5.

IMPLICATIONS FOR DESIGN

The identified facilitation strategies, methods, and existing innovations can serve as sources of inspiration for the design. Their qualities can be incorporated to support the desired interactions and create the intended user experience.

FACILITATORS IN THE END-OF-LIFE COMMUNICATION SCHEME

The identified facilitation strategies and tools for end-of-life communication are incorporated into the end-of-life communication scheme (see Figure 18). These facilitators can act as a bridge, helping to overcome the barriers described in Section 2.4.

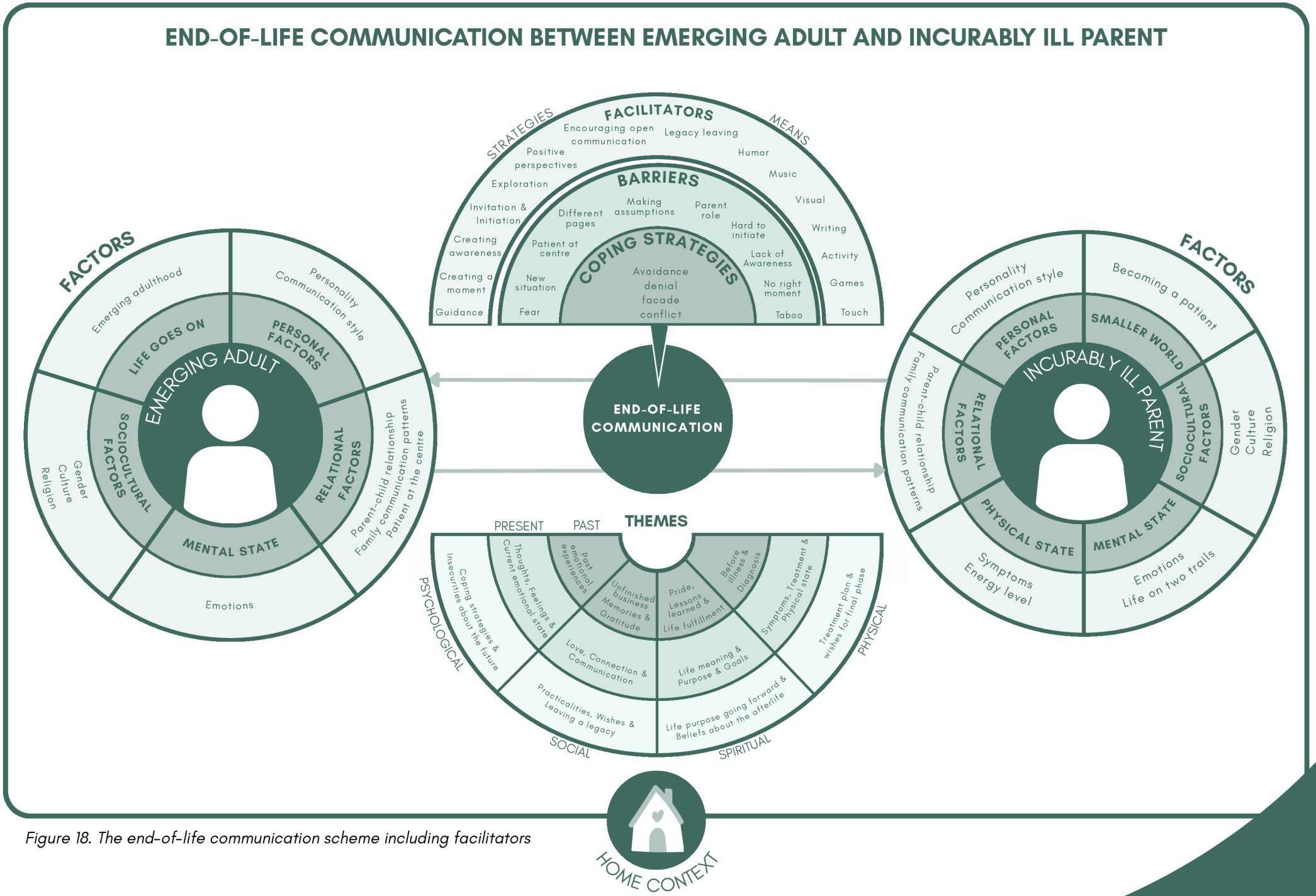


Figure 18. The end-of-life communication scheme including facilitators

2.6. Timeline - the end-of-life process

This section addresses the following research question:
Sub-RQ5: How does the emotional navigation of the end-of-life process evolve over time for both the emerging adult and their incurably ill parent?

To explore this question, a journey map was developed using insights gathered from experience experts through interviews, as well as from books written by individuals with lived experience. (See Figure 19 for the journey map.)

THE END OF LIFE PROCESS OVER TIME

Learning about the diagnosis, and thereby entering the beginning of the end-of-life process is often described as an emotional rollercoaster, marked by a wide range of intense and shifting emotions Like Floris (emerging adult) states:

"The beginning really was an emotional rollercoaster of emotions. From everything sucks to a bit of hope to everything sucks. It comes in waves." - Floris

After some time, the situation tends to settle into a calmer phase. There is more space for hope, and a new perspective begins to emerge. People often shift their focus toward spending meaningful time with loved ones. Although feelings of loss continue to appear in waves, a sense of a new "normal" gradually develops.

As people try to move on with their lives, they may begin to put on a façade and avoid conversations about the end of life. This avoidance can, in turn, lead to feelings of isolation and loneliness.

"Nobody asks me how I am doing, while I am feeling down. Is this my last christmas? How do I recover from everything I have been through since July? How do I go on with life from here?" -Oskam (2021)

Over time, the world of the parent gradually becomes smaller, as their social interactions and activities diminish, while the emerging adult's life continues to move forward.

As the end draws nearer, a growing sense of time pressure emerges, often prompting more open conversations about the end of life before it is too late. The final phase before passing is described as overwhelming and confronting.

"At the same time, you feel that it is now or never, if you want to have conversations, you have to do it now." - Leander

After the parent has passed, communication often takes on a symbolic form, which can manifest differently for each individual. Examples include rituals, letters, or symbolic objects such as butterflies, which serve as personal ways to maintain a sense of connection.

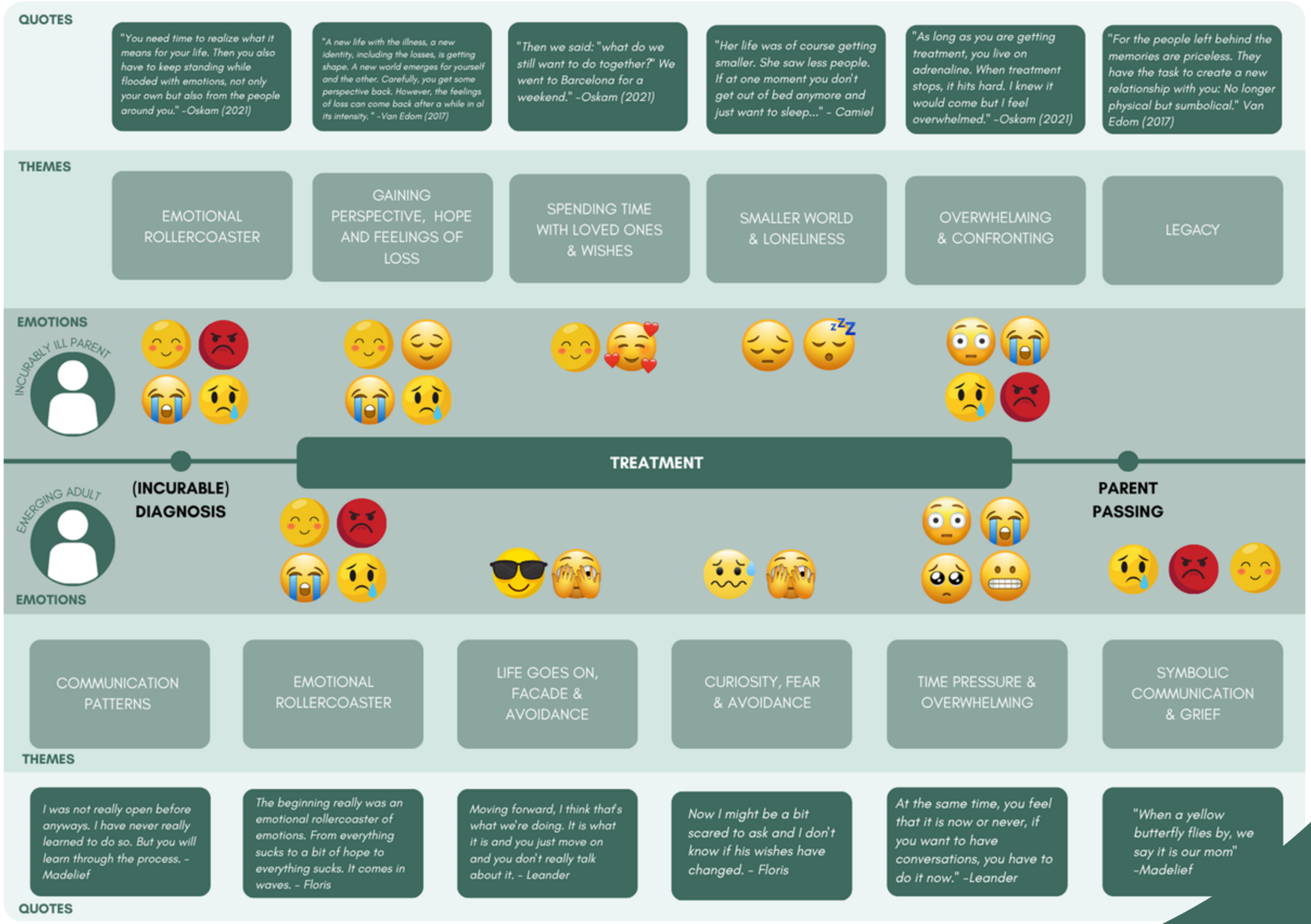


Figure 19. End-of-life communication journey map.

THREE PHASES

Based on this journey map, a timeline was created to illustrate how communication dynamics evolve throughout the end-of-life process (See figure 20). It is important to note that this process may vary for each individual and family; the presented timeline reflects a generalised representation derived from the collective insights of the experience experts. This timeline is presented from the viewpoint of the emerging adult, as the parent's perspective after their passing cannot be known.

Three main phases of the end-of-life process were identified, each with its own characteristics.

1. THE ADAPTATION PHASE

The adaptation phase begins with the onset of symptoms and the moment of diagnosis. During this period, both the parent and the emerging adult must adjust to the new reality. This phase is often described as an emotional rollercoaster, marked by feelings of panic and time pressure. These intense emotions can also lead to moments of closeness and open communication, as people feel the need to discuss their wishes.

2. THE "NEW NORMAL" PHASE

The "new normal" phase follows once initial adaptation has occurred. Life gradually continues, and both individuals attempt to re-establish routines. Although feelings of loss remain present, this period is generally calmer, allowing more room for hope and new perspectives. The parent's world becomes smaller over time, while the emerging adult's life moves forward, which can be conflicting and cause emotional distance.

3. THE TERMINAL PHASE

The terminal phase occurs as the end of life approaches. Both the parent and the emerging adult experience a renewed sense of time pressure, which can feel overwhelming and confronting. However, this awareness of limited time can also bring them closer together and encourage more meaningful communication. After the parent's passing, communication becomes symbolic.

IMPLICATIONS FOR DESIGN

For the design, the "new normal" phase presents the most promising opportunities. During this phase, there is a chance to bring people back together at a time when they might otherwise be drifting apart. Additionally, this phase is less overwhelming than the adaptation or terminal phases, providing enough emotional space for meaningful interaction with a concept.

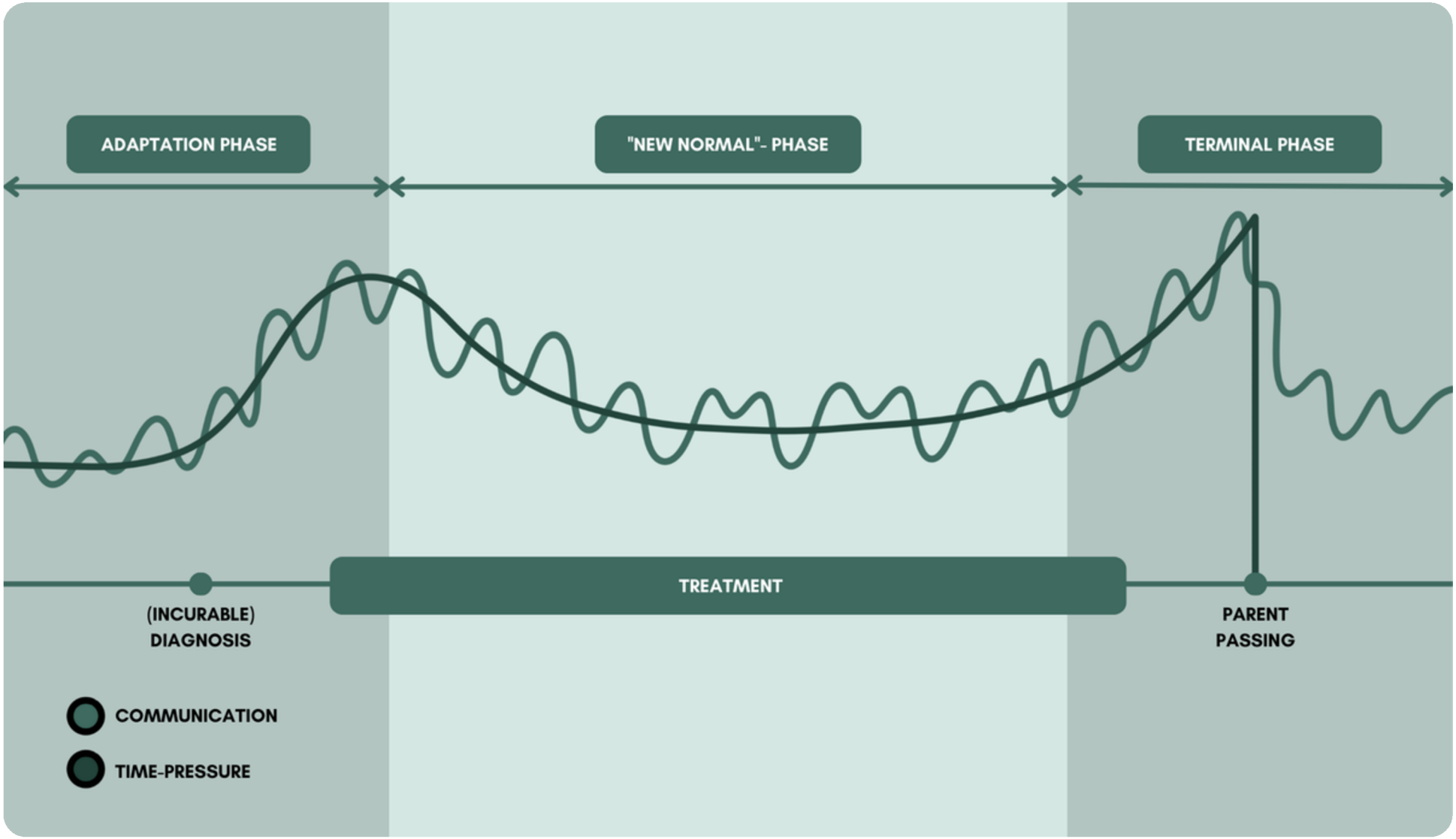


Figure 20. End-of-life communication timeline from the emerging adult viewpoint.

2.7. Communication between Wout & Iris

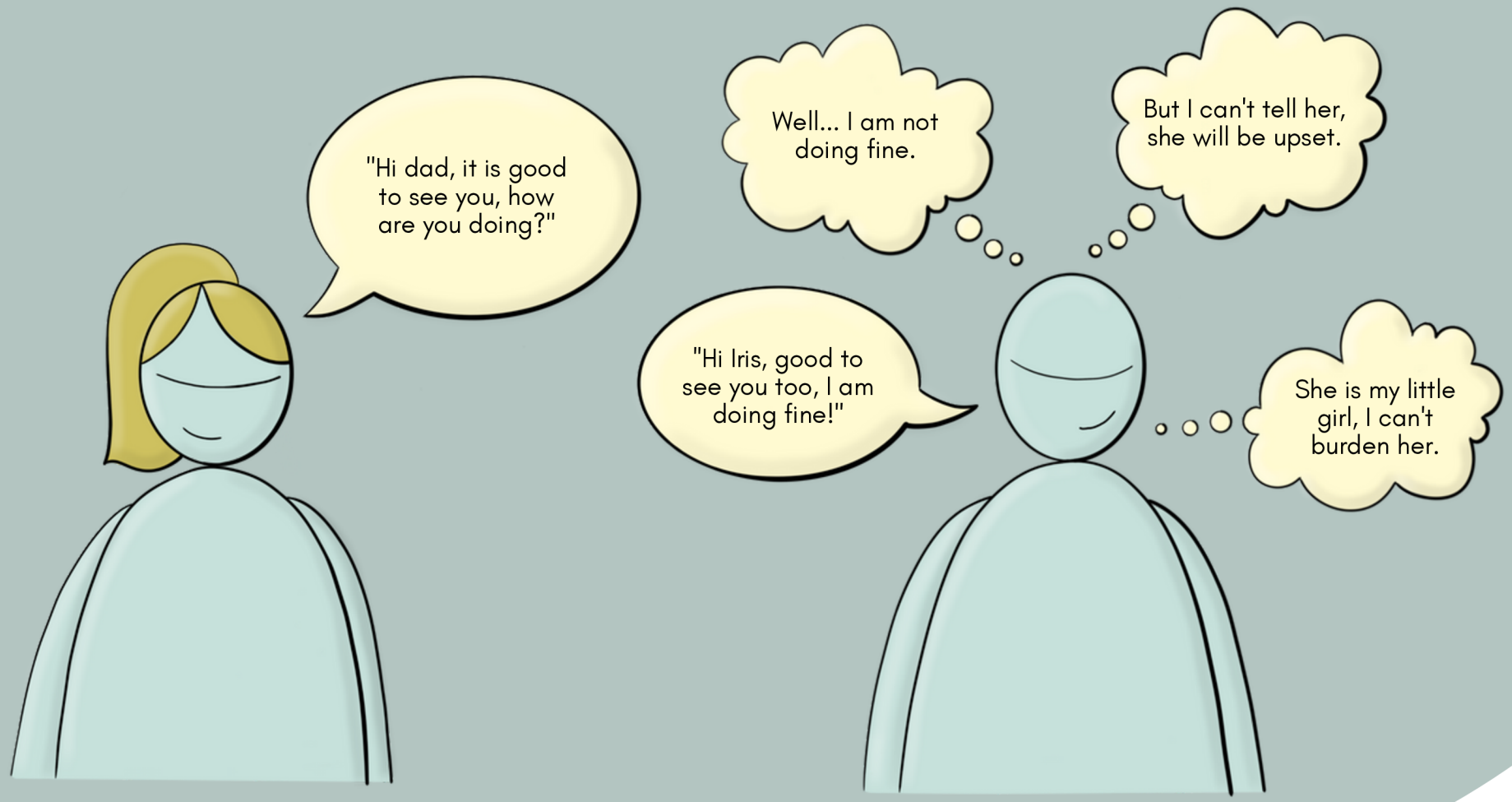


Wout began chemotherapy a few weeks ago and is currently coping with overwhelming emotions, physical symptoms, and feelings of insecurity.

After a week at university, Iris returns home, worried about her father's and struggling to cope with her own intense emotions.



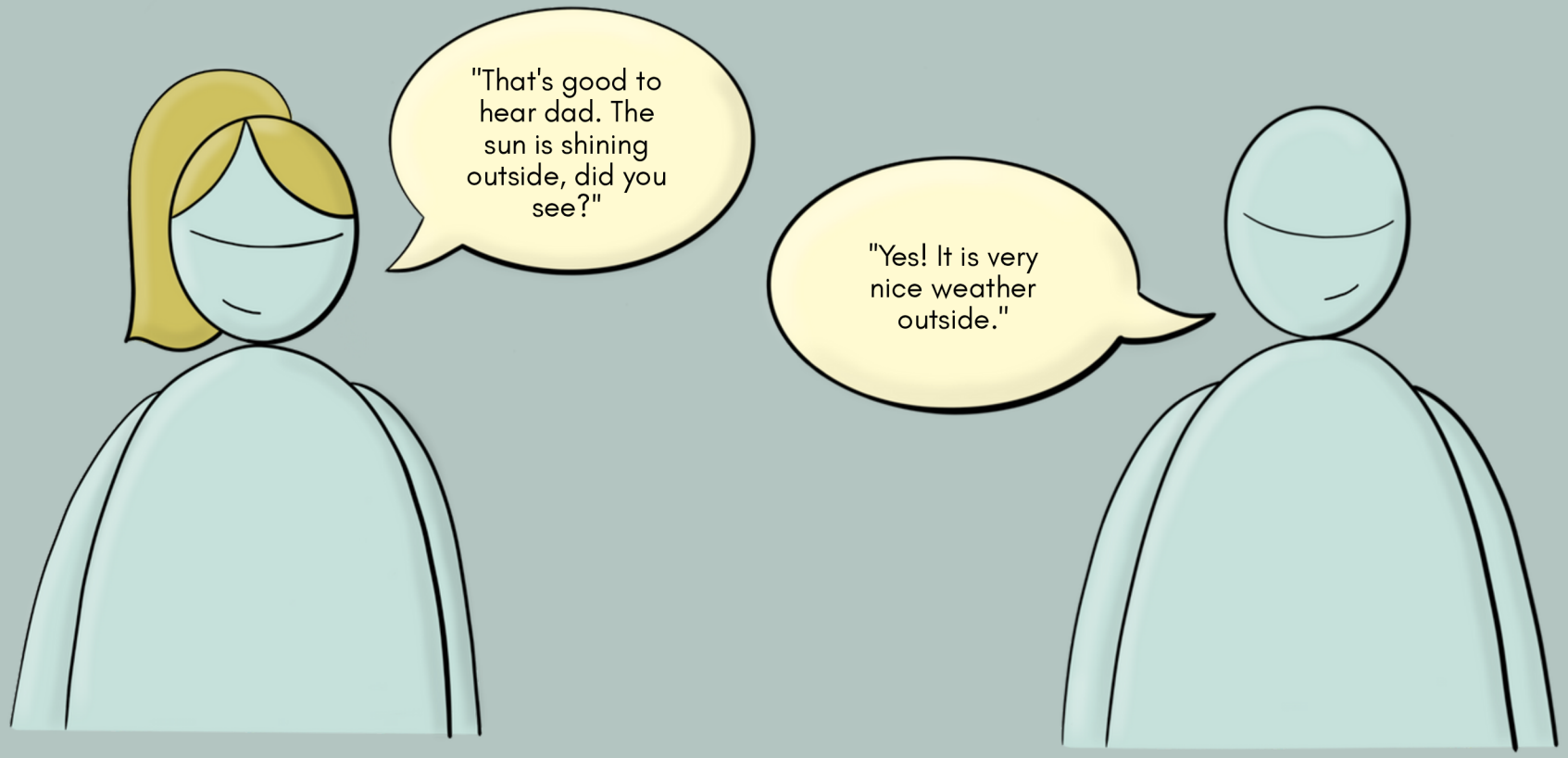
Upon seeing her father, Iris initiates the conversation by asking how he has been feeling.





Iris wonders whether her father is being completely honest with her. She wants to discuss the difficult topics with him, but certain fears and hesitations are holding her back.

Iris decides to let it go and shift the conversation to something more casual.



Discover
KEY INSIGHTS

FACTORS

Factors impacting end-of-life communication between emerging adults and their incurably ill parent include: sociocultural factors, personal factors, relational factors, Life goes on VS smaller world, physical and mental state.

Since there are many factors that influence the end-of-life communication process, and these can vary greatly from person to person, it became clear that any design solution must be flexible and allow room for personal interpretation.

THEMES

By combining the four pillars of palliative care with three temporal categories, past, present, and future, twelve subgroups of important end-of-life themes emerged. These subgroups can serve as inspiration for themes within the design.

What became evident throughout the research is that, in addition to communicating about wishes, feelings, perspectives, and practical matters, it is equally vital to communicate about **love and connection**, across the past, present, and future. Ultimately, **Love is what it all comes down to**.

BARRIERS

Multiple barriers to effective end-of-life communication for emerging adults and their incurably ill parent were identified, including: new situation, parent roles, being on different pages, taboo, difficulty initiating conversations, making assumptions, no right moment, lack of awareness, the patient being at the centre, and, most importantly, **fear**. These barriers can give rise to coping strategies such as avoidance/denial, façade, and conflict.

Ultimately, however, motivated by Love, the primary goal seems to be to prevent themselves and their loved one from experiencing negative emotions. They want to protect themselves and the other, but the strategies used do not always foster connection or effective communication between the two.

FACILITATORS

Strategies that facilitate effective end-of-life communication include: Guidance, Creating a moment, Invitation and initiation, Creating awareness, Positive perspectives, Exploration and Encouraging open communication. Means for facilitating end-of-life communication include: Legacy leaving, Humor, Music, Visual, Writing, Activity, Games and Touch. These facilitating strategies and means can inspire design in the next phase of the project.

TIMELINE

The end-of-life process exists of three phases: the adaptation phase, the "new normal" phase and the terminal phase. **The “new normal” phase** presents the most promising opportunities for design. During this phase, there is a chance to bring people back together at a time when they might otherwise be drifting apart.

THE END-OF-LIFE COMMUNICATION SCHEME

By combining all findings, a communication scheme was developed. This scheme illustrates the full range of factors, themes, barriers, coping strategies, and facilitators involved in end-of-life communication between emerging adults and their incurably ill parent (see figure 21). It is the same scheme presented in Section 2.5, shown here again as it provides a summary of the chapter.

Examining this scheme highlights the complexity of end-of-life communication. Numerous factors influence how this communication unfolds, and since everyone is different, it is evident that the design should be flexible, allowing room for personal interpretation.

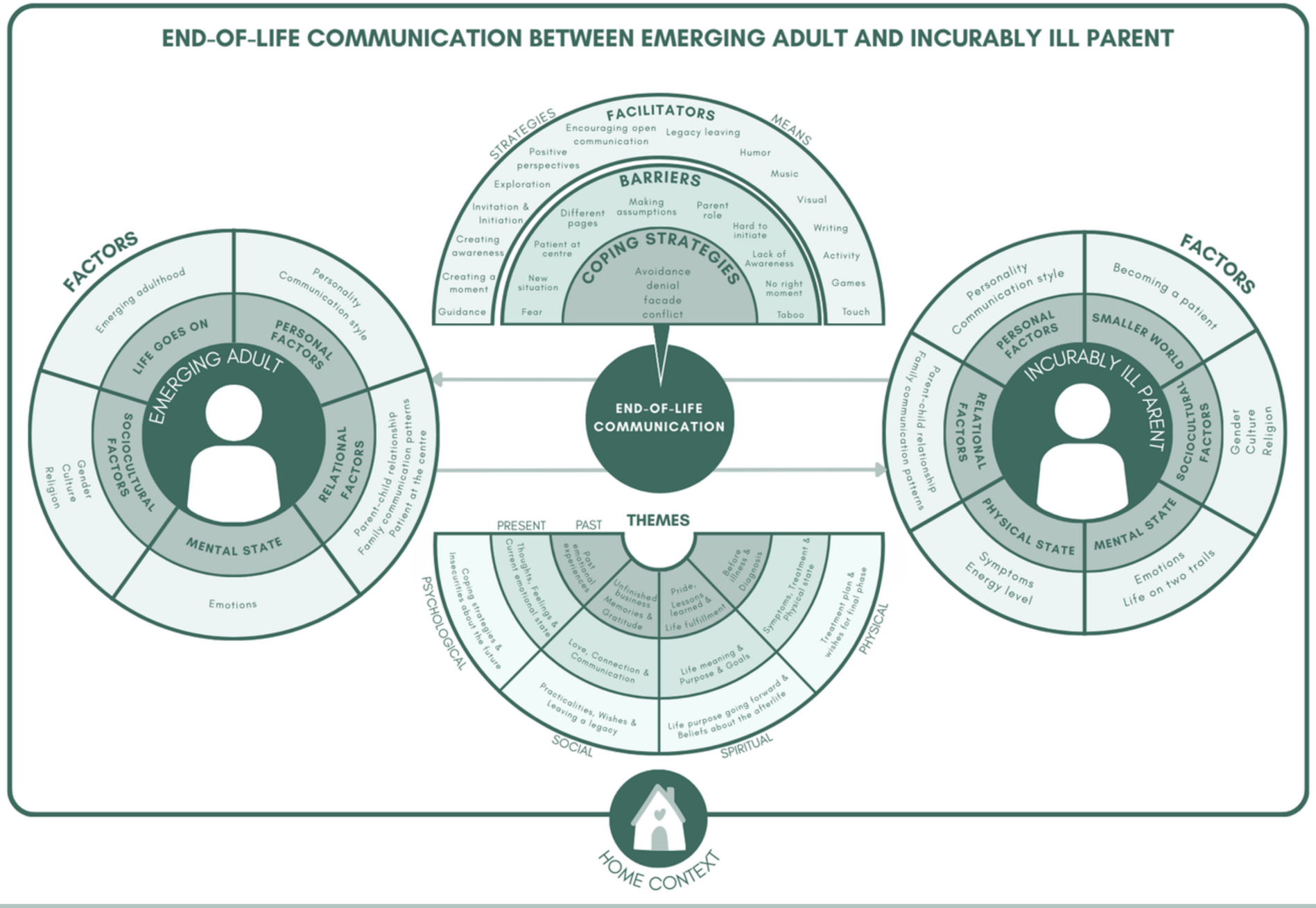


Figure 21. The end-of-life communication scheme (same as page 47.)

Define
CHAPTER 3

OVERVIEW

3.1. Design goal
3.2. Interaction vision
3.3. Interaction qualities & requirements

INTRODUCTION

This chapter explains the design vision. Section 3.1. states the design goal. The project's interaction vision is presented in section 3.2., and section 3.3. outlines the interaction qualities and requirements.

3.1. Design goal

The research shows that communication during the end-of-life phase can be a significant challenge. As outlined in Section 2.2, many factors influence this process, including social, relational, personal, contextual, mental, and physical aspects. Additionally, as discussed in Section 2.4, several barriers can hinder effective communication possibly leading to: **avoidance, conflict, denial, or maintaining a façade**.

The end-of-life phase is a vulnerable time, it is important that people connect during this time. As Geraldine van Pelt (former palliative care worker) states: '

'It is so important that the proces goes well, you can only do it once." -Geraldine van Pelt (former palliative care worker)

Based on the research, the following design goal is formulated:

"*The goal is to **foster connection** and create **mutual understanding** between emerging adults and their terminally ill parent during **the new "normal" phase** of the EoL-process at home, by creating space for **lightheartedness** and **open communication** about needs and wishes.* "

FOSTER CONNECTION AND CREATE MUTUAL UNDERSTANDING

The concept aims to foster a deeper connection between the emerging adult and their incurably ill parent. It should offer an opportunity for them to grow closer and to better understand each other's feelings, needs, and wishes.

THE NEW "NORMAL" PHASE

The concept will focus on the new "normal" phase of the end-of-life communication process, as described in Section 2.6. This phase occurs when individuals have, to some extent, adapted to the new reality of the situation.

Because this period is generally less overwhelming than the adaptation or final phases, it offers the most suitable moment to introduce an intervention. During this stage, the parent's world often becomes smaller, while the child's life continues to move forward. This imbalance can create friction, leading to feelings of loneliness or a sense of not being heard. Therefore, this phase presents a valuable opportunity to reconnect and strengthen relationships.

LIGHTHEARTEDNESS AND OPEN COMMUNICATION

Many people avoid conversations about the end of life out of fear. Fear of strong emotions, fear of how others might react, or fear of becoming a burden. To truly connect people, it's important to create space for lightheartedness within this sensitive topic. The concept should make communication feel lighter, more engaging, and even allow room for humor.

To foster genuine connection and mutual understanding, open communication is equally essential. The concept should encourage users to speak openly about the themes introduced in Section 2.3, helping them share thoughts and feelings with honesty and care.

3.2. Interaction vision

As a source of inspiration and guidance during the ideation phase of this project, an Interaction Vision was developed. This serves as an analogy for how interacting with the final concept should feel. It highlights how different aspects of the interaction can convey specific qualities. The Interaction Vision chosen for this project is as follows:

"Interaction with the concept should be like cooking a new recipe together."

Imagine cooking a recipe together that neither of you has tried before. You're both in the kitchen, following the instructions while adding your own touches and tasting along the way to make sure everything is just right. Soft music plays in the background as you share a drink and good conversation. Finally, you plate the dish and enjoy the meal you've created together (see Figure 22 for an impression).



Figure 22. Interaction vision (GettyImages (MonstArrr_) via canva.com)

QUALITIES	AFFORDANCES
Explorative (& Open)	New recipe, new techniques, different ingrediënts &tasting during cooking.
Comfortable (, Nostalgic & Safe)	Home context, smells & activity you have done together before.
Lighthearted	Background music, drinks & talking while doing something.
Connecting	Creating something together & standing next to each other.
Guiding	The recipe steps, instructions on packaging & helping each other.
Evokes curiosity	Not knowing the outcome yet, different ingredients & tastes and smells.

3.3. Interaction Qualities & Requirements

To define a clear vision of how people should interact with the concept, a set of interaction qualities and criteria was established (see Figure 23).

INTERACTION QUALITIES

EXPLORATIVE

Interaction with the concept should invite exploration. It should be open and flexible, allowing people the space to discover, experiment, and get to know each other better.

COMFORTABLE

The interaction should feel comfortable and natural. The concept should foster a sense of safety, creating a relaxed atmosphere.

LIGHTHEARTED

The interaction should be lighthearted, never heavy or pressuring. There should be room for playfulness, fun, and humor.

CONNECTING

The interaction should foster connection. The concept should bring people together and create meaningful opportunities to engage and bond.

GUIDING

The interaction should feel guiding. The concept should gently lead users through the experience.

EVOKES CURIOSITY

The interaction should spark curiosity. The concept should inspire users to explore, learn, and engage more deeply.



Figure 23. Interaction qualities

ADDITIONAL CONCEPT REQUIREMENTS

In addition to the interaction qualities, several other requirements for the concept have been defined:

BALANCE: DIRECT VS. SOFT

There is a need for emerging adults and incurably ill parents to communicate about difficult topics. The concept should encourage these conversations and gently push users beyond their initial fear. However, it is essential that this is done with sensitivity and care, ensuring the interaction remains soft and non-intimidating (See figure 24).

BALANCE: OPEN VS. GUIDING

While the concept should provide guidance throughout the experience, it must also leave room for openness and personal interpretation. Users should feel supported and not lost, yet still have the freedom to engage in their own way (See figure 24).

EMERGING ADULT & INCURABLY ILL PARENT

The concept should be designed for two users: an emerging adult and an incurably ill parent.

LOW EFFORT

Because the incurably ill parent may have limited energy, the concept should require minimal effort.

HOME SETTING

The concept should be suitable for use in a home environment, allowing interaction in a familiar and comfortable setting.

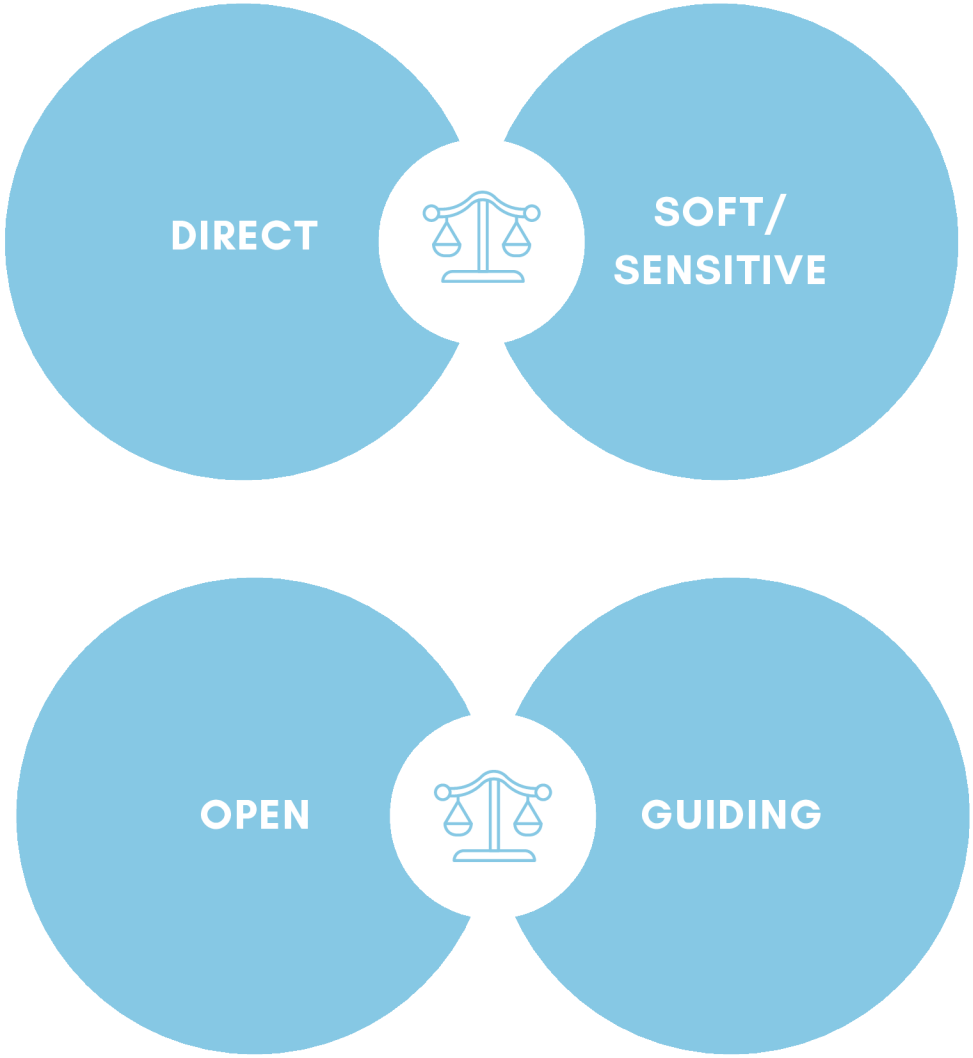


Figure 24. Additional requirements

Define

SUMMARY

DESIGN GOAL

*"The goal is to **foster connection** and create **mutual understanding** between emerging adults and their terminally ill parent during **the new "normal" phase** of the EoL-process at home, by creating space for **lightheartedness** and **open communication** about needs and wishes. "*

INTERACTION VISION

"Interaction with the concept should be like cooking a new recipe together."

INTERACTION QUALITIES

Interaction with the concept should be:

-Explorative
-Comfortable
-Lighthearted
-Connecting
-Guiding
-Evoking curiosity

ADDITIONAL REQUIREMENTS

-Balance between Direct & Sensitive
-Balance between Open & Guiding
-Two users: Emerging adult & incurably ill parent
-Low effort
-Home setting

Develop

CHAPTER 4

OVERVIEW

4.1. Design approach
4.2. Concept directions
4.3. Concept Direction Choice
4.4. Concept development

INTRODUCTION

This chapter discusses the development of the concept. Section 4.1. outlines the design approach, followed by Section 4.2., which introduces four concept directions. Section 4.3. then describes the selected direction and the rationale for its choice. Finally, Section 4.4. presents the development of the final concept.

4.1. Design approach

DESIGN APPROACH

Several methods were used during the ideation phase, each contributing to the development of creative concepts. These methods are described below.

HKJ METHOD

The HKJ method was applied throughout the ideation phase. By asking "How could you..." questions, new ideas emerged and alternative perspectives were explored.

FUNDAMENTAL NEEDS

The fundamental needs by Desmet (2020) were used as design lenses during the design phase. The fundamental needs were analysed to identify which ones are affected in the end-of-life context for both the emerging adult and the incurably ill parent. The affected fundamental needs were then used as a design lens.

CARDS

A set of cards was created and used during the individual brainstorm sessions and co-design sessions. The set consisted of three decks: one containing barriers identified in the research phase, one with facilitators and sources of inspiration also derived from the research, and one featuring fundamental needs (Desmet, 2020). During the sessions, cards were drawn blindly, sometimes one from each deck, or combinations such as a fundamental need with an inspiration card, or a barrier with an inspiration card. Ideas were then generated based on the content of the drawn cards. By continuously drawing new cards, new combinations and ideas emerged.

BRAINSTORM SESSIONS

Several brainstorming sessions were conducted individually. These sessions combined the various methods mentioned before and included sketching as part of the ideation process.

CO-DESIGN SESSIONS

As part of the design process, two co-design sessions were conducted with a fellow student. The sessions involved sketching, creating quick prototypes, and engaging in discussions. See Appendix B.1.1. & B.1.2. for more information and outcomes of the co-design sessions.

PROTOTYPING AND TESTING

Later in the process, prototyping was used as a design method. The prototypes were tested, which led to new insights and informed subsequent design choices.



Figure 25. Design methods

4.2. Concept directions

Based on the ideas that arised during brainstorming, four concept directions were developed. (See appendix B.1.3. for all the ideas)

CONCEPT DIRECTION 1: TIME CAPSULE

DESCRIPTION

The first concept direction centers on **leaving a legacy** (See figure 26). It takes the form of a box in which the emerging adult and their incurably ill parent can collect meaningful items such as letters, photographs, and other personal mementos. Once the box is filled, they lock it with a key.

When they bury the key and water the spot, a small tree begins to grow , creating a symbolic place that represents their connection. This place can serve as a comforting spot for the emerging adult to visit after their parent has passed away.

If they ever wish to revisit the memories, they can dig up the key and open the box to relive the moments stored inside. However, simply knowing that the box exists, filled with shared memories, may already provide a deep sense of consolation.

QUALITIES

- The emerging adult and the incurably ill parent engage in a meaningful activity together, which can serve as an opportunity and invitation to discuss end-of-life themes in a natural way.
- The parent may feel reassured by leaving a legacy, knowing that a part of them will continue to live on beyond their lifetime.
- The child may find comfort and continuity in having both a tangible box of memories and a physical place to return to.

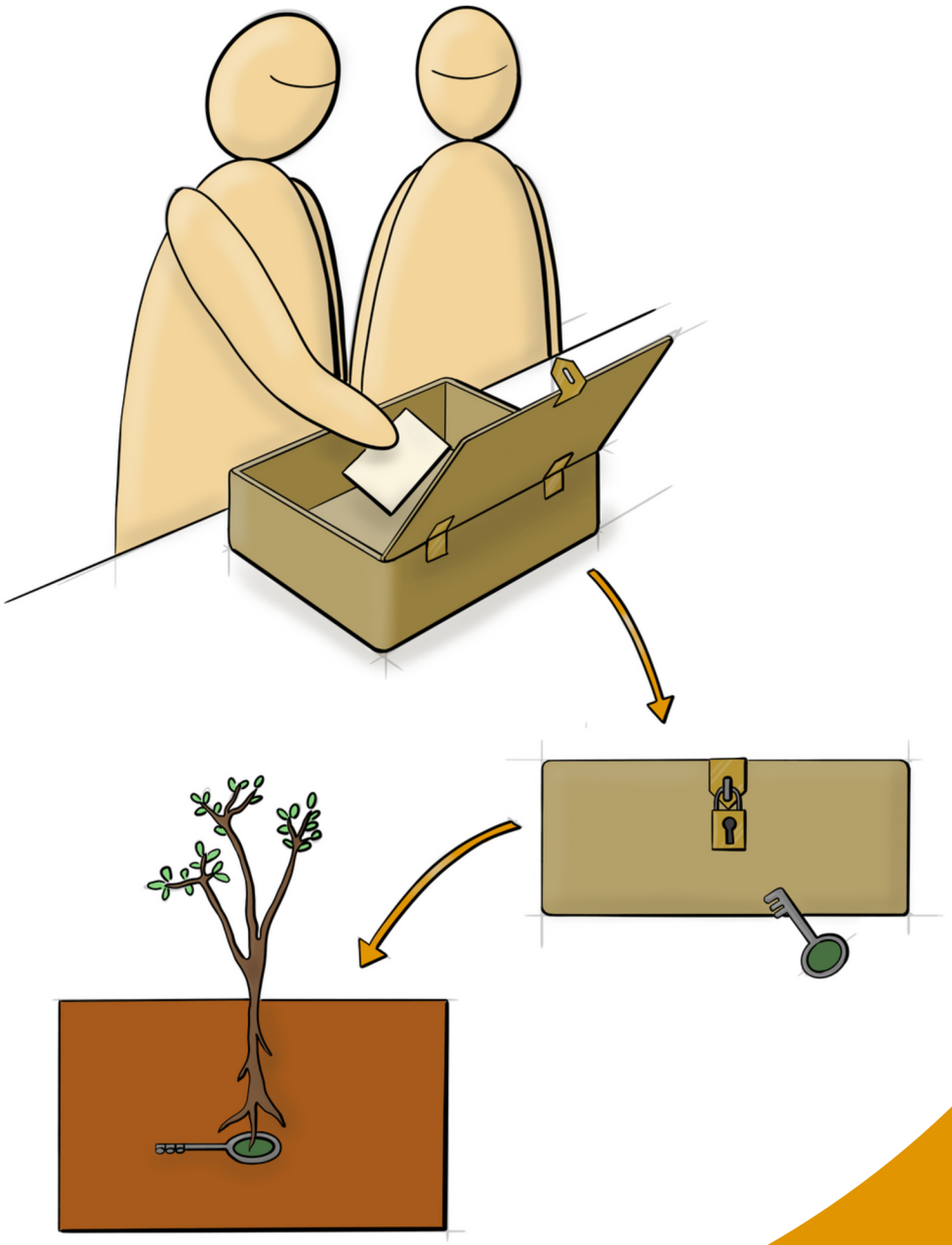


Figure 26. Time capsule.

CONCEPT DIRECTION 2: MOSAÏC

DESCRIPTION

The second concept direction focuses on **expressing worries and fears**. It involves a set of tiles, each associated with a different color representing a theme: Spiritual, Physical, Social, and Psychological (See figure 27).

On each tile, the emerging adult and their incurably ill parent can write down their feelings, fears, and worries related to that theme. Afterward, they smash the tiles together and use gold glue to reassemble the pieces into a mosaic artwork. Through this process, they create something beautiful out of something broken, both literally and symbolically.

QUALITIES

- The activity invites open sharing of worries and fears, encouraging meaningful conversations that can foster connection and emotional release.
- They can choose when they want to work on a tile; it doesn't have to be completed in one sitting. This allows them to take their time and engage with the activity whenever they have the energy for it.
- Breaking the tiles can serve as a powerful and freeing gesture, helping to relieve tension or heavy emotions.
- Creating something together provides a natural opportunity for conversation. Because both are focused on the activity and working with their hands, they are not required to maintain eye contact, which could make it easier to talk about difficult or sensitive topics.
- The resulting mosaic artwork becomes a tangible reminder of their bond and the valuable conversations they shared.

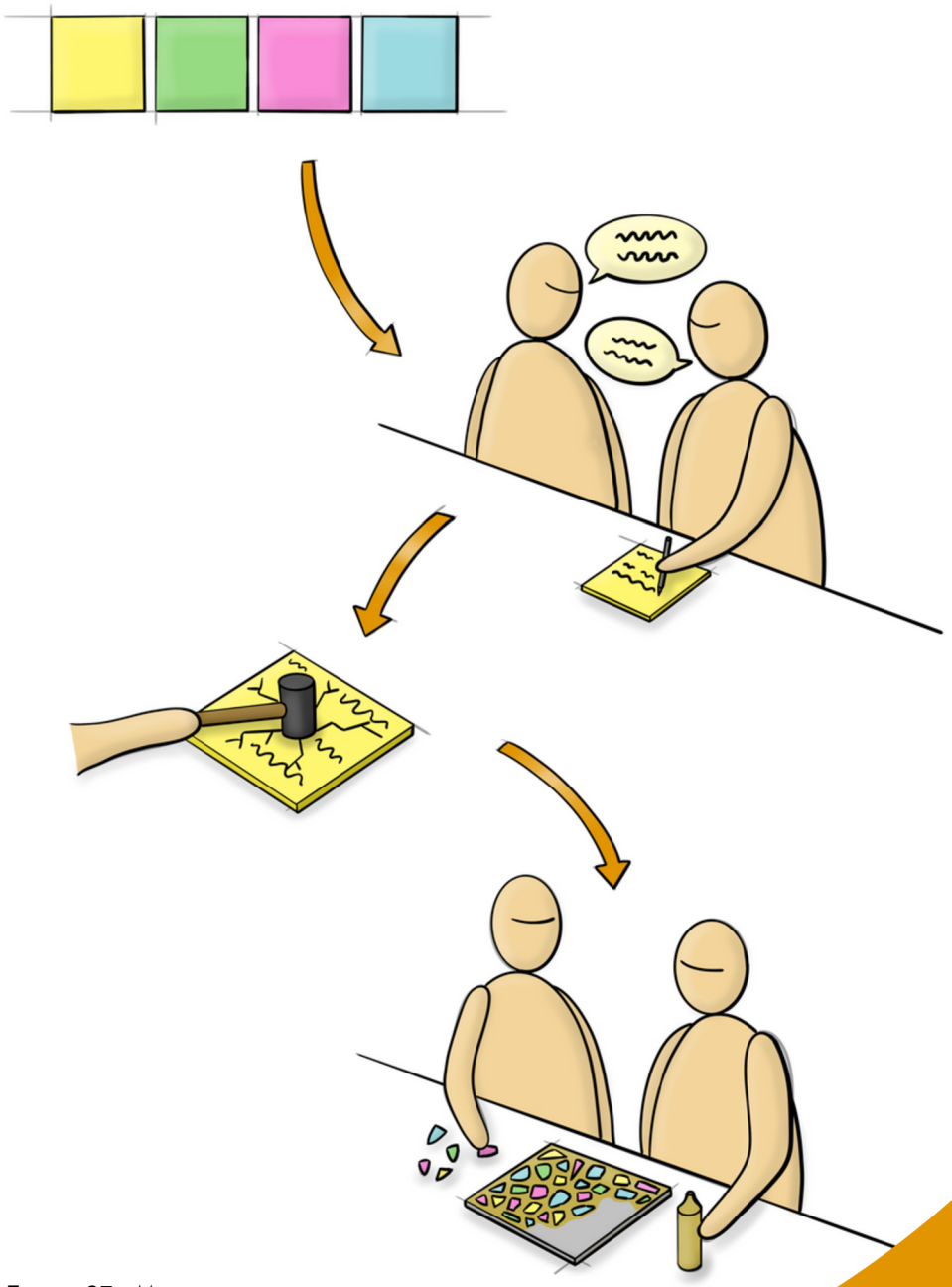


Figure 27. Mosaïc.

CONCEPT DIRECTION 3: AI LIFESTORY

DESCRIPTION

The third concept focuses on **legacy leaving by the incurably ill parent**. It takes the form of an AI-assisted platform where the emerging adult can submit questions they have about their parent's life. The AI also suggests example questions to help inspire and guide them.
Next, the parent answers these questions through audio recordings. The AI then analyzes the recordings and compiles them into a personalized book about the parent's life, complete with written stories and illustrations. The finished book is sent to their home, allowing them to read and reflect on it together (See figure 28).

QUALITIES

- The emerging adult is given the opportunity to ask all the questions they might have, without needing to ask them directly, which can make sensitive conversations easier.
- The parent may feel reassured knowing their life story is preserved, leaving behind a meaningful legacy for their child.
- Because questions can be answered seperately, the parent can take their time and respond whenever they have the energy.
- The emerging adult can find comfort and connection in revisiting the book whenever they wish.

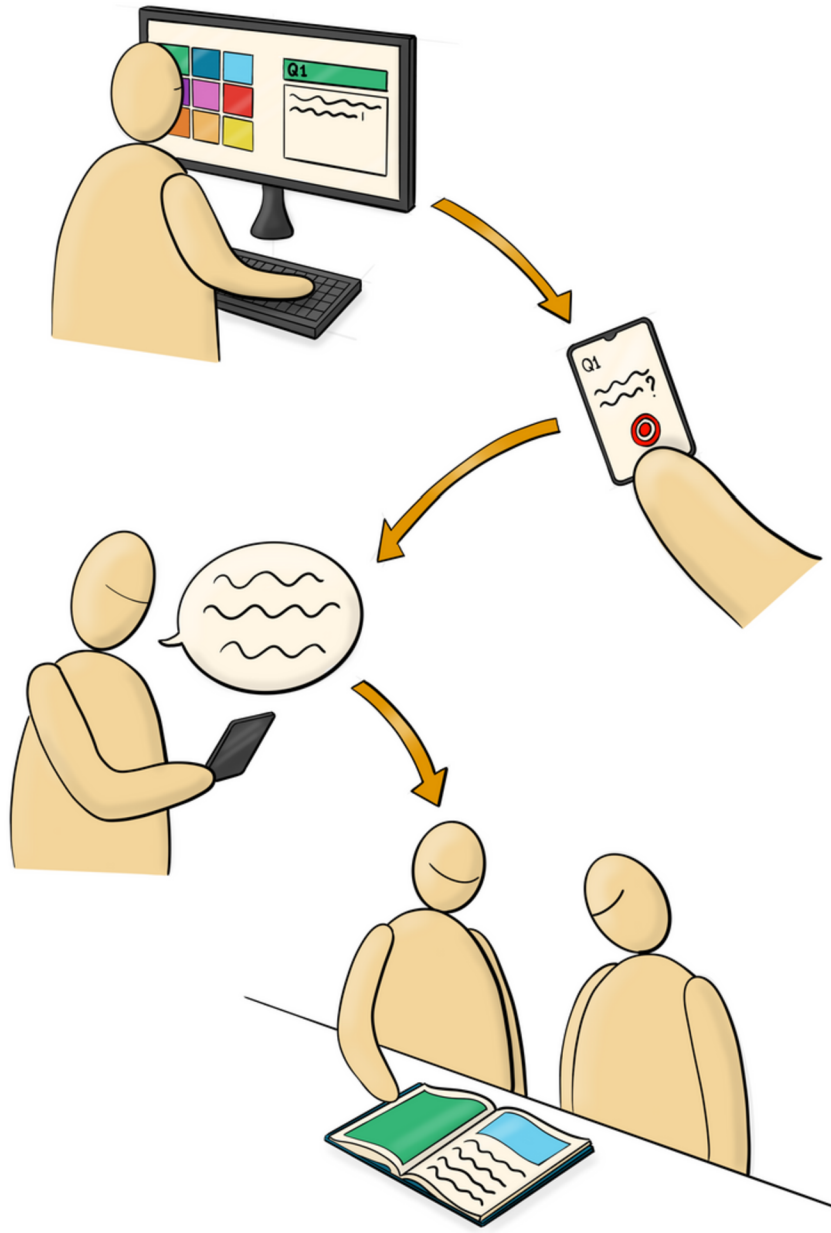


Figure 28. AI Lifestory

CONCEPT DIRECTION 4: MAILBOX

DESCRIPTION

The last concept focuses on creating **moments for open communication**. It takes the form of a mailbox that can be placed in the home. The mailbox comes with a set of colorful cards, each linked to a specific theme. These include: cards with images or illustrations, cards with predefined themes, cards with compliments, and blank cards where they can write their own themes, questions, or messages.

The emerging adult and their parent can place cards in the mailbox whenever they wish, for instance, when they have a question, a topic they want to discuss, or something they want to share. The other person can see that a new card has been added and decide when they are ready to talk about it.

A slider mechanism on the mailbox indicates readiness for conversation: when set to green, it means they are open to talking; when set to red, they prefer to wait. Once both sides are ready, they open the mailbox together and discuss the cards inside (See figure 29).

QUALITIES

- The mailbox creates opportunities for open and meaningful conversations, helping to address difficult topics as well as moments of appreciation and connection.
- Both participants can decide when they are ready to talk, giving them autonomy and emotional space.
- The cards inside the mailbox evoke curiosity and serve as gentle invitations to start conversations.
- Over time, the saved cards can become tangible reminders of their bond and shared moments, forming a meaningful legacy.

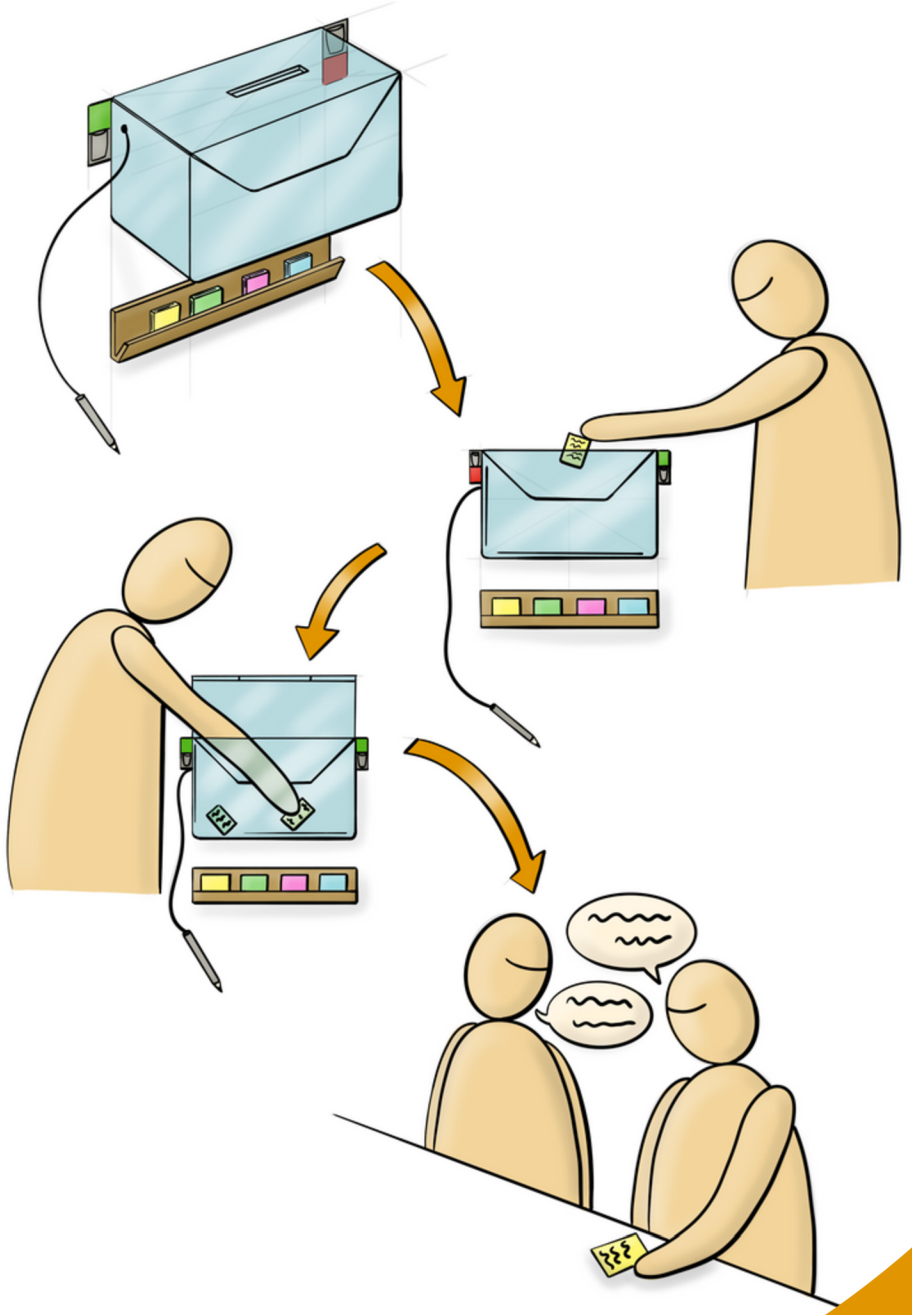


Figure 29. Mailbox.

4.3. Concept Direction Choice

To select a concept direction, the strengths and potential drawbacks of each concept were evaluated (See Appendix B.1.4.), and a decision was made through formal discussion regarding which concept had the most potential. Since the qualities of each concept are described in detail in Section 4.2, they are summarized briefly in this section.

CONCEPT DIRECTION CHOICE

Through formal discussion and evaluation of the positives and negatives, the decision was made to move forward with **Concept Direction 2: Mosaïc** (See figure 30)**.**

This concept was selected for several reasons. It had the fewest negatives, many of which are manageable, and it consistently sparked the most joy for the designer, making it the strongest choice based on both analysis and intuition.

In comparison, the time capsule concept is too simple yet simultaneously complicated. The AI-Lifestory concept lacked direct communication, limiting opportunities for meaningful connection, and the mailbox concept presented complexities that were harder to resolve. For these reasons, Mosaïc was chosen as the concept direction to develop further.

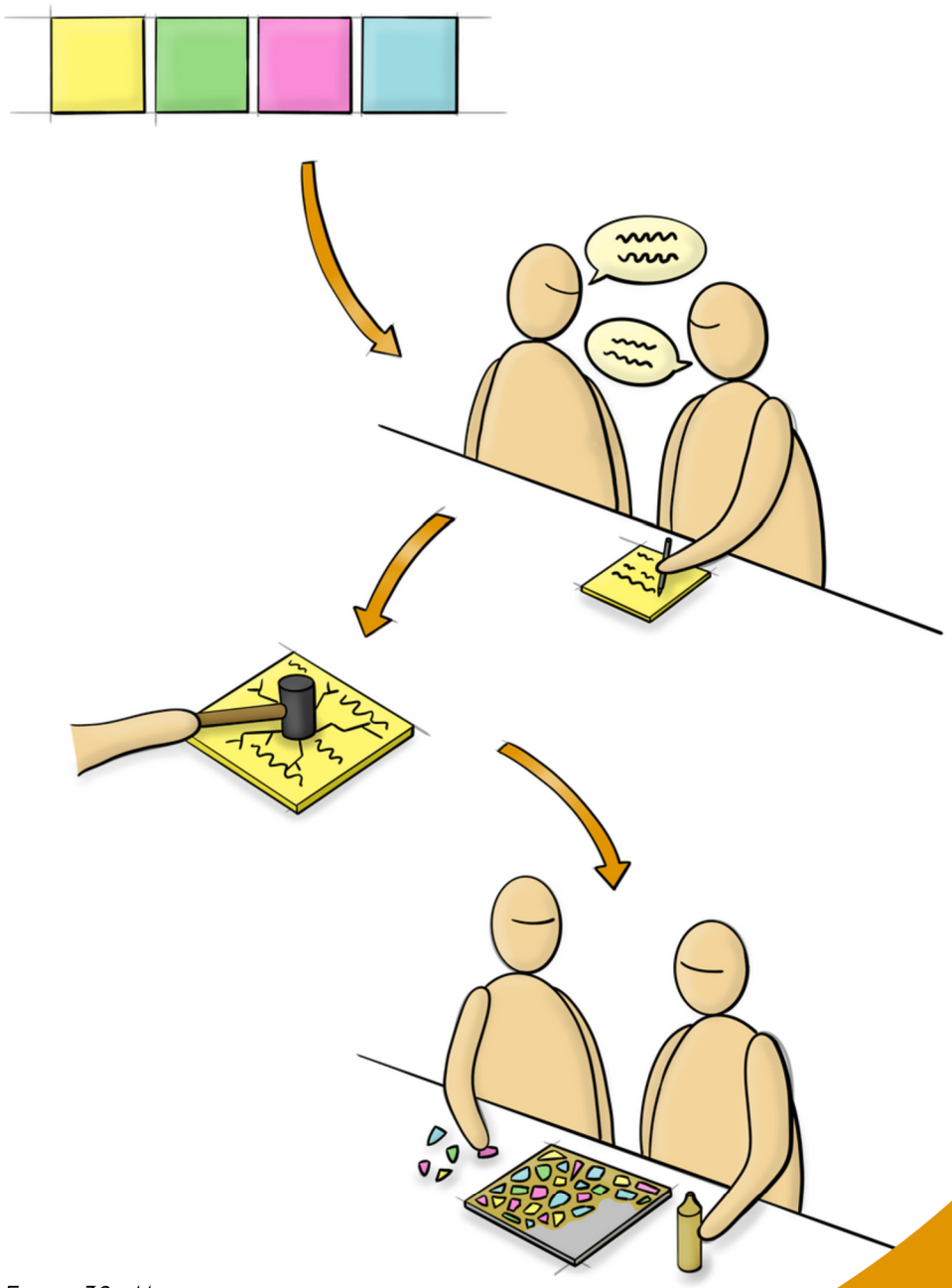


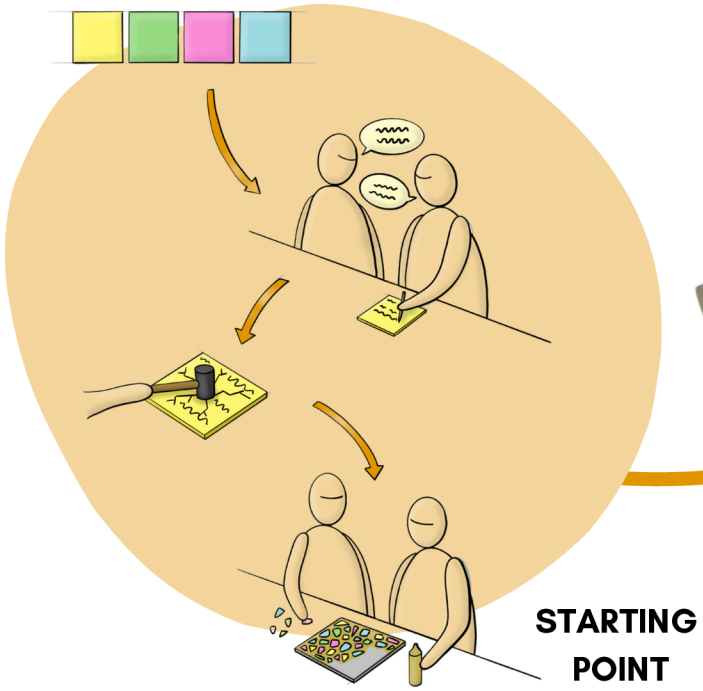
Figure 30. Mosaïc.

4.4. Concept Development

PROCESS

This section presents the most important decisions and key steps in the development of the concept based on prototyping and testing activities. A complete record of the concept development is available in Appendix B2. The section provides a concise overview to illustrate how the concept evolved over time supported by figures 30-36.

The starting point for the concept is the concept direction: Mosaïc.

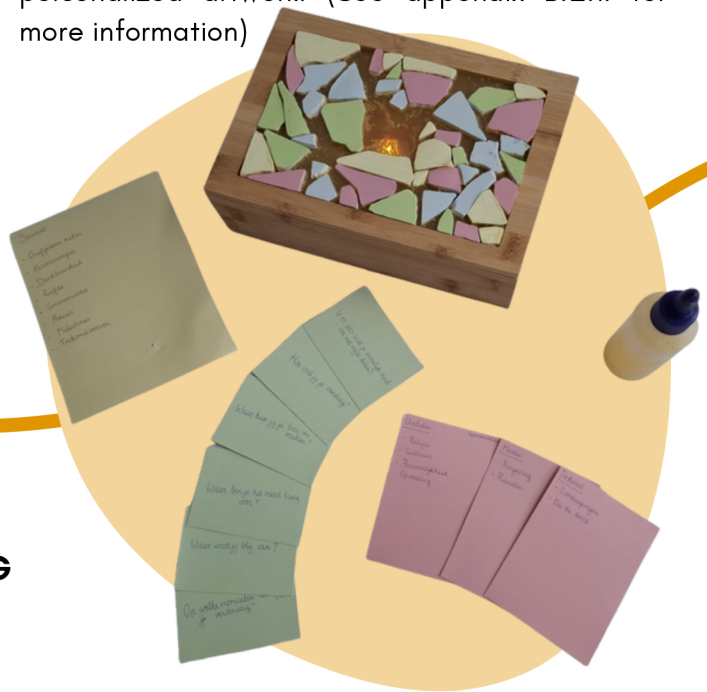


STARTING POINT

PROTOTYPE 1

The first prototype introduced the concept of a box to give the idea an additional dimension. The box also functions as a memory box, allowing users to store personal reflections. The mosaic, made from premade tiles for safety, is created on the transparent lid. A light is incorporated to provide the opportunity for a ritualistic experience.

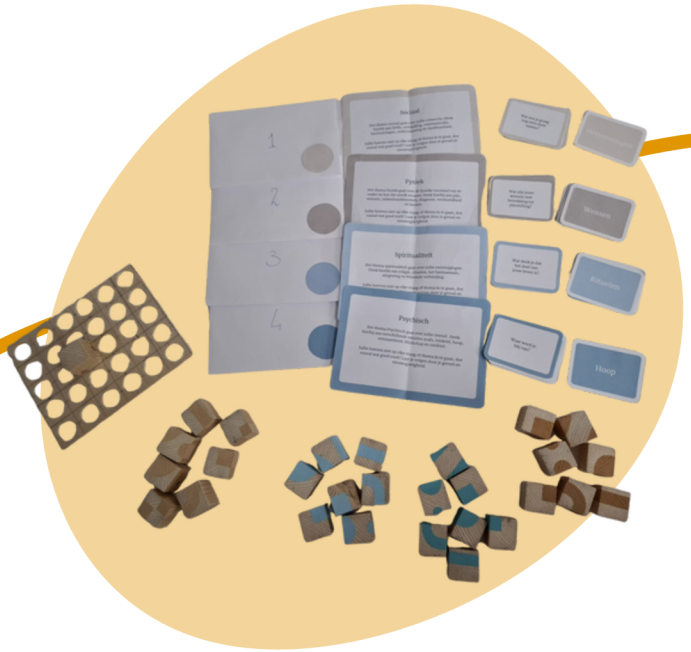
To prompt conversation, cards with subthemes or questions are included. Based on these conversations, users can write words or draw on the back of the mosaic tiles, gradually creating a personalized artwork. (See appendix B.2.1. for more information)



PROTOTYPE 1

PROTOTYPE 2

The second prototype introduced a new method of creation and a different aesthetic using wooden blocks. Each colour corresponds to a specific theme, with accompanying cards containing subthemes and questions. The cards are presented in envelopes to evoke a sense of curiosity (See appendix B.2.2. for more information)



PROTOTYPE 2

Figure 31. Concept development part 1

PROTOTYPE 3

The third prototype included shapes connected to subthemes and a list of example questions for guidance. The shapes provide more space for writing and drawing. When all conversations are done, the shapes can be put between two transparant plates to create a personal artwork with their drawings and writing on the back. (See appendix B.2.3. for more information)

BACK TO THE FIRST IDEA

After prototyping and testing. The choice was made to go back to the mosaïc box idea. Even though the idea needs work, it seemed to be the most logical and meaningful concept.

A new plan was made where smaller iterations were done and more formal communication was used.

INSPIRATION

The main inspiration for this concept is Día de los Muertos in Mexico, which translates to “Day of the Dead.” During these days, people honour their loved ones who have passed away through joyful remembrance and symbolic rituals.
Altars (Offrendas) are made to honor lost loved ones. They are often decorated with marigolds, which strong scent is believed to guide the spirits (The Grace Museum, n.d.).
Although the day centres around death, it is not a sombre occasion. People sing, dance, attend parties and parades, and wear colourful costumes (Ward, 2025). (See appendix B.2.4. for more information)



OUTCOME PROTOTYPE 3

BACK TO THE FIRST IDEA



Rom creator via canva.com



Getty Images (FG Trade Latin) via canva.com



Gettyimages (Francesca Casillas) via canva.com

INSPIRATION

Figure 32. Concept development part 2

THEMES

During the previous tests, it became clear that words and themes carry different meanings for different people. Terms such as psychological and spiritual evoke particular associations or energies, and participants often had preconceived feelings about them. For example, spirituality was sometimes perceived as too abstract or vague, making it difficult for participants to connect with.

To address this, the decision was made to replace the original four themes, Spiritual, Psychological, Physical, and Social, with three new ones: Past, Present, and Future. The original themes are now woven through these three temporal stages as subthemes without them being mentioned. (See appendix B.2.4. for more information)

DRAWER

A new design goal emerged: users should be able to view their artwork as well as the contents of the box simultaneously. Several sketching and prototyping iterations were conducted, leading to the selection of a drawer-like structure where the interior slides out.

The aesthetic of the box is inspired by ofrendas, incorporating levels and shapes reminiscent of flower petals. The mosaic tiles are also designed in a petal shape. Additionally, a slit at the top of the box allows users to display a picture or card, like on an altar. (See appendix B.2.4. for more information)

CARDS

Based on insights from previous tests, users were provided with enough space to draw and write on the back of the question cards, allowing participants to capture reflections.
Each card also includes an area for a mosaic leaf, on which users can write a summarizing word that represents the theme for them personally.
In addition, the design of the cards was carefully aligned with the overall aesthetics of the concept. (See appendix B.2.4. for more information)

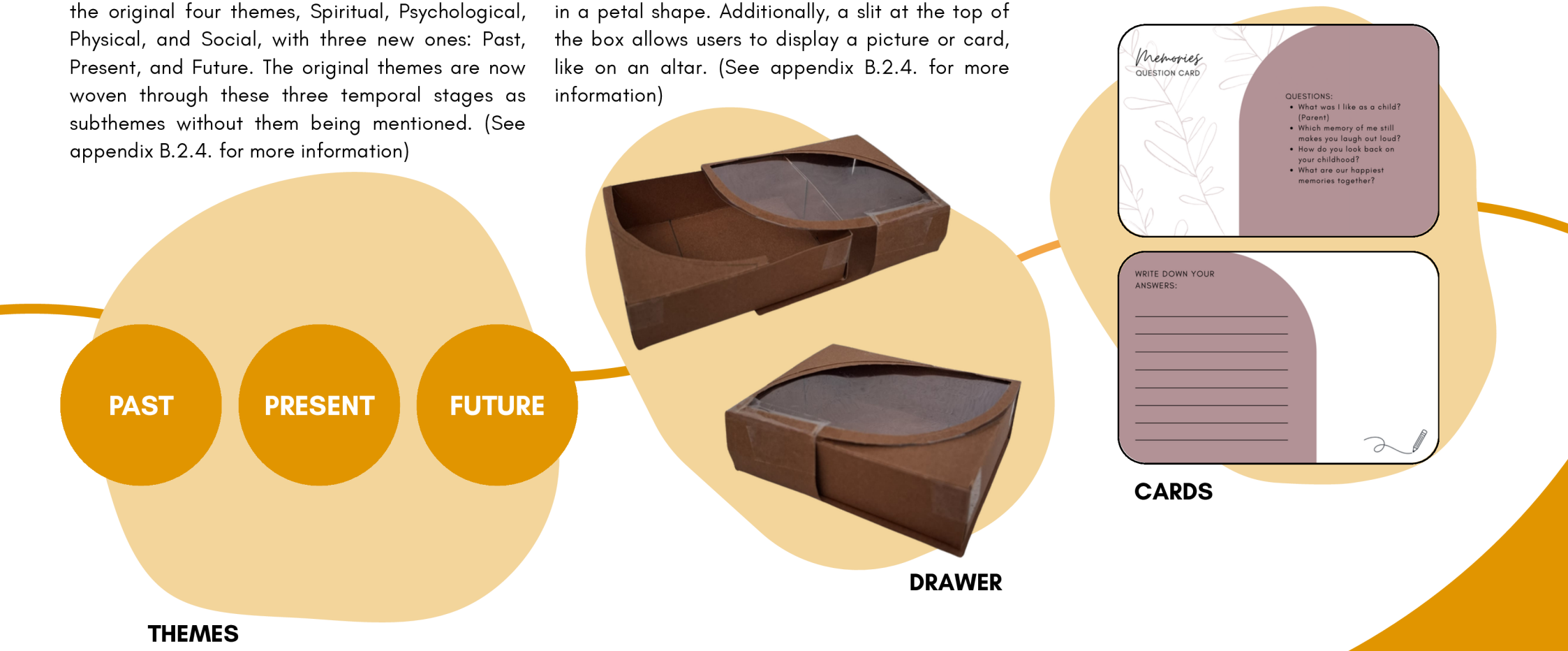


Figure 33. Concept development part 3

AESTHETICS AND TEXTURES

The interior of the box will be lined with fabric. An exploration was conducted to determine the most suitable fabric type and colour. In parallel, different types of wood and mosaic tile colours were evaluated, experimenting with multiple combinations to assess their effects.

Various combinations of wood, tile colours, and fabric were tested to identify the most harmonious pairing. The final choice was a medium-light wood paired with suede fabric. Six mosaic tile colours were selected, allowing participants to create personalized combinations based on their preferences. (See appendix B.2.4. for more information)

GENTLE YET DIRECT QUESTIONS

The questions on the cards were carefully reconsidered, particularly with respect to the "energy" of words. The goal was to create questions that were direct yet gentle, encouraging meaningful conversation without feeling confrontational. (See appendix B.2.4. for more information)

ASSIGNMENTS

During an interaction with ChatGPT, additional insights emerged regarding question presentation.

This led to the idea of introducing assignments alongside questions. Assignments could provide an active, experiential dimension, as performing an activity may elicit emotions or memories that can then be discussed.

For each theme, there are four subthemes with questions and two assignments. (See appendix B.2.4. for more information)

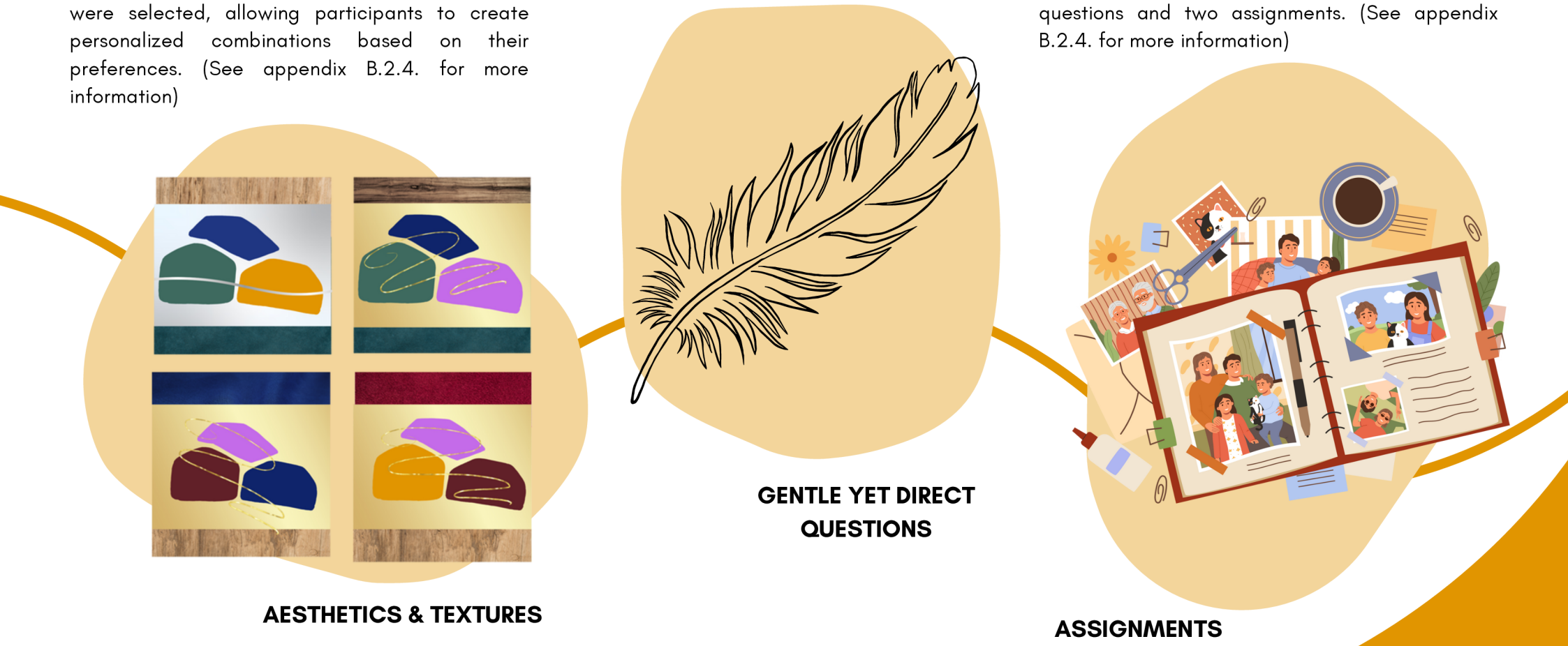


Figure 34. Concept development part 4

PROTOTYPE LEAFE V1

A prototype of the concept was created and tested, leading to the following key- insights:

- For some questions, it was unclear who the intended respondent was.
- Certain aspects of the interaction were not immediately clear, such as the ability to take the stone from the card; however, participants explored the process and found their own way to complete the tasks.
- The letters on the cards were small, making them difficult to read.

(See appendix B.2.5. for more information)

LOGO

The following name was chosen for the concept:

- Leafe, a combination of Leaf, Leave, and Lief (Dutch for “sweet”).

A visual exploration was conducted to develop a suitable logo. Initial designs were considered too harsh, so a completely different approach was explored, resulting in the final logo. (See appendix B.2.6. for more information)

MANUAL

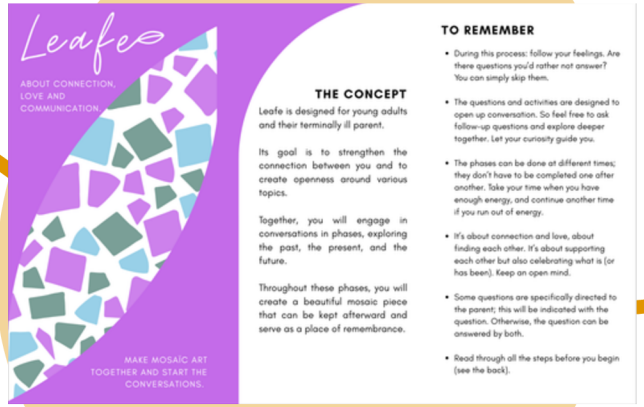
The manual was refined to better align with the overall aesthetics of the concept. Additional illustrations were added to clearly demonstrate how the concept works, improving participant understanding. (See appendix B.2.6. for more information)



PROTOTYPE LEAFE V1

Leafe

LOGO



MANUAL

Figure 35. Concept development part 5

PRESENTATION OF CONTENTS

It was decided to present the sets of cards in a gift-like format, using ribbons and title cards. This approach creates a more personal and caring experience for the user.

As recommended, bags were created using the same suede fabric as the box lining to hold the mosaic filler stones and additional materials. This ensured that all components matched the overall aesthetics of the concept. (See appendix B.2.6. for more information)

CLARITY

The wording on the cards was updated to clarify who should answer each question. Instead of simply stating (Parent), the text now reads “Ask the question to the parent”, making the instructions more explicit.

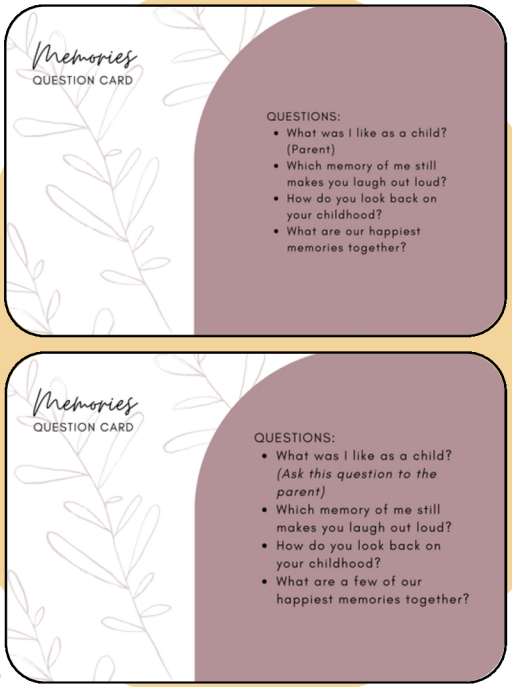
Additionally, the font size on the cards was increased, addressing readability issues identified in previous testing. (See appendix B.2.6. for more information)

FINAL PROTOTYPE

The iterative process has resulted in the final prototype, which is presented and explained in detail in the next chapter



PRESENTATION OF CONTENTS



CLARITY



FINAL PROTOTYPE

Figure 36. Concept development part 6

Develop
SUMMARY

DESIGN APPROACH
Several methods were used during the ideation phase, each contributing to the development of creative concepts. The methods include: the HKJ-method, fundamental needs (Desmet, 2020), prompt cards, brainstorm sessions, sketching and co-design sessions.

CONCEPT DIRECTIONS
Four concept directions were created based on ideation: Concept direction 1: Time Capsule, Concept direction 2: Mosaïc, Concept direction 3: AI lifestory and Concept direction 4: mailbox.

CONCEPT DIRECTION CHOICE
Through formal discussion and evaluation of the positives and negatives, the decision was made to move forward with Concept Direction 2: Mosaïc.

CONCEPT DEVELOPMENT
Through multiple rounds of prototyping and testing, the concept was refined, leading to the final design, which is described in the next chapter.

Deliver

CHAPTER 5

OVERVIEW

5.1. The Final Concept: Leafe
5.2. Scenario - How does it work?
5.3. Evaluation
5.4. Wout & Iris Connecting

INTRODUCTION

In this chapter, the final concept is presented. Section 5.1. introduces the concept, followed by a user scenario in section 5.2.. The evaluation of the concept is presented in section 5.3.. The chapter concludes with a part of Iris and Wout's story, illustrating how they connect through the concept in section 5.4..

5.1. The Final Concept: Leafe

In this section, the final concept is presented. It begins with a general introduction, followed by a detailed explanation of each component of the concept.

CONCEPT INTRODUCTION

The final concept (see Figures 37 and 38) is called Leafe. The name combines several meanings: Leave, referring to the end of life of a parent; Leaf, since the concept is inspired by leafs; and the Dutch word Lief, meaning sweet.

At its core, Leafe is an activity that facilitates connection between an emerging adult and their terminally ill parent. Together, they create a mosaic artwork while engaging in conversations about end-of-life themes.

The concept consists of three phases, Past, Present, and Future, each containing a set of cards with specific themes. These cards feature questions or assignments designed to prompt meaningful discussion. After completing each card, a summarizing word is written on a mosaic leaf, which can then be attached to the box. Once all cards have been completed, the artwork is finalized with smaller mosaic stones.

Finally, the box serves as a keepsake, a place to store photos and mementos, and a tangible reminder of shared memories.



Figure 37. Final Concept Leafe

COMPONENTS DISPLAYED



Figure 38 Final Concept unpacked.

PARTS EXPLAINED

BOX

The box is composed of two parts: the outer shell and the drawer. (See figure 39) The top of the outer shell features a transparent, leaf-shaped window that serves as the surface for arranging the mosaic tiles. Its see-through design allows the light source housed in the drawer to illuminate the mosaic when switched on. A shallow groove on the top also makes it possible to place a photograph above the window.

The drawer holds the components of the concept: the manual, the cards with questions and assignments, the mosaic tiles, and additional supplies needed to create the artwork.



Figure 39. Final Concept Box.

TEXTURES

The box incorporates a variety of tactile materials (see figure 40). The interior of the drawer is lined with soft suede, providing a gentle and protective surface for the meaningful items stored inside. The envelopes are crafted from textured paper, the wood offers a warm and pleasant feel, gold foil accents highlight the logo, and the mosaic tiles introduce an extra interesting texture.



Figure 40. Textures

ADDITIONAL SUPPLIES

The concept includes a set of additional supplies needed to complete the activities. Inside the box are two pouches. One pouch contains small mosaic filler tiles that can be used to complete and refine the artwork. The second pouch holds a marker for writing on the mosaic leaves , glue to attach the tiles to the box, transparent mosaic filler to finish the artwork and a remote control for adjusting the light inside the box (see figure 41).



Figure 41. Additional supplies:
All purpose glue (12ml) by Collall
Transparant mosaic filler by Creartec
Paint marker (gold & silver) by Edding 791
Ledlight set & remote by Baltimore
Mosaic tiles by Mozaiektegeltjes-enzo

MANUAL

A manual has been designed for the concept (see Figure 42). The front side provides an explanation of the concept along with several practical tips. On the back, a step-by-step guide outlines the process of engaging with the concept. A larger version of the manual can be found in Appendix C1.1.

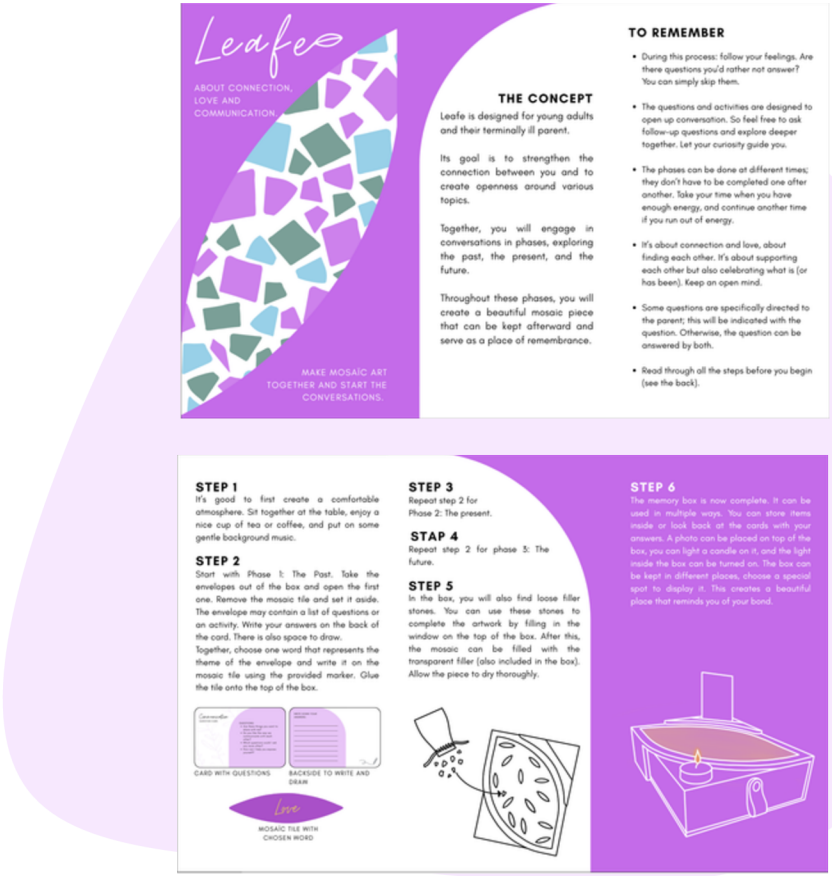


Figure 42. Manual

QUESTION AND ASSIGNMENT CARDS

The box contains three sets of cards, each corresponding to one of the three temporal phases: 1. Past, 2. Present, and 3. Future. Participants work through each phase individually, with the flexibility to split a phase across multiple sessions if the parent's energy level requires it.

Each set includes six cards stored in labeled envelopes. Four cards contain reflective questions, while the remaining two provide assignments. The back of every card offers space for writing or drawing, encouraging personal expression and deeper reflection.

Each card is paired with a mosaic leaf tile. After completing a card, participants summarize its theme in a single word and write it on the tile. The tile is then glued onto the top of the box, gradually forming a meaningful, personalized mosaïc artwork. (See figure 43)



Figure 43. Cards

The questions and assignments are about important themes identified in section 2.3. Assignments could for example be: going through old photos (Past), listening to music (Present) or writing each other cards with wishes (Future).

The questions are designed to be direct, addressing important themes that may be difficult but need to be explored. At the same time, they are framed gently to create a softer, more approachable experience. This combination of soft yet direct wording can help users feel less pressured and more comfortable during the conversations.

For example, rather than asking, *"What do you still want to do together?"*, the question is phrased as "*What do you want to do together?*" or "*What things are on your bucket list?*" Similarly, instead of asking, *"Is there something you find hard to tell me?"*, the questions used are *"Is there something you would like to share?"* or *"How can I help you express yourself?"* (See figure 44). (See appendix C1.2. for all the question and assignment cards)



Figure 44. Nuance in questions

OUTCOME EXAMPLE

Once the mosaic artwork is complete, the box becomes a space for reflection and remembrance. The emerging adult and their terminally ill parent can fill it with cherished items such as photos, jewelry, or letters. They may choose to turn on the light inside the box, place a picture on top, and light a candle, creating a gentle ritual to share together, or one that can continue after the parent has passed away. Over time, the box becomes a tangible reminder of their shared moments and conversations (See figure 45).



Figure 45. Final concept outcome example.



5.2. Scenario: How does it work?

This section presents a possible user scenario illustrating how the concept could be experienced in practice (See figure 46 - 49). It is important to note that this represents just one example, users are encouraged to personalize the concept and may choose to engage with it in their own unique way.



Leafe gets delivered to Violets home.



Violet introduces the box to her mom and asks if she would like to try it out together.



They start by reading the manual.



They explore what is inside the box.



The manual tells them to create a comfortable setting: Violet makes tea and turns on some soothing background music.



They start with phase 1: The past. They read the first question and discuss their answers.

Figure 46. Scenario part 1.



They write down the answers on the back of the card.



They decide on a word that summarizes their answers and write it on the mosaïc leaf.



They glue the mosaïc leaf to the top of the box.



The next card they open contains an assignment: they are asked to find a photo of themselves that represents how they view their shared past.



They repeat the same process for all the cards in phase 1.



A week later, Violet asks her mom to go through phase 2 of the box: The present.

Figure 47. Scenario part 2.



Some days later, her mom suggests to follow through with phase 3: the future.



After some valuable conversations, they glue the smaller mosaïc tiles on the box.



Violet finishes the artwork using transparant mosaïc filler.



They decide on a good spot for their box.



Violets mom wrote her a letter and adds it to the box.



Violet adds a stuffed animal and the bracelet she got from her mother to the box.

Figure 48. Scenario part 3.



A few months later, violets mom passes away.



While Violet grieves, she takes the box up to her room and reads the cards they wrote as well as the letter her mom wrote to her.



Once in a while, she turns on the light in the box and lights a candle on top for her mom.

Figure 49. Scenario part 4.

5.3. Evaluation

This section presents the evaluation method and the outcomes of testing the concept. It begins with an explanation of the procedure, followed by a presentation of the results and a discussion of the key insights derived from the test.

PROCEDURE

The goal of the evaluation is to assess how well the concept meets the established criteria and to identify any pain points or areas for improvement. Based on this goal, the following evaluation questions were formulated:

- *How do users experience the interaction with the concept, and to what extent does it meet the established criteria?*
- *What pain points or challenges do users encounter while engaging with the concept?*

To be able to answer these questions, the final concept was delivered to a To answer these questions, the final concept was tested with a pair of participants: a mother and her son. They engaged with the concept at their own pace. Following this, they completed a questionnaire (see Appendix C2.1.) and participated in a semi-structured interview based on their answers in the questionnaire.

The questionnaire was designed around the established criteria: Guiding, Connecting, Explorative, Lighthearted, Comfortable, and Evoking Curiosity. In addition, it included questions about the clarity of the concept, the quality of conversations it prompted, the creative aspects, its aesthetics, and the effects experienced after using the concept.

PARTICIPANTS

As mentioned, the participants were a mother and her son (See figure 50). For this evaluation, it was decided **not** to test the concept with individuals currently facing a parent's incurable illness, as this was considered too vulnerable.

However, the mother who participated has experience as a palliative care nurse, which may provide valuable insights into the concept's application. The names of the participants are fictitious.

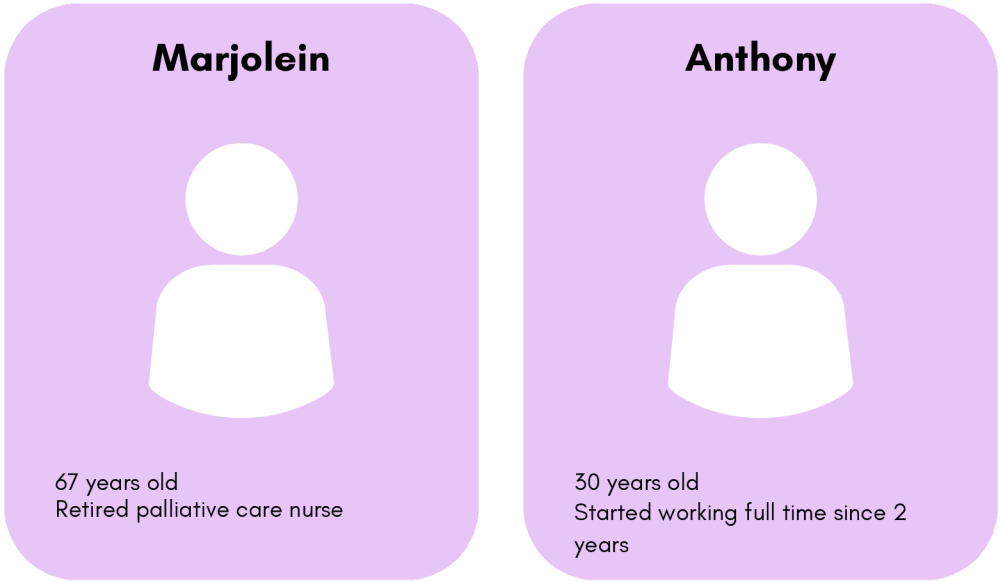


Figure 50. Participants final evaluation.

RESULTS EQ1

The first evaluation question of the evaluation will be addressed in two parts. First, the users' experience with the concept will be described, followed by an assessment of how well the concept meets the established criteria.

EQ1: How do users experience the interaction with the concept, and to what extent does it meet the established criteria?

EXPERIENCE WITH THE CONCEPT

Participants responded positively to the concept, reporting that engaging with it was both meaningful and valuable.

"*It is a good way of opening conversations. I have a better understanding of how my mom views things now.*" - ***Anthony***

"*It was so nice to do this with my son. A lot of things came up which I loved to discuss with my son. It was a really valuable experience.*"
- ***Marjolein***

"*The box looks very nice and special. It is very special to create the mosaïc together with the words on the tiles.*" - ***Marjolein***

CRITERIA

GUIDING

Both participants experienced the concept as guiding. They reported that the manual was clear and that the overall functioning of the concept was easy to understand. However, Marjolein mentioned that some of the questions were quite challenging, which occasionally made them struggle.

"*The questions were quite hard, we sometimes struggled to find out where we wanted to go with the conversation.*" - ***Marjolein***

"*I did not feel lost. Some emotions came up that you usually do not discuss, that was nice.*" - ***Marjolein***

CONNECTING

Both participants experienced the concept as connecting. Marjolein reported that her connection with her son felt deeper after engaging with the concept. Anthony mentioned that, although he did not feel their relationship necessarily changed, since it was already strong, he did get to know his mother better. This suggests that the concept had a positive effect on both bonding and mutual understanding.

"*It has a positive effect, I feel like our bond deepened and that feels good.*"- ***Marjolein***

"*After the conversations with my son, I have to think about the nice moments and everything that came up every day.*" -***Marjolein***

"*I had a good and valuable conversation with my mom. I got to know my mom even better.*" - ***Anthony***

EXPLORATIVE

Marjolein reported that she experienced the concept as explorative. She explained that the questions encouraged them to reflect on life together, bringing underlying feelings and emotions to the surface, allowing them to explore these together.

Anthony described the concept as somewhat explorative. However, he did mention that he was able to discover and reflect on new things throughout the process.

"*Through the questions, you think about life together.*" - ***Marjolein***

LIGHTHEARTED

The concept was experienced as lighthearted by Marjolein. She mentioned that, although some moments were emotional, the experience never felt awkward. She also noted that there was room for humor during the conversations.

On the other hand, Anthony reported that he did not experience the concept as particularly lighthearted. However, he emphasized that it did not feel heavy or uncomfortable either, and that there was room for humor throughout the process. The low rating for lightheartedness is likely due to the criteria not being fully clear. The term lightheartedness may be too ambiguous and open to different interpretations.

"*It did not feel heavy, but my mom and I talk easily*". - ***Anthony***

"*Sometimes, it was emotional, because you talk about you family and a lot of things come up.*" - ***Marjolein***

COMFORTABLE

The concept was experienced as comfortable by both participants. They explained that this was largely because they are already accustomed to discussing difficult topics. Anthony mentioned that, although it initially felt slightly outside his comfort zone, he did not feel uncomfortable during the process

"*It did feel out of my comfort zone at the beginning since I did not know how personal it would be, but I did not feel uncomfortable.*"- ***Anthony***

EVOKES CURIOSITY

The concept evoked curiosity in both participants. They expressed interest in learning how the other person viewed certain topics, particularly their perspectives on life and the end of life.

'*I was curious how my son looks at things in such a process, it is nice to experience.*" - ***Marjolein***

"*My curiosity grew for some themes. Some of them I was already curious about but have not come up before.*" -***Anthony***

OPEN VS GUIDING

Both participants felt that there was room for flexibility during the process. They appreciated being able to ask follow-up questions and adapt the activities to their own preferences, such as skipping or rephrasing certain questions. However, as mentioned earlier, they did not feel lost or without guidance at any point in the process.

"*Every theme is presented, this way you can discuss anything you want with your child.*" - ***Marjolein***

"*You can also ask other questions that are not on the cards because of the open setting created.*" - ***Anthony***

"*Some things we did our own way, the way we prefer.*" -***Anthony***

SOFT & DIRECT

They did not feel that the questions were too direct. However, they state that their bond was good to start with and that they don't know what it would feel like for people who do not have that. This would need further exploration and testing.

> "*If you have a relationship where you can not touch upon things or discuss things, it would be different. Then you might have to answer things you don't want.*" ***-Marjolein***

RESULTS EQ2

In this section, the second evaluation question is discussed.

EQ2: What pain points or challenges do users encounter while engaging with the concept?

CHALLENGING QUESTIONS

As mentioned earlier, some of the questions were experienced as challenging, and participants occasionally struggled to find ways to discuss them.

AESTHETICS

The aesthetics of the concept were generally perceived as pleasing. However, Anthony noted that he had to get used to the size of the box and suggested that he would prefer a smaller version.

CHOOSING ONE WORD

Selecting a single word to summarize each conversation was found to be difficult for both participants. For Anthony, writing the words on the tiles did not add much value to the experience. Marjolein, however, appreciated this element, explaining that it was meaningful to see a visual summary of their conversations reflected in the completed mosaic.

> "*I thought it was hard sometimes to summarize a whole conversation in one word, and I don't know what it adds to the experience*" ***-Anthony***
>
> "*If you read the words, you can see what we have talked about. It all comes back when you look at it.*" ***-Marjolein***

STARTING THE CONVERSATIONS

Anthony reported that initiating the conversations felt somewhat overwhelming. Since it was unclear what the experience would be like, starting a full discussion felt like a significant step.

> *Maybe there could be a way to make the first step smaller. Because now the step to begin can be quite big. You don't know how much time it will take and how personal it will become.*
> ***-Anthony***

TARGET GROUP

The participants noted that, because they already had a strong relationship, engaging in the conversations felt relatively easy. However, they expressed curiosity about how the concept would work for individuals who are not accustomed to discussing personal or sensitive topics, or who may be less open, expecting that it would likely be more challenging in such cases.

They also suggested that it could be valuable to have these conversations before a parent becomes ill, as this allows for planning and preparation. This highlights that the concept could be useful for
a broader range of target groups beyond the original scope.

"*It could be confronting if you are not used to talking about difficult topics.*" ***-Marjolein***

It could be very emotional or people might get into fights. If the relationship is not good and you are going to dicuss these themes. There might be a lot that will come up. There are people that are not good at talking their whole life, and they won't be good at it untill the day they die." ***-Marjolein***

CONCLUDING

The concept performs well across the established criteria. It was experienced as both guiding and open, allowing users to feel comfortable and curious while engaging with it. There was room for humor, and the concept was not perceived as heavy. It also fostered connection and mutual understanding, with effects that extended beyond the sessions.

PAIN POINTS

The main pain points identified during the evaluation include:

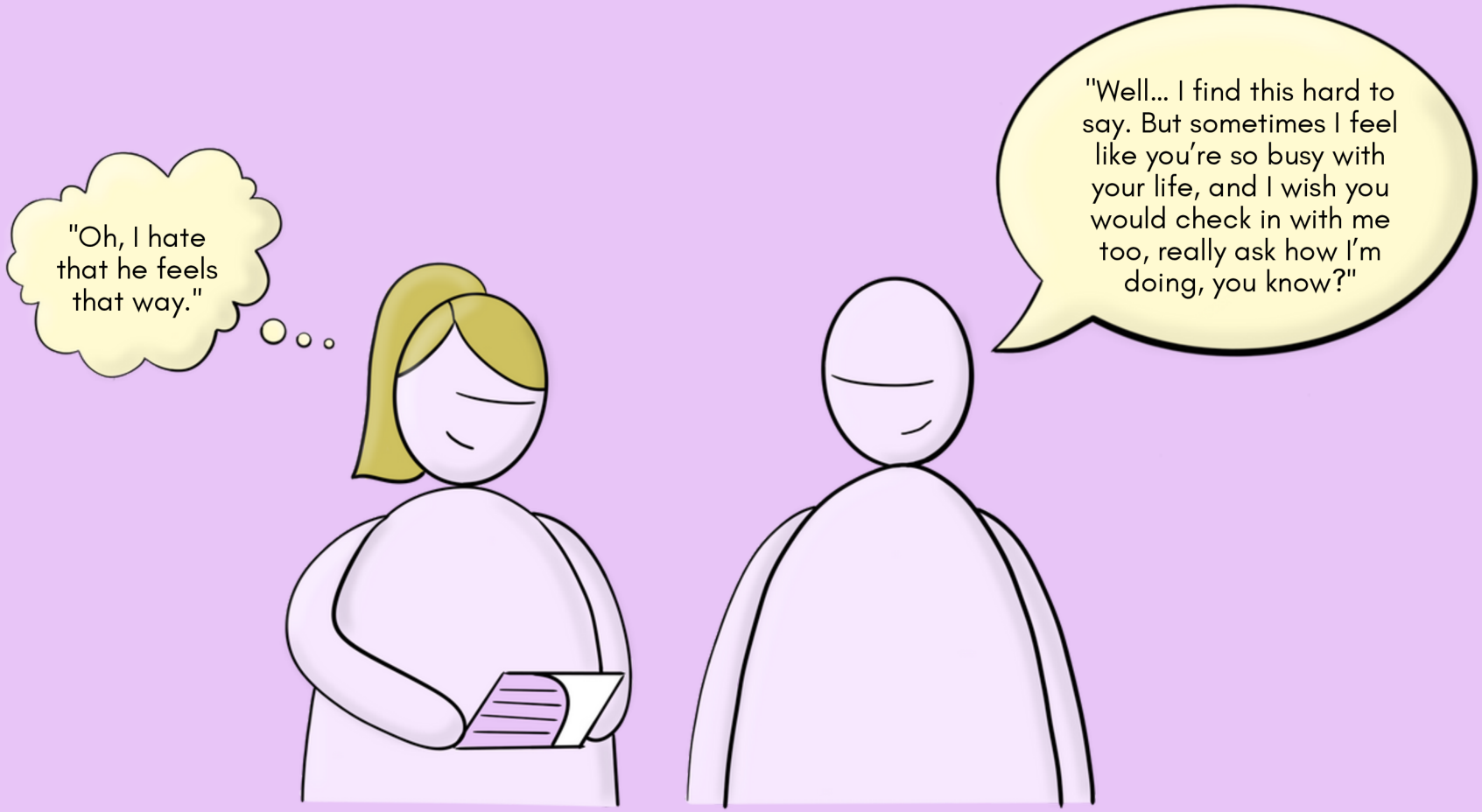
- Some questions being challenging to discuss.
- Difficulty in choosing a single word to summarize conversations.
- Initiating the conversations, which some participants found overwhelming.
- The pre-existing relationship between participants, which could influence how the process unfolds.

5.4. Wout & Iris Connecting

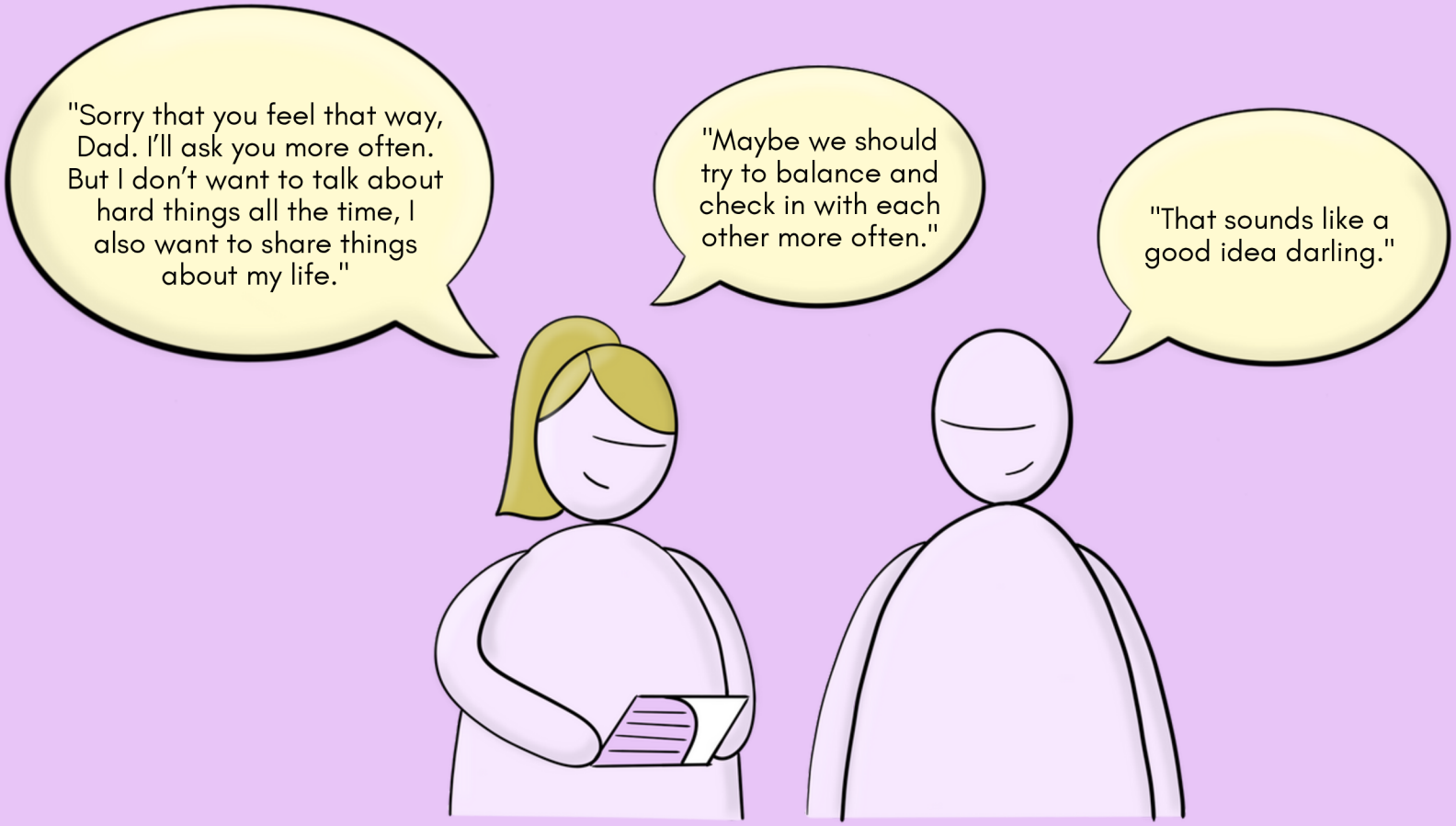
Iris and Wout are in Phase 2 of the Leafe concept. They are about to answer questions about support, and Iris reads one of the questions aloud.



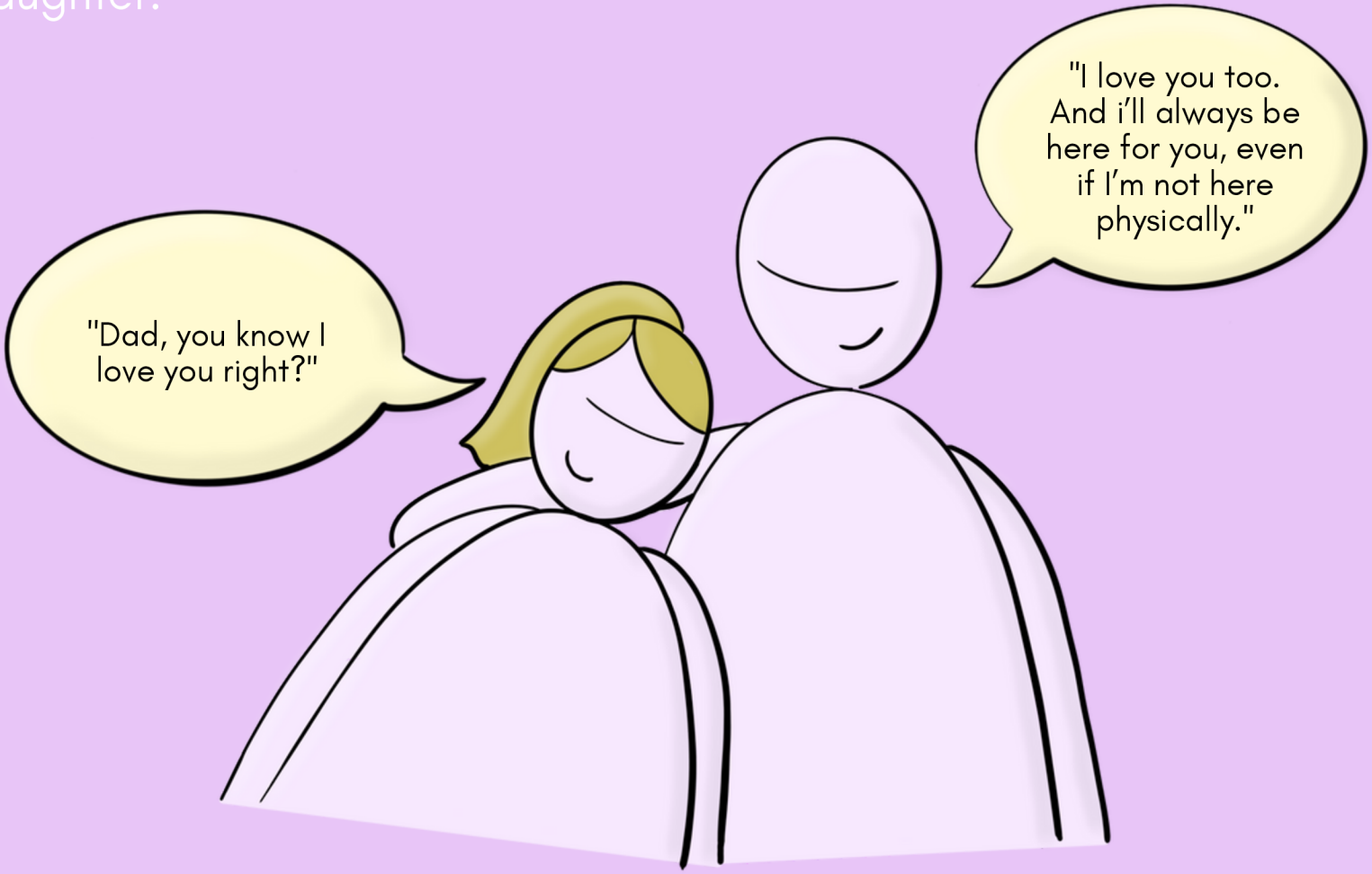
Wout starts by answering the question.



Iris responds to Wouts answer and then shares her own response to the question.



Wout and Iris express their love for each other and Wout reassures his daughter.



Deliver

KEY INSIGHTS

THE FINAL CONCEPT

At its core, Leafe is an activity that facilitates connection between an emerging adult and their terminally ill parent. Together, they create a mosaic artwork while engaging in conversations about end-of-life themes.

The concept consists of three phases, Past, Present, and Future, each containing a set of cards with specific themes. These cards feature questions or assignments designed to prompt meaningful discussion. After completing each card, a summarizing word is written on a mosaic leaf, which can then be attached to the box. Once all cards have been completed, the artwork is finalized with smaller mosaic stones.

Finally, the box serves as a keepsake,a place to store photos and mementos, and a tangible reminder of shared memories.

EVALUATION

The concept performs well across the established criteria. It was experienced as both guiding and open, allowing users to feel comfortable and curious while engaging with it. There was room for humor, and the concept was not perceived as heavy. It also fostered connection and mutual understanding, with effects that extended beyond the sessions.

PAIN POINTS

The main pain points identified during the evaluation include:

- Some questions being challenging to discuss.
- Difficulty in choosing a single word to summarize conversations.
- Initiating the conversations, which some participants found overwhelming.
- The pre-existing relationship between participants, which could influence how the process unfolds.

Conclude

CHAPTER 6

OVERVIEW

6.1. Design goal reflection
6.2. The Future of Leafe - Recommendations
6.3. Personal reflection
6.4. Iris Remembering

INTRODUCTION

This chapter serves as the conclusion of the graduation project. It includes a reflection on the design goal in section 6.1., section 6.2. presents recommendations for the future development of the concept and section 6.3. offers a personal reflection on the project experience. The chapter concludes with a part of Iris and Wout's story, in which Iris remembers her father in section 6.4..

6.1. Design goal reflection

The design goal formulated in the beginning of the design phase:

> *"The goal is to **foster connection** and create **mutual understanding** between emerging adults and their terminally ill parent during **the new "normal" phase** of the EoL-process at home, by creating space for **lightheartedness** and **open communication** about needs and wishes. "*

To conclude this design project, a reflection on the design goal is needed. Is it achieved? And in what ways?

FOSTER CONNECTION

The concept successfully fosters connection by facilitating open discussions and the creation of a personal artwork together. This connection extends beyond the completion of the artwork, as users can continue to reflect on meaningful conversations and engage in personal rituals inspired by the concept.

CREATE MUTUAL UNDERSTANDING

The concept promotes mutual understanding through its wide range of themes and the comfortable environment it provides. Users are encouraged to ask follow-up questions and pose their own questions, which helps them gain deeper insight into each other's perspectives and strengthens their relationship.

THE NEW "NORMAL" PHASE

The concept is well-suited for the new normal phase. It requires time and emotional energy, both of which are more available during this phase compared to the adaptation or terminal phases, which tend to be more overwhelming. Although the concept demands engagement, users remain in control of how they participate. They can pause and resume at any moment, allowing them to progress at their own pace.

CREATING SPACE FOR LIGHTHEARTEDNESS

The themes within the concept are, of course, not always light. However, during evaluation the concept was not experienced as heavy, awkward, or uncomfortable, and there was room for humor throughout the process.

CREATING SPACE FOR OPEN COMMUNICATION

The concept provides space for communication by creating a dedicated moment focused on end-of-life topics. Engaging in the process, sitting together, creating an artwork, and writing and gluing tiles, facilitates a more natural conversation. Being occupied with their hands reduces the need for constant eye contact, making discussions less confronting.

In addition, the concept successfully fosters open communication through its prompts on a variety of themes while leaving the approach up to the users. Participants can choose how to engage, ask follow-up questions, and pose their own inquiries, creating a flexible and comfortable environment for meaningful dialogue.

CONCLUDING

To conclude, the concept aligns well with the design goal and succeeds in fostering connection and mutual understanding by creating space for lightheartedness and open communication.

6.2. The Future of Leafe - Recommendations

The following recommendations are based on the evaluation, as well as reflections on the research and design process.

FURTHER RESEARCH AND TESTING

The concept was not tested in the intended context with an emerging adult and their incurably ill parent due to the sensitivity of the situation. Future iterations could benefit from conducting such testing, as it may provide valuable insights and further inform the design.

Additionally, further testing is recommended with individuals who are not accustomed to discussing challenging themes. This could offer insights into how the concept can be made more accessible and gentle, ultimately helping to make these conversations easier to initiate and navigate.

This project focused exclusively on the interaction between the emerging adult and their incurably ill parent. Future research could explore the influence of other people in the situation and how they might play a role in the concept.

TARGET GROUP

This concept could also be beneficial for a broader target group. It may be useful in situations where the child and parent are older, or in relationships where one partner is incurably ill. Different versions could be developed for different groups, with questions tailored to their specific needs.

The concept may also hold value for people who are not currently facing an incurable illness. Discussing the included themes can help individuals find connection and mutual understanding in many life situations. Life is unpredictable, someone may pass unexpectedly, move far away, or a relationship may become strained. Having something meaningful created together could offer comfort, knowledge or peace at some point in the future.

START OF THE CONVERSATIONS

As found during the evalation, beginning with the conversations was found to be overwhelming. Design iterations should focus on making the initial step of starting a conversation less overwhelming. For example, an introduction card (See figure 51) could allow users to practice and familiarize themselves with the process before engaging with a full set of prompts.



Figure 51. Example introduction card.

PERSONALISATION

Adding personalisation options could enhance the meaningfulness of the concept. Users could choose their own colors for the mosaic tiles, select from different types of wood, or opt for gold or silver details (See figure 52). These choices could help make the concept more personal.

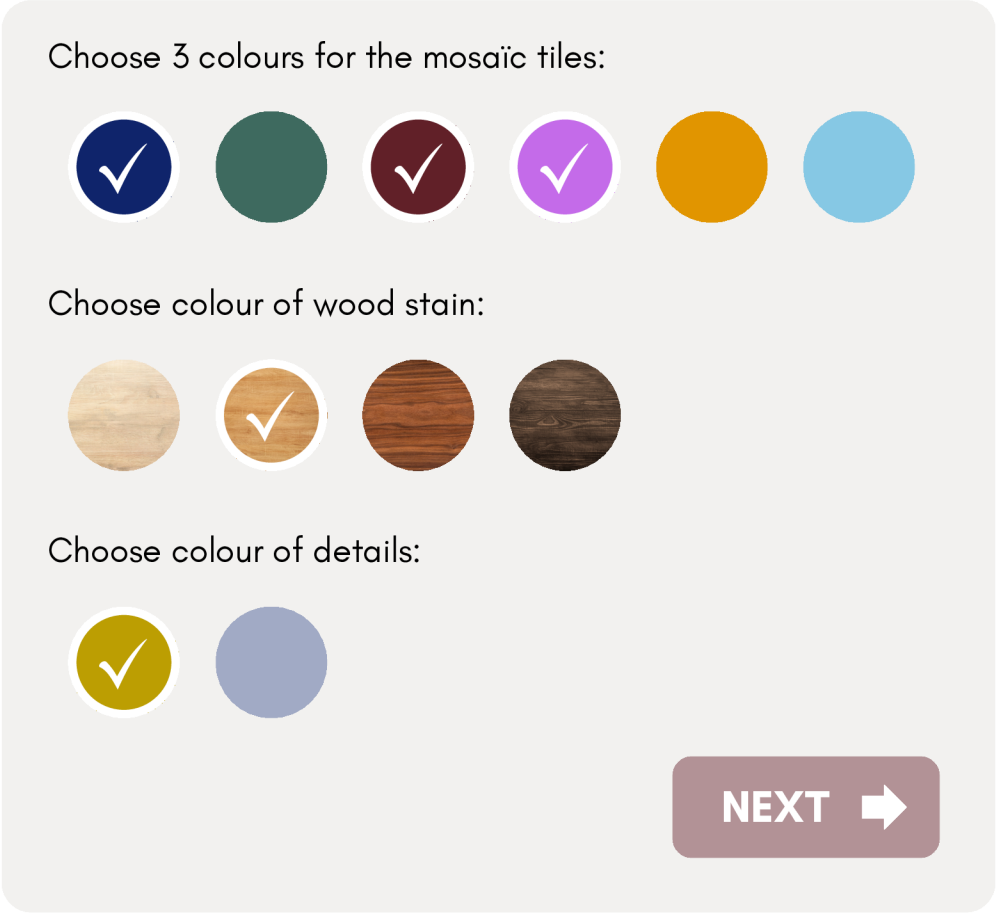


Figure 52. Personalisation of concept.

MARKETING

It would be valuable to explore potential distribution and marketing strategies for the concept. How could it be sold? Could it be recommended by healthcare professionals, family members, or friends? How do people learn about Leafe? Understanding how the target group becomes aware of the concept is essential for successful distribution.

One option is to sell the concept through a dedicated website, allowing users to order it online. This would make it widely accessible and easy to find for individuals seeking support or solutions for their communication challenges. An online platform also enables simple sharing, as users can forward the link to others.

Printed materials, such as flyers or posters, could be distributed through general practitioners, hospices, psychologists, and community spaces for people living with incurable illnesses. This approach helps ensure that the concept reaches the right audience and invites them to explore it further.

Additionally, social media could serve as a valuable marketing channel. Providing informational posts and explanatory videos can help raise awareness.

PRODUCTION

The prototypes in this project were handmade, which is not feasible for large-scale production due to time, cost, and pricing constraints. The components could, for example, be redesigned for easy assembly and produced in factories. Future iterations should explore scalable production methods to make the concept more accessible.

6.3. Personal reflection

During this graduation project, I have learned many valuable lessons.

Some practical lessons include the importance of starting to write from the very beginning. I did not do this, and I learned the hard way how much work it is to create a comprehensive report. Deadlines also proved to be a helpful structure: when a deadline was approaching, I could focus better and procrastinate less.

I have also learned how crucial the people around you are during a project like this. Their support helped me navigate challenges, and being able to discuss my project with others often led to new insights and perspectives.

Looking back, the best way to describe my experience is that it was an emotional rollercoaster.

I chose the theme of communication between an emerging adult and their incurably ill parent based on my own experiences. My father had cancer and would not recover, and I noticed that communicating about end-of-life themes was sometimes difficult. I wanted to create something that could help others in similar situations, and I feel that I have achieved this with my concept. Seeing the impact of the concept during the evaluation was truly heartwarming.

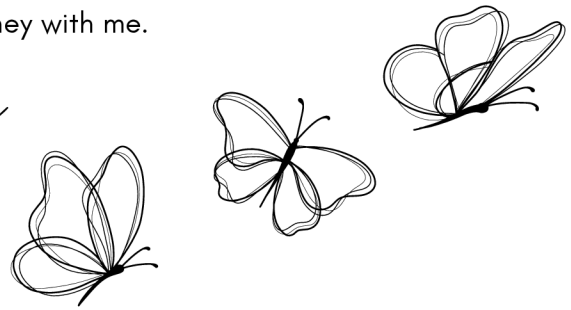
Through this project, I also learned how to conduct research on a sensitive topic and work with participants in such a context. This was sometimes challenging, as I had to consciously separate my personal experiences from the research process to avoid influencing participants.

Perhaps the most important lesson I have learned is to keep going, even at a slow pace. My father passed away in April, sooner than expected, in the middle of my graduation project. I am forever grateful for the meaningful conversations we had about this project before his passing. His loss was extremely difficult, and while I would have absolutely loved to share the completed project with him, this experience taught me resilience. I learned to take the time to grieve, to be kind to myself, and at the same time, to keep moving forward. I also learned to accept that “good is good enough”, perfection is not always necessary. Completing this project under such circumstances is something I am incredibly proud of.

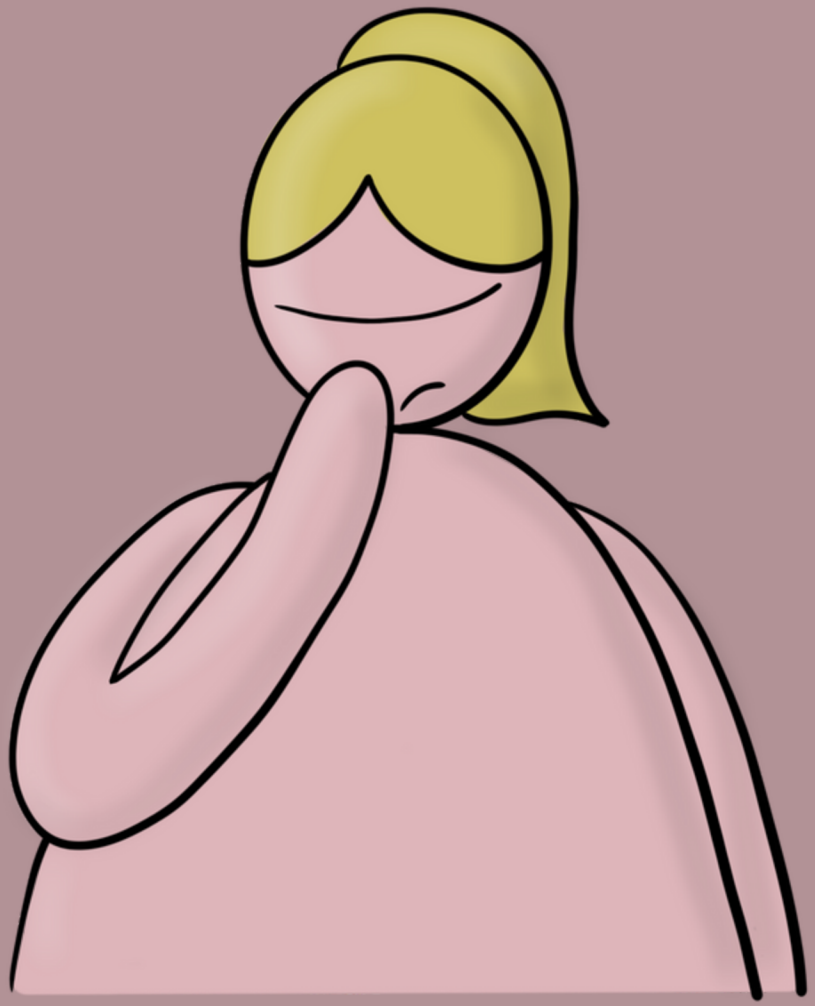
I am happy with the outcome of my research and the concept I developed. I hope it can help and inspire others in the future.

Thank you for coming on this journey with me.

Yours faithfully, Anne

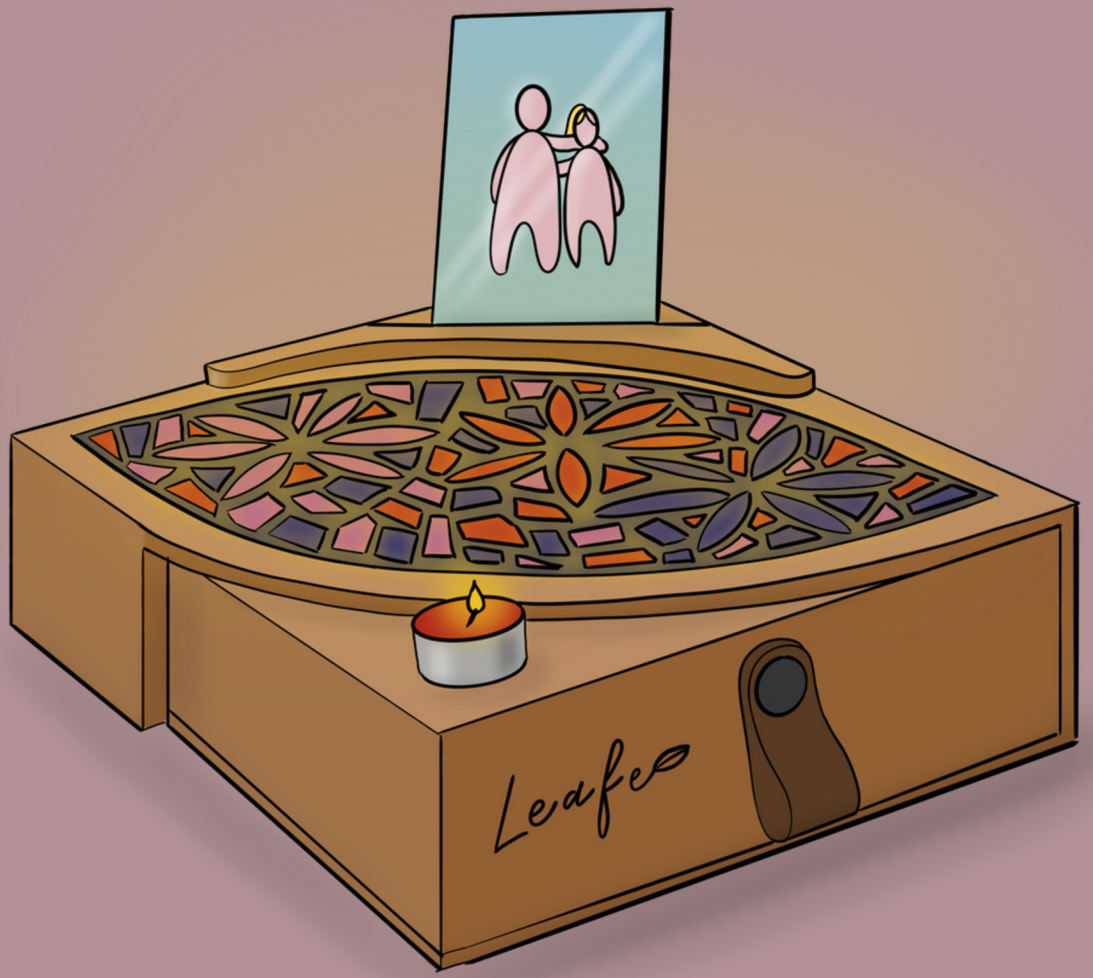


6.4. Iris Remembering



Wout has passed away, and Iris is grieving the loss of her father. The grieving process is incredibly difficult. Her emotions come in waves, at times feeling overwhelming.

Iris finds comfort in the box she created with her father. She keeps a photo of them together on top and lights a candle for him every day. When she turns on the light inside the box, the mosaic artwork glows softly, becoming even more beautiful.





Whenever Iris feels sad, she opens the box and looks through the pictures and cards inside. There is space for both tears and laughter. This way, she continues to feel connected to her father.

Conclude

KEY INSIGHTS

DESIGN GOAL CHECK

The concept aligns well with the design goal, although there is still room for improvement in terms of lightheartedness.

RECOMMENDATIONS

It could be highly beneficial for future iterations of the concept to explore several aspects, including testing in the real-life context, personalisation, marketing strategies, scalable production methods, the influence of others in the situation, making the initial steps of the process easier, and refining the target group.

PERSONAL REFLECTION

I have learned many valuable lessons throughout this graduation project. These include starting the writing process earlier, setting deadlines to maintain momentum, discussing the concept with others to gain new perspectives, conducting research on sensitive topics, and developing resilience in the face of personal and professional challenges.

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Appendix A
DISCOVER

OVERVIEW

A1. Project Brief
A2. Ethics
A3. Interview and Context mapping procedure
A4. Context mapping analysis
A5. Inspiration

INTRODUCTION

This appendix provides additional information on the research phase of the project. It includes the project brief (A1.) and the ethical approach (A2.) adopted for the study. Furthermore, it presents the interview and context-mapping procedure (A3.), and the subsequent analysis of the context-mapping activities (A4.). In addition, inspiring innovations for informal end-of-life communication were identified (A5.).

A1. Project Brief

DESIGN FOR our future

TU Delft

Personal Project Brief – IDE Master Graduation Project

Name student Anne Mostert **Student number**

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT
Complete all fields, keep information clear, specific and concise

Project title **Supporting and enhancing communication about illness and end-of-life needs and wishes between young adult children (18 to 30 years) and their terminally ill parent.**

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

Introduction

Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)

My graduation will be about the communication between Young adult children and their terminally ill parent about illness and end-of-life needs and wishes in an at home context.

Terminally ill individuals face numerous challenges, including physical impairments, uncertainty, and financial strain [1]. Conversely, when a parent becomes terminally ill, their young adult children encounter their own set of challenges: transitioning from child to caregiver [2], feeling responsible while striving not to burden their parent [3], managing conflicting demands, and navigating personal ideals, family expectations, and societal pressures [4].

This situation is difficult for both parties, underscoring the importance of effective communication. However, various factors can influence the effectiveness and quality of this communication, such as practical barriers, avoidance behaviors, parent-child roles, typical communication patterns, gender, culture, spirituality, humor, and legacy considerations.

Supporting and enhancing communication could lead to a higher quality of the end-of-life process and maybe even the process of grief.

[1] Lundquist, M. (2017). Fathers facing advanced Cancer: an exploratory study. Journal Of Social Work in End-of-Life & Palliative Care, 13(4), 266–283. https://doi.org/10.1080/15524256.2017.1403410
[2] Read, T., & Wuest, J. (2007). Daughters Caring for Dying Parents: A Process of Relinquishing. Qualitative Health Research, 17(7), 932–944. https://doi.org/10.1177/1049732307306123
[3] Roscoe, L. A., & Barrison, P. (2018). Dilemmas Adult Children Face in Discussing End-of-Life Care Preferences with Their Parents. Health Communication, 34(14), 1788–1794. https://doi.org/10.1080/10410236.2018.1536946
[4]Scheinfeld, E., & Lake, P. K. (2019). Why Is It Just So Hard? Making Sense of End-of-Life Communication Between Adult Children and Their Terminally Ill Parental Figures. OMEGA - Journal Of Death And Dying, 83(3), 611–629. https://doi.org/10.1177/0030222819859163

→ *space available for images / figures on next page*

DESIGN FOR our future

TU Delft

Personal Project Brief – IDE Master Graduation Project

Problem Definition

What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice.
(max 200 words)

The primary issue in this context is strained communication caused by practical, psychological, relational, and sociocultural barriers.

I aim to address this problem by enhancing communication, enabling individuals to care for one another, fostering deeper connections, and ensuring that both parties feel heard and seen.

I see an opportunity in utilizing diverse forms of communication beyond verbal expression. Alternative forms of communication—such as art, poetry, writing, music, movement, and touch—could make discussing this challenging topic easier, more meaningful, or even more enjoyable.

Assignment

This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence) As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format*:*

Design/Investigate/Validate/Create) a (what will be the deliverable -> prototype/ roadmap/process/ intervention/approach/ guideline/strategy/...) to (what should it do -> create/ understand/evaluate/validate/improve/execute/analyse/...) (the objective -> experience/ value/process/product/...) for (whom -> target group/ client/...) in (what context).

Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)

My goal is to design a **supportive intervention** that **enhances communication** about **illness and end-of-life needs and wishes** between **young adult children** (18-30 years) and their **terminally ill parents** in a **home** setting to help both parties to **take care of each other**, to **feel seen** and to foster **emotional connection**.

I aim to take a human-centered design approach to achieve my goal. My research phase will include methods such as interviews, observation, and context mapping to gain deep insights into the users' needs, emotions, and experiences. For the design activities, I will focus on exploratory interaction design processes, including creating an interaction vision, conducting prototyping-testing iterations, facilitating co-design sessions, and employing rapid prototyping techniques.

Iteration will be central to my project, allowing me to move fluidly between testing and prototyping, as well as between research and creation. I also want to emphasize the critical role of the user throughout my process by adopting a co-design approach, ensuring their perspectives and input guide and inform each stage of development.

Figure 53. Project brief - part 1.

introduction (continued): space for images

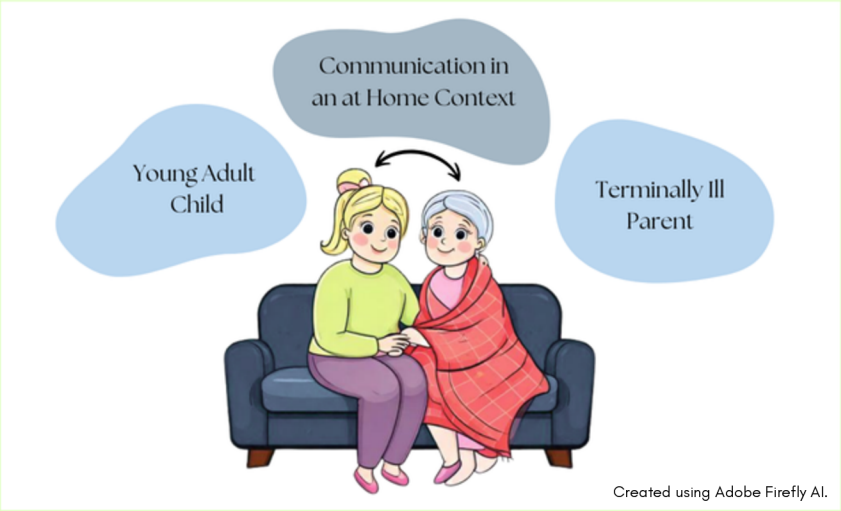


image / figure 1

image / figure 2

Project planning and key moments

*To make visible how you plan to spend your time, you must make a planning for the full project. You are advised to use a Gantt chart format to show the different phases of your project, deliverables you have in mind, meetings and in-between deadlines. Keep in mind that all activities should fit within the given run time of 100 working days. Your planning should include a **kick-off meeting**, **mid-term evaluation meeting**, **green light meeting** and **graduation ceremony**. 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 course activities).*

Make sure to attach the full plan to this project brief.
The four key moment dates must be filled in below

Kick off meeting	11 February 2025
Mid-term evaluation	08 April 2025
Green light meeting	10 June 2025
Graduation ceremony	1 July 2025

In exceptional cases (part of) the Graduation Project may need to be scheduled part-time. Indicate here if such applies to your project

Part of project scheduled part-time	
For how many project weeks	
Number of project days per week	

Comments:

Motivation and personal ambitions

Explain why you wish to start this project, what competencies you want to prove or develop (e.g. competencies acquired in your MSc programme, electives, extra-curricular activities or other).

Optionally, describe whether you have some personal learning ambitions which you explicitly want to address in this project, on top of the learning objectives of the Graduation Project itself. You might think of e.g. acquiring in depth knowledge on a specific subject, broadening your competencies or experimenting with a specific tool or methodology. Personal learning ambitions are limited to a maximum number of five.
(200 words max)

My primary motivation for this project is to help people. I want to make a meaningful impact on how individuals experience the end of life, helping them find connection during this profound time. Additionally, I chose a sensitive topic to demonstrate my empathetic skills as a designer and to create solutions that truly resonate with the human experience.

Figure 54. Project brief - part 2.

*The dates have changed due to personal reasons

A2. Ethics

It is important to handle the project ethically. Therefore, an HREC application was done and approved. A data management plan was created in order to handle data appropiately.

All participants had to sign a consent form. See the next pages for an empty version of the consent form (See figure 55 & 56). This consent form is based on a template created by the Technical University of Delft.

Theoretical experts had the choice how they want to be mentioned in the thesis and if they wanted to remain anonymous.

Experience experts will always be mentioned using a fictitious name. They did have the choice if they wanted audio, pictures and video's to be anonymised.

Since the graduation date has changed due to personal reasons, a second round of asking for consent was performed. All participants were contacted and asked if they still felt good about their participation.

Research with Experience experts:

You are being invited to participate in a research study titled: Supporting and enhancing communication about illness and end-of-life needs and wishes between young adult children (18 to 30 years) and their terminally ill parent. This study is part of the masters graduation project being done by me, Anne Mostert, from the TU Delft (Master: Design for Interaction at the faculty of Industrial Design Engineering).

The purpose of this research study is to gain knowledge on the communication process between a young adult child and their terminally ill parent when communicating about illness and end-of-life needs and wishes and will take you approximately 45 minutes to complete. I will be asking you to answer questions about end-of-life needs, wishes, experienced emotions and barriers and facilitating end of life communication.

As with any online activity the risk of a breach is always possible. To the best of my ability your answers in this study will remain confidential. I will minimize any risks by processing your data anonymously and presenting the research outcomes using a fictitious name. Raw (unprocessed) data like videos, pictures and audio taken during the research activities will not be shared with third parties (my supervisors excluded) and will be deleted within 6 months after graduation.

The processed data will be used for my graduation thesis, video, poster, presentation and other deliverables related to the graduation project, which will be published in the TU Delft repository and thus open to the public.

I understand that talking and thinking about this sensitive topic can be distressing. Your participation in this study is entirely voluntary **and you can withdraw at any time**. You are free to omit any questions, take breaks or skip questions or tasks. If you don't feel good about your participation after the research activity, data can be removed up to one week before publication:

In case of questions or concerns, please feel free to contact me:
Anne Mostert

PLEASE TICK THE APPROPRIATE BOXES	Yes	No
A: GENERAL AGREEMENT – RESEARCH GOALS, PARTICPANT TASKS AND VOLUNTARY PARTICIPATION		
1. I have read and understood the study information dated [*17/03/2025*], or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	☐	☐
2. I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions, take breaks and withdraw from the study **at any time**, without having to give a reason.	☐	☐
3. I understand that taking part in the study involves: Answering interview questions and doing a context-mapping exercise including crafting, writing and drawing. Video and audio recording, having pictures taken and notes made. This data will be collected to analyse the activity and support research outcomes. Raw unprocessed data will be destroyed within 6 months after graduation.	☐	☐
4. I understand that the study will end on	☐	☐
B: POTENTIAL RISKS OF PARTICIPATING (INCLUDING DATA PROTECTION)		
5. I consent to the study involving the following risks: mental discomfort and anxiety. I understand that these will be mitigated by the opportunity to withdraw at any moment and to refuse to answer certain questions or tasks.	☐	☐
6. I give permission for collecting specific personally identifiable information (PII) [name, surname, phone-number, email address and address (For administrative purposes only)] and associated personally identifiable research data (PIRD) [Gender, culture, religion, age, health status, occupation, video's, pictures, audio, quotes, observations, views, motivations and values] with the potential risk of my identity being revealed possibly impacting my public/professional reputation.	☐	☐
7. I understand that some of this PIRD is considered as sensitive data within GDPR legislation, specifically religion, health status, views and motivations.	☐	☐
8. I understand that the following steps will be taken to minimise the threat of a data breach, and protect my identity in the event of such a breach: A fictitious name will be used for the participant in research output and other data will be processed to the preference of the participants, and thus can be processed anonymously (blurred face, voice alteration).	☐	☐
9. I consent that personal information will be collected that can identify me, such as my name, signature, phone number, email address and address and that they will not be shared with third parties.	☐	☐
10. I consent that the raw unprocessed (identifiable) personal data I provide will be destroyed within 6 months after the study. Excluding this consent form (Name & signature), which will be stored for legal reasons.	☐	☐
11. I give consent to be asked questions about my health, like the illness I deal with and how my symptoms affect communication. I consent that the answers and insights I provide to these questions can be used in research output pseudonymized (Fictitious name that ensures the data is not directly identifiable to me).	☐	☐
C: RESEARCH PUBLICATION, DISSEMINATION AND APPLICATION		
12. I consent that after the research study the information I provide will be used for a graduation thesis, video, poster and presentation for the master design for interaction at TU Delft and will be published in the TU Delft repository and thus open to the public. The information could be used by	☐	☐

Figure 55. Consent form experience expert - part 1.

PLEASE TICK THE APPROPRIATE BOXES	Yes	No
the researcher or others in attempt to understand and improve the situation or other relevant issues. It can also be used for job and portfolio purposes. I consent that the information I provide that will be used in these outputs can include: Gender, culture, religion, age, health status, occupation, video's, pictures, audio, quotes, observations, views, motivations and values.		
13. I consent that my responses, views or other input and information (Gender, culture, religion, age, health status, occupation, observations, experiences, views, motivations and values) can be quoted, stated and used anonymously, using a fictitious name, in research outputs.	☐	☐
14. I consent that Video's, pictures and audio will be made and can be used for research output in the following manner: (Please choose one out of three options and tick no for the other two).		
A. Video's, pictures and audio can only be used for data analysis and so only findings derived from them can be used in research outputs.	☐	☐
B. Video's, pictures and audio can be used anonymously (blurred face & voice alteration) in research outputs.	☐	☐
C. Recognisable video's, pictures and audio can be used in research outputs.	☐	☐
15. I consent that any drawing, writing, image or work I create during the research activity can be used in the research output with my fictitious name mentioned.	☐	☐
D: (LONGTERM) DATA STORAGE, ACCESS AND REUSE		
16. I give permission for the processed information in the research outputs that I provide to be archived in the TU Delft repository so it can be used for future research and learning.	☐	☐
17. I understand that access to this repository is open to the public.	☐	☐

Signatures

_____ _____ _____

Name of participant [printed] Signature Date

I, as researcher, have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

_____ _____ _____

Researcher name [printed] Signature Date

Study contact details for further information: Anne Mostert ,

Please reach out to me if you have any questions or feelings regarding this research.

Figure 56. Consent form experience expert - part 2.

A3. Interview & context mapping procedure

Interviews were conducted with both experiential experts and theoretical experts. The experiential experts were recruited through personal connections and social circles, while the theoretical experts were contacted via email or contact forms available on websites.

The interviews followed a semi-structured format to allow for elaboration and follow-up questions where relevant. The interview guides for the experiential experts and theoretical experts are presented in Figure 57 and Figure 58.

After discussing all interview questions, participants were invited to take part in a context mapping exercise. In this activity, they were asked to create two collages: one representing the current situation of communication between an emerging adult and their terminally ill parent, and another illustrating how end-of-life communication could be facilitated (see Figure 59). See figure 60 for a picture of an experience expert performing the context mapping exercise. Participants were provided with sheets containing images and words (see Figure 61), as well as crafting materials such as glue, scissors, and pens.

Interview experience experts

Procedure:

- Making acquaintance
- Introduction
- Signing consent form
- Interview questions
- Context mapping
- Round off

Materials:

- Consent forms
- Pens
- Glue
- Scissors
- Context mapping forms
- Phone: audio recording
- List of questions

Introduction text:

First of all, thank you very much for your participation. I will now explain what we are going to do. We will start with a consent form. Here you can read what will happen during this interview and give your consent for the collection and processing of data.
Next, I will ask you a number of interview questions. This is a semi-structured interview, which means that I have a number of topics I want to discuss, but I also give the conversation space to bring up new themes.
After that, there will be a small exercise in which you create a small collage about the topic. I want to emphasize that there is no right or wrong. Everything you say can be valuable for my research.
You can stop the interview at any time without having to give a reason.

Interview questions/ topics:

- Can you tell me something about yourself?
- How did you experience that period?
- Were there any questions you were struggling with during your parent's end of life?
- In what way did you communicate with your parent about the end of life (or not)?
- What made communication with your parent difficult or easy?
- Which themes emerged during communication with your parent about the end of life or the illness?
- How do you think communication between young adults and their terminally ill parent can be facilitated and improved?

Can you give examples?

Figure 57. Interview procedure experience experts.

Interview theoretical experts

Procedure:

- Making acquaintance
- Introduction
- Signing consent form
- Interview questions
- Context mapping
- Round off

Materials:

- Consent forms
- Pens
- Glue
- Scissors
- Context mapping forms
- Phone: audio recording.
- List of questions.

Introduction text:

First of all, thank you very much for your participation. I will now explain what we are going to do. We will start with a consent form. Here you can read what will happen during this interview and give your consent for the collection and processing of data.
Next, I will ask you a number of interview questions. This is a semi-structured interview, which means that I have a number of topics I want to discuss, but I also give the conversation space to bring up new themes.
After that, there will be a small exercise in which you create a small collage about the topic. I want to emphasize that there is no right or wrong. Everything you say can be valuable for my research.
You can stop the interview at any time without having to give a reason.

Interview questions/ topics:

- Can you tell me something about yourself and explain what kind of work you do?
- Have you experienced the situation (or a similar one) during your work?
- Which factors can influence communication between a young adult and a terminally ill parent at the end of life?
- What makes communication with a child difficult/easy if you are terminally ill?
- What makes communication with a parent difficult/easy if they are terminally ill?
- Which themes are discussed during communication between a young adult and a terminally ill parent about the end of life?
- How do you think communication between young adults and their terminally ill parent can be facilitated and improved?

Can you give examples?

Figure 58. Interview procedure theoretical experts



Figure 59. Context mapping exercise, current situation and facilitation.



Figure 60. Context mapping exercise with experience expert.



Figure 61. Provided images and words for context mapping exercise.

A4. Context mapping analysis

During the context-mapping exercises, it was noticed that the experience experts had a really hard time doing the exercise for the facilitation of end-of-life communication. This seems logical afterwards since they are not professional. It was therefore chosen to have the experience experts only perform the current situation exercise.

An analysis was done of the seperate collages. Another analysis was done for the images used and how many times they were used by the experience experts and the theoretical experts.

Insights gained from the context-mapping exercise:

- During this difficult period, love and family remain central themes (see Figure 62).
- The theoretical experts emphasized the importance of considering underlying factors that influence communication.
- When depicting the current situation, many theoretical experts selected barriers such as avoidance, ignoring, and conflict. Several participants also added the term protection, indicating that avoidance of communication often stems from a desire to protect the other person from emotional distress.
- In contrast, when illustrating facilitation of end-of-life communication, theoretical experts emphasized connection as a key element. This connection was represented through elements such as love, touch, spirituality, non-verbal and indirect communication, and humor.
- Interestingly, both negative and positive emotions were included in the collages representing facilitated communication. This suggests that an ideal situation should allow space for both emotional dimensions. The objective is not to eliminate negative emotions but rather to foster connection through sharing the emotional burden.



Figure 62. Context mapping exercise by experience expert: Floris

A5. Inspiration

Innovations that support (end-of-life) communication were identified and analysed. They are presented page 125, together with their key qualities.

Two of the innovations were acquired and tested: the Rouw & Ruimte Deck by Vertellis and the Uitvaarwensenspel by Cathelijne de Vries. The outcomes of these tests are presented on pages 126.

ROUW EN RUIMTE-DECK - VERTELLIS

A card deck including questions about grief.

- Guidance.
- Encourages open communication.
- Creates a moment.

By Vertellis. (Vertellis Nederland, n.d.)

HET UITVAARTWENSENSPEL

A game about funeral wishes.

- Guidance.
- Game aspect.
- Activity.
- Exploration.

By Cathelijne de Vries. (Uitvaartwensenspel, 2019)

DE PARELKOFFER

A set of tools created to support people who had a stillborn child/miscarriage.

- Guidance.
- Legacy leaving.

By Rouwkost. (Stichting Rouwkost, 2025)

BLOEMENBAND

A band created for coffins that can hold flowers.

- Nature
- Life in death

Founded by Jantine Kraaijeveld. (Bloemenband, 2025)

KINTSUGI

Japanese art of Kintsugi, where repairing is done with gold.

- Beauty in the broken.
- Activity.
- Creativity.

Info by: Risner (2022).

TEATOPICS

Cards with questions attached to teabags.

- Creating a moment.
- Encourages open communication.

By Pickwick. (Pickwick NL, n.d.)

PAP, VERTEL EENS

A journal for parents with questions about their life.

- Legacy leaving
- Writing
- Memories

By Elma van Vliet. (HarperCollins Holland, 2024)

THE GRIEF DECK

Set of visual artworks with prompts about moving through loss.

- Guidance
- Visual
- Creates a moment

By Adriene Jenik and the artists' literacies institute. (The Artists' Grief Deck, 2021)

LOTGENOOTJE

Weighted stuffed animal.

- Consolation

Founded by Marien Jansen. (Lotgenootje, n.d.)

BUTS & BOFN

A set of blocks designed to express emotions.

- Expression of emotions
- Visual
- Creativity
- Activity

Founded by Jeanette van Tricht (Buts en Bofn, 2025).

Figure 63. Inspiration for facilitating end-of-life communication

THE ROUW EN RUIMTEDECK

The Rouw en Ruimte Deck by Vertellis By Vertellis. (Vertellis Nederland, n.d.) was analyzed to explore the types of questions it contains and the underlying themes they address. The deck consists of question cards designed to encourage conversations about loss and grief.

Through a clustering process, several key themes emerged that revealed how the grief situation was being addressed and informed the themes used in the design iterations. :

- Memories
- The experience of the loss
- Social
- Saying goodbye
- Practical
- Facilitating
- Spiritual
- Legacy

Additional insights:

- Including a quote on each card adds an extra dimension to the experience. Such quotes can help players relate to the theme or serve as guidance and emotional support.
- Certain questions, such as "What would you do/say if you could go back?", may be perceived as confrontational, as they refer to situations that are impossible to change.

TESTING THE UITVAARTWENSENSPEL

The Uitvaartwensenspel (Funeral Wishes Game) (Uitvaartwensenspel, 2019) by Cathelijne de Vries was tested to gain insights into how a game might facilitate difficult conversations and how it could serve as inspiration for future design developments.

The Uitvaartwensenspel is a board game in which players roll a die and, depending on the square where their pawn lands, answer a specific type of question. The question categories include true or false, agree or disagree, religion and rituals, music, and do you know what you want questions.

Testing the game together with a participant yielded several key insights:

- Some questions were perceived as dry, harsh, or confrontational, and at times lacked emotional sensitivity.
- Knowledge-based questions were considered interesting because they provided some lightness to the game; however, they could also feel boring or confronting.
- Questions about religion were only engaging when they related to the participant's own beliefs.
- Questions addressing one's own ideas and wishes were found to be the most meaningful and often led to deep, reflective conversations.
- During play, we began rolling the die again whenever it did not land on yellow or blue squares (which represented the deeper questions), as these were considered the most engaging.
- The music category added variety and humor to the game, although the provided song list felt impersonal.
- The game element itself made it easier to initiate conversations about sensitive topics by providing a structured reason to talk about them.
- The notion of "winning" the game felt somewhat strange, as the session ended abruptly once a player won, sometimes rather quickly, disrupting the reflective atmosphere.

Appendix B

DEVELOP

OVERVIEW

B1. Design approach & Ideation

B.1.1. Co-design session 1

B.1.2. Co-design session 2

B.1.3. Ideas

B.1.4. Positives & Negatives concept directions

B2. Concept development

B.2.1. First prototype and test : Mosaïc

B.2.2. Second prototype and test : Blocks

B.2.3. Third prototype and test : Plates

B.2.4. Iterating Mosaïc

B.2.5. Testing Leafe V1

B.2.6. Changes to leafe after test

INTRODUCTION

This appendix provides additional information on the development of the concept. Section B1. presents further details on the design approach and ideation process. Section B2. outlines the development of the final concept.

B.1.1. Co-design session 1

During the ideation phase, co-design sessions were conducted with fellow students. This section describes the first of these sessions. For the activity, various crafting supplies, paper, pens, and snacks were provided to create a relaxed and creative atmosphere.

The session mainly focused on identifying the key needs of the target group and exploring possible ways to address them. The written outcomes of the discussion can be found in Figure 65.

One idea that emerged involved writing down questions you might have for their parent or child in the context and putting them into a "mailbox". (See figure 64) Participants took turns drawing one at random to experience how it would feel to answer it.

Drawing the questions blindly sparked curiosity and joy. At the same time, knowing that the question had been written by the person sitting in front of you added another layer of intrigue. You become curious about what the other person wants to know, which can also create a sense of nervousness. This exercise highlighted **the fine line between something feeling excitingly curious and slightly intimidating.**

It was also discussed **when the questions should be drawn,** at what moment this would feel appropriate. For instance, what if one person is not ready or lacks the energy to answer certain questions? This aspect remains open for further exploration and refinement in future iterations

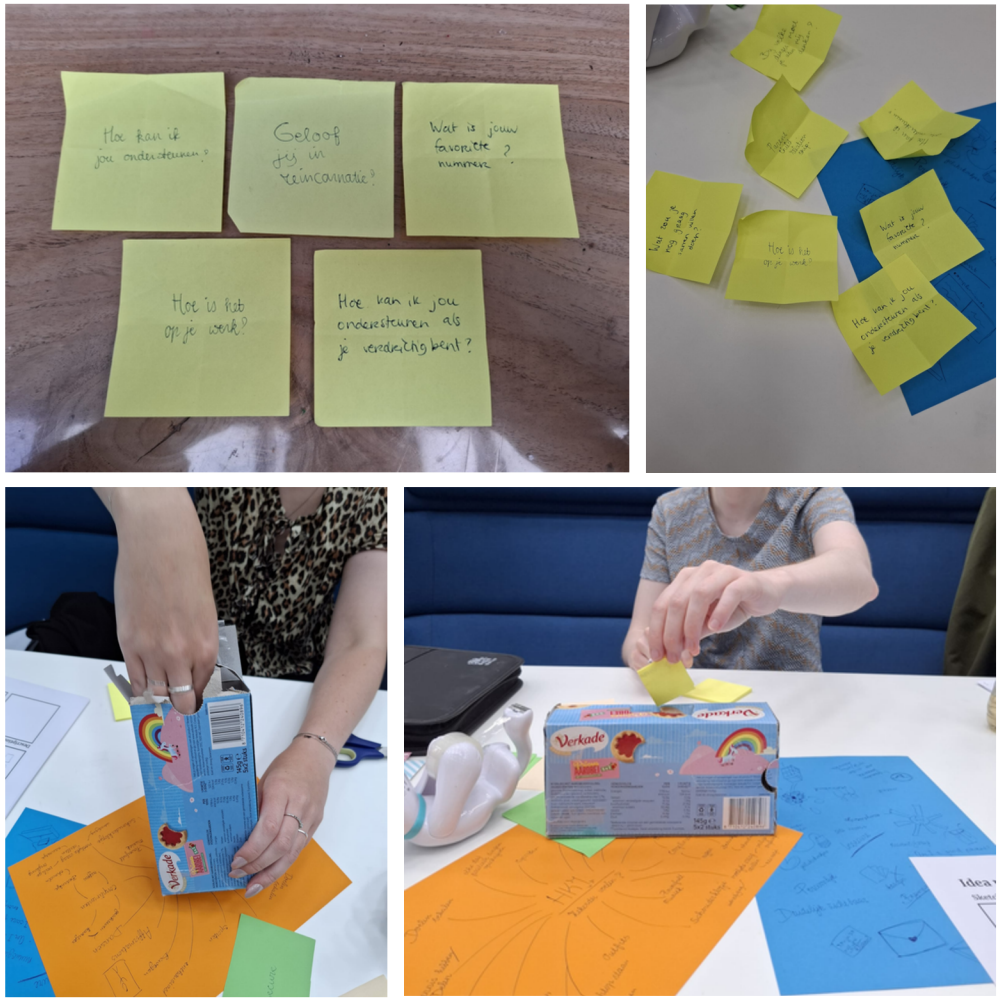
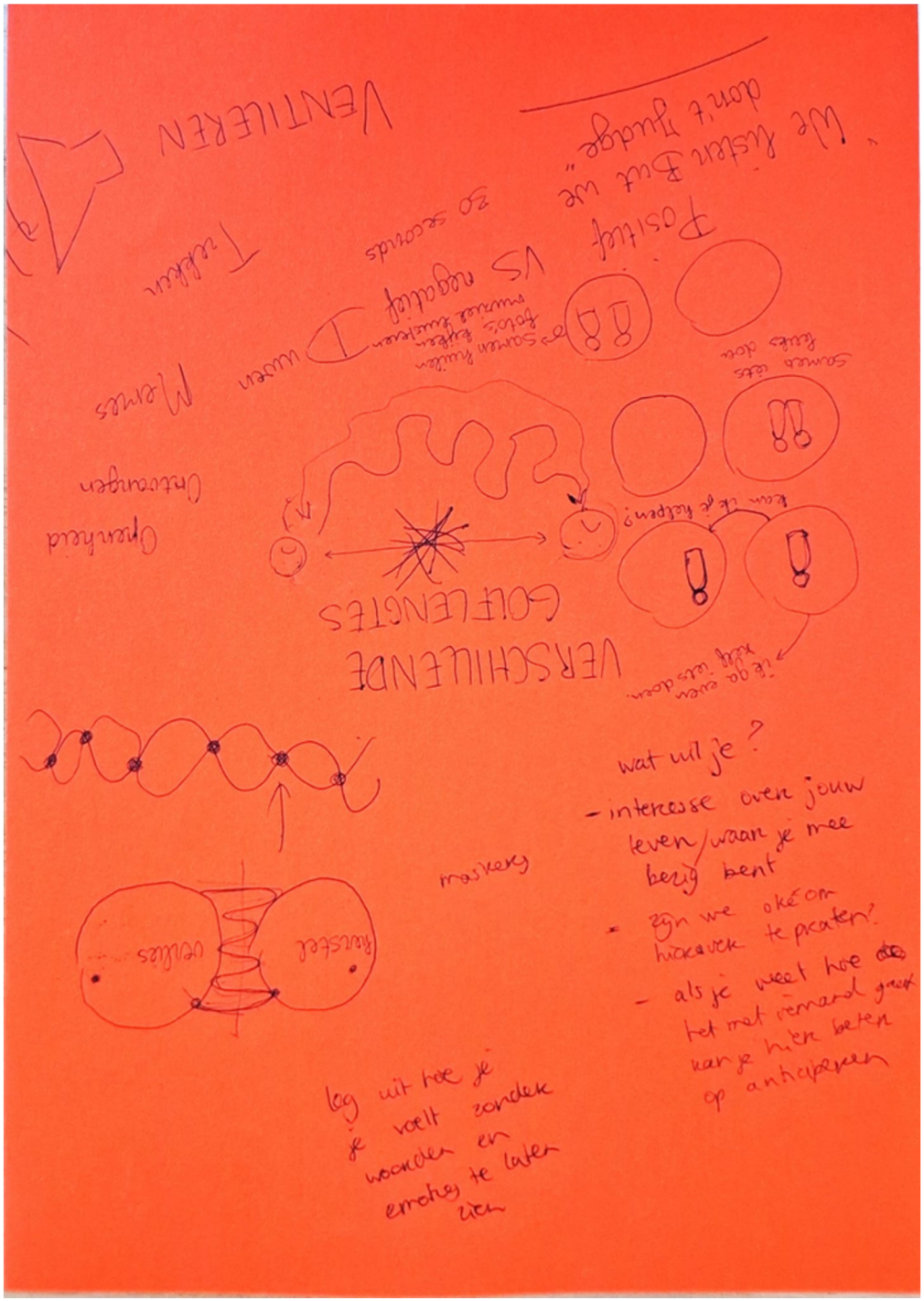


Figure 64. Mailbox idea exploration



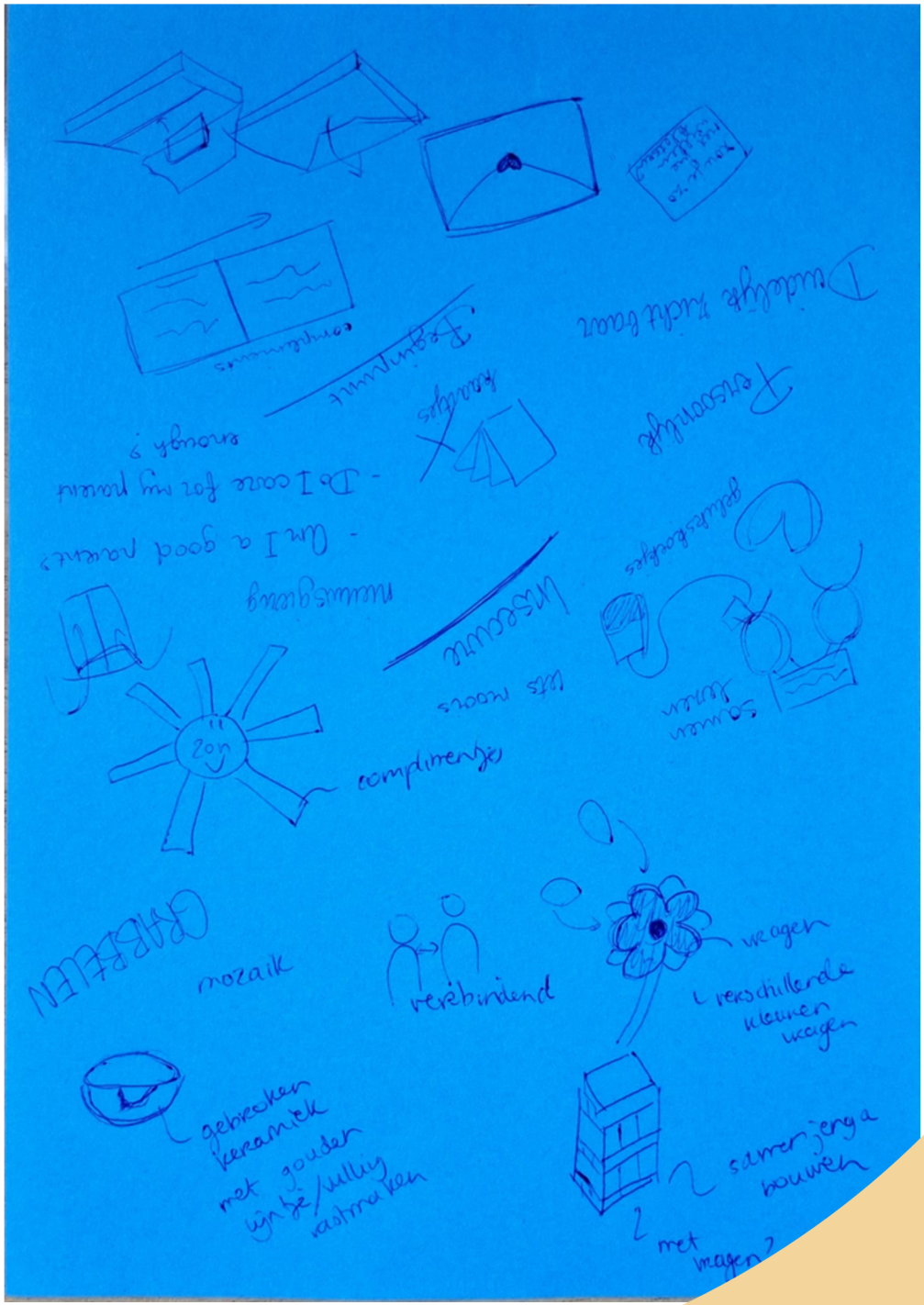


Figure 65. Co-design session 1 discussions

B.1.2. Co-design session 2

During the ideation phase, co-design sessions were conducted with fellow students. This section describes the second of these sessions. For the activity, various crafting supplies, paper, pens, and snacks were provided to create a relaxed and creative atmosphere (See figure 66).

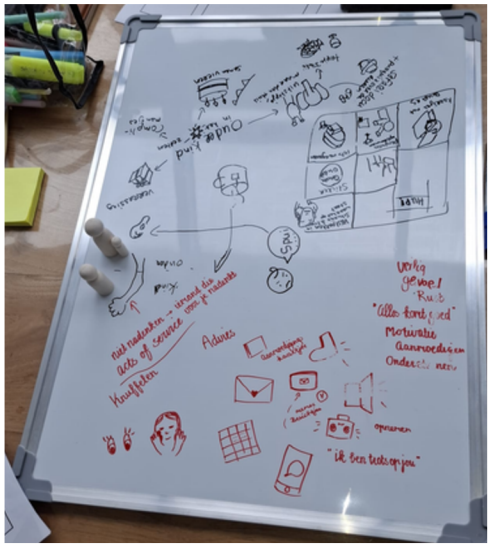
The main goal of this session was to generate a wide range of ideas. The cards described in Section 4.1. were used for this purpose, combining either a barrier and a facilitator, or a barrier and a fundamental need lens (Desmet, 2020)

For each combination, participants sketched and discussed potential ideas (see Figure 67). After each round, new cards were drawn, and the process continued.

Promising ideas were documented on idea forms, with examples shown in Figure 68.



Figure 66. Co-design session 2 setup



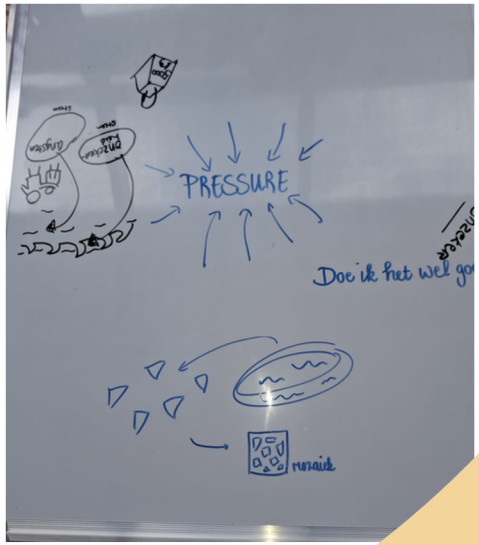


Figure 67. Ideation during Co-design session 2

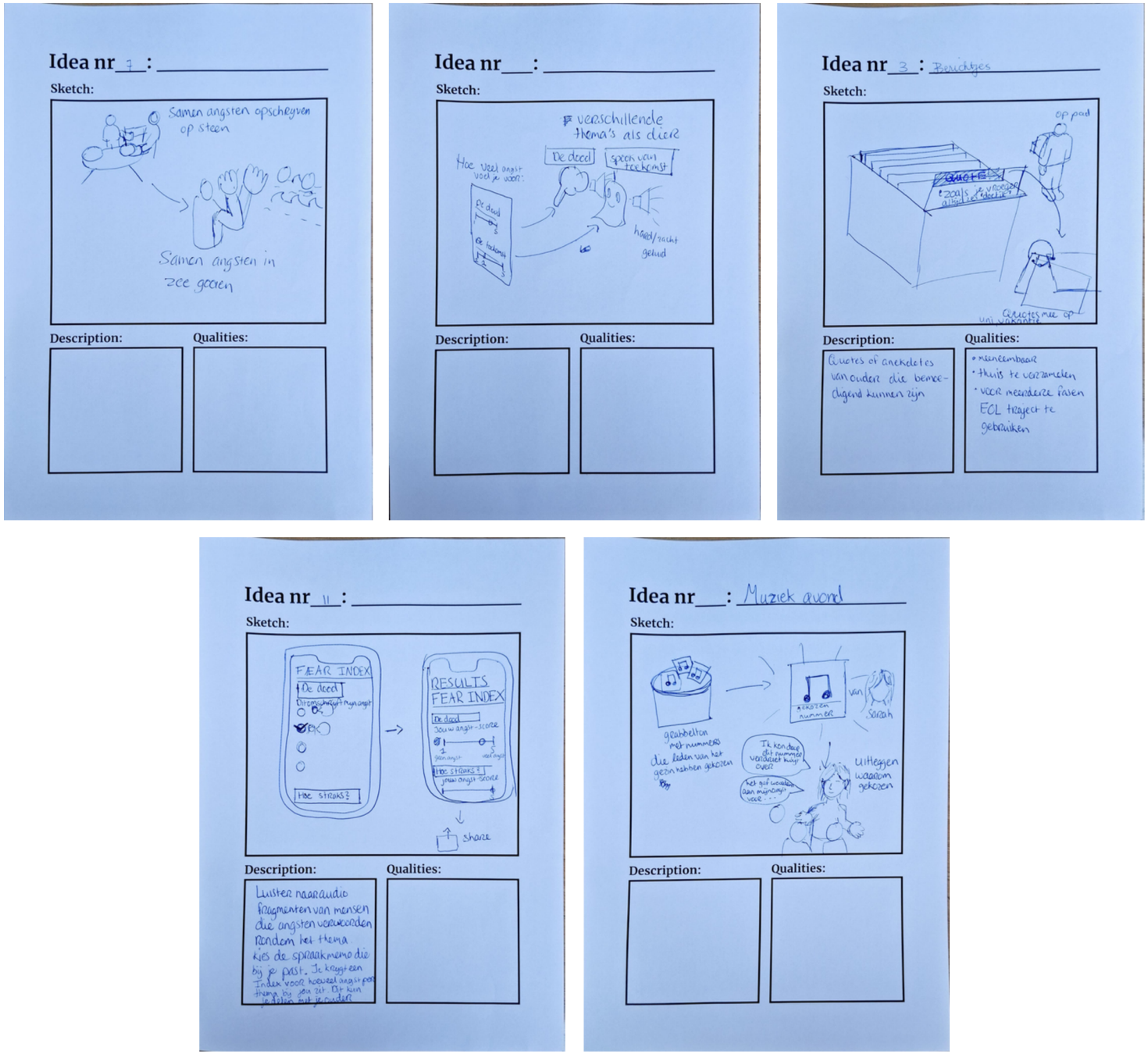
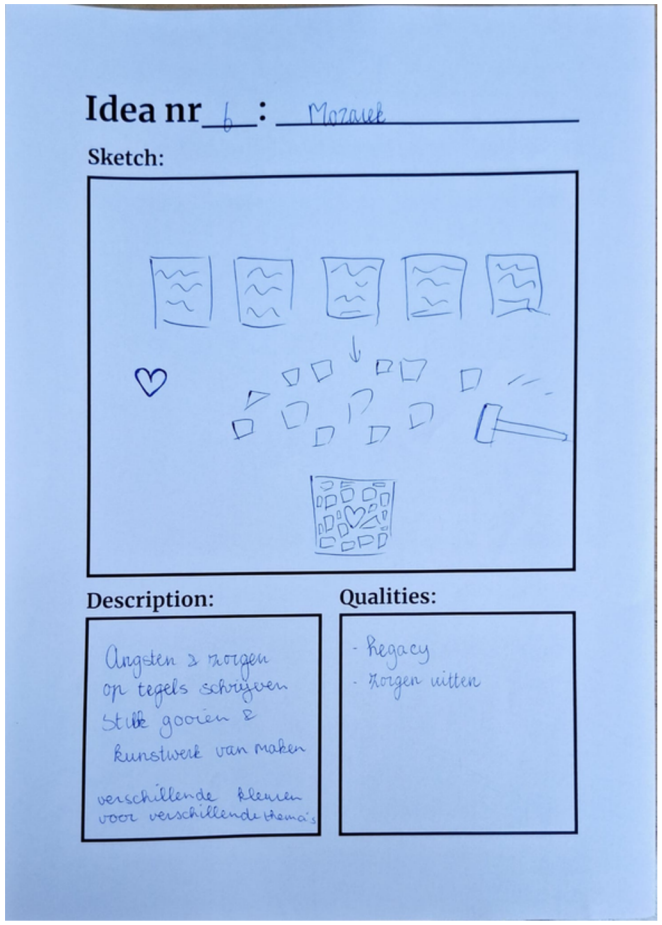
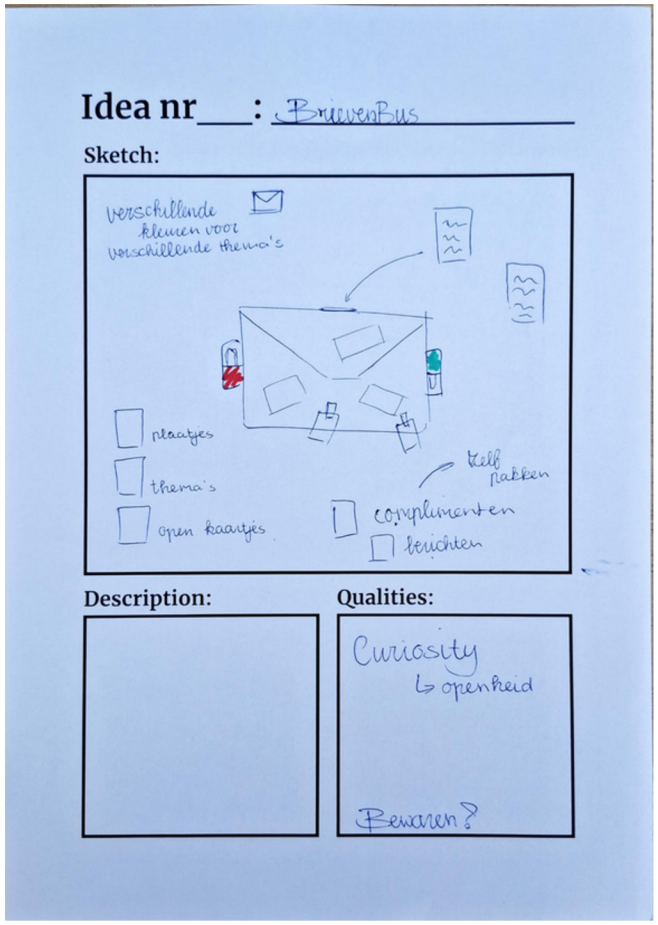


Figure 68. Ideas documented by fellow student

B.1.3. Ideas





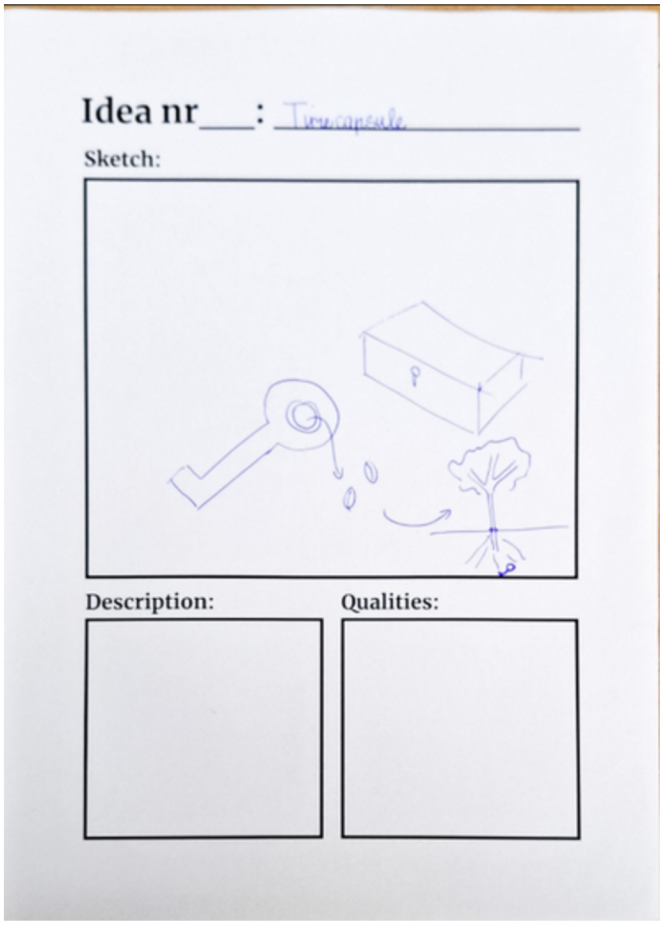
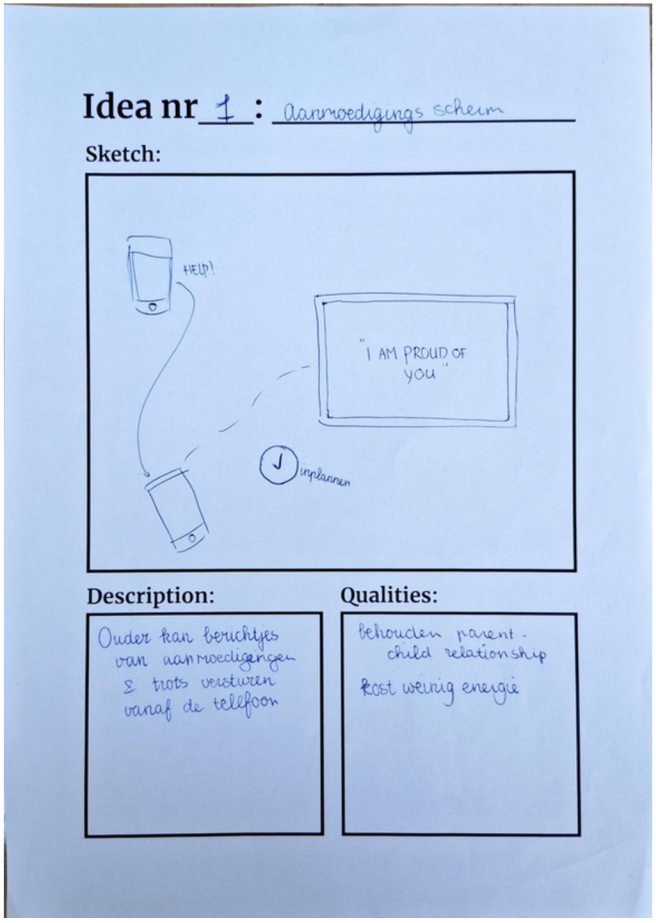
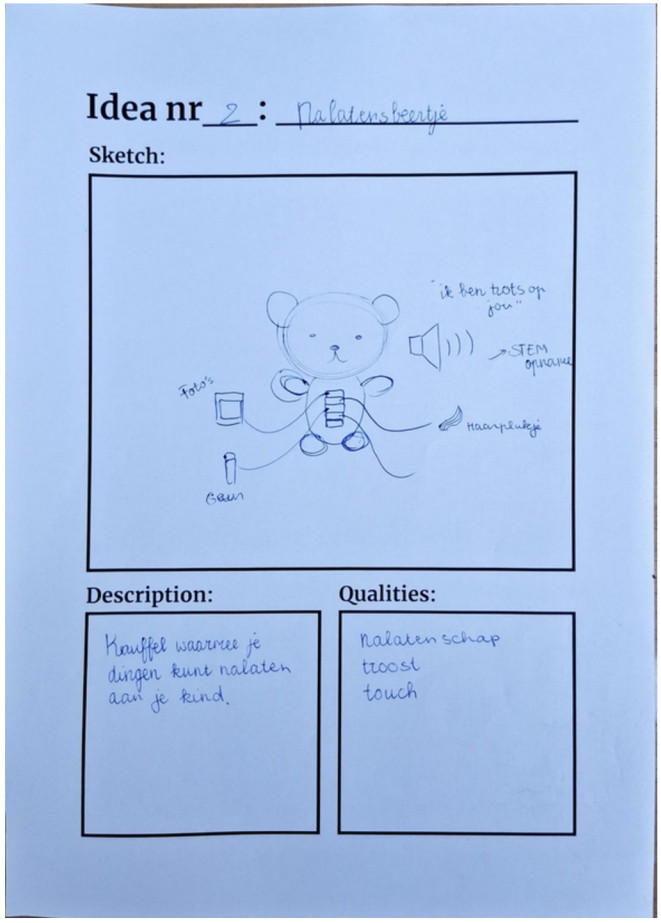


Figure 69. Ideas forms part 1





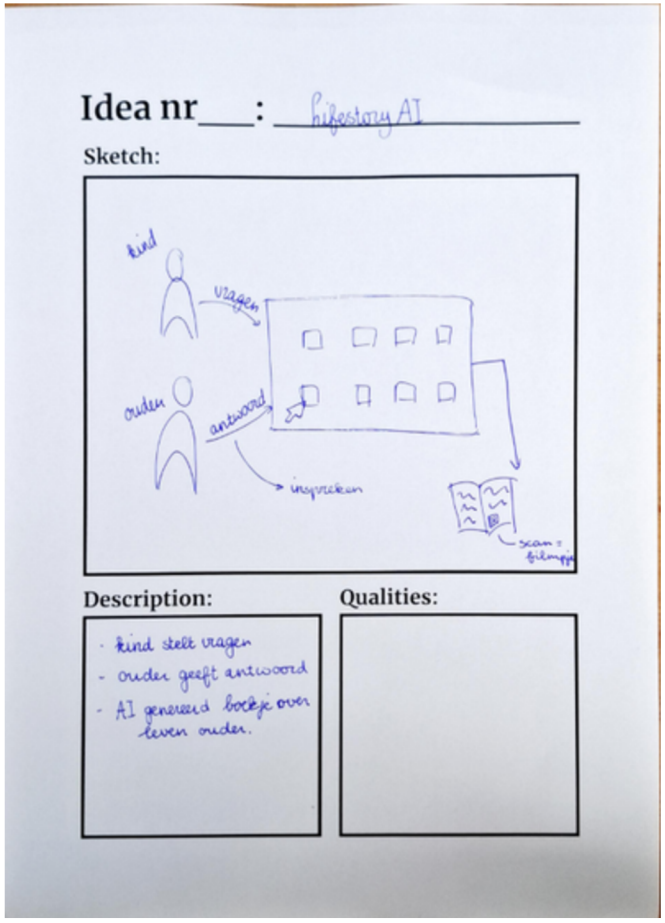
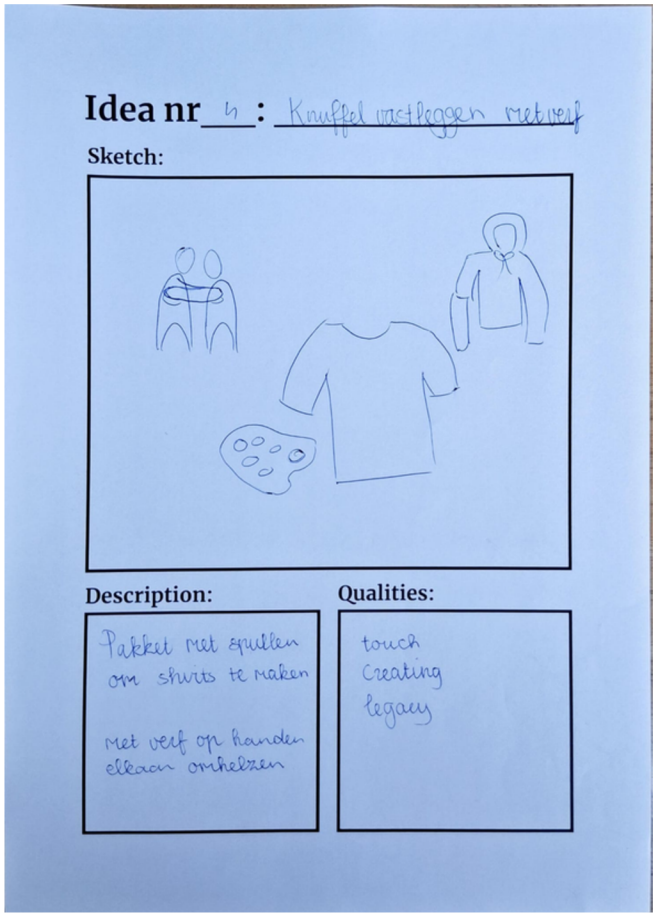
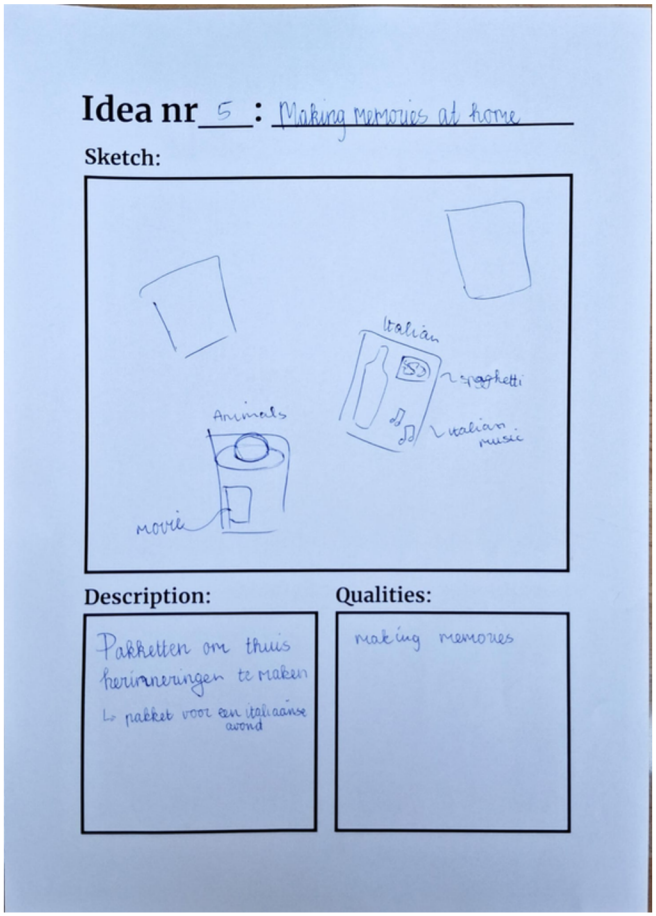


Figure 70. Ideas forms part 2





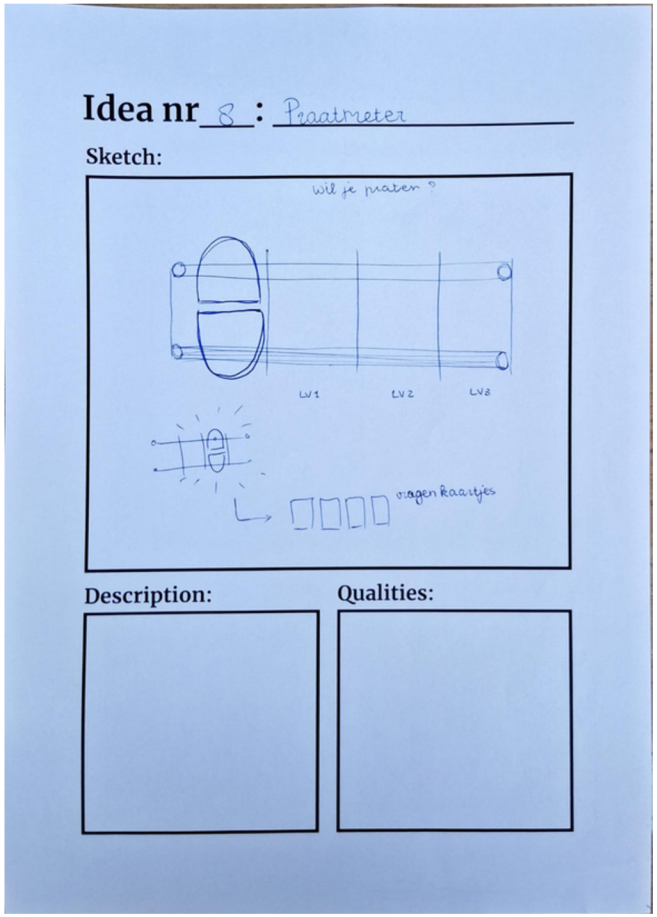
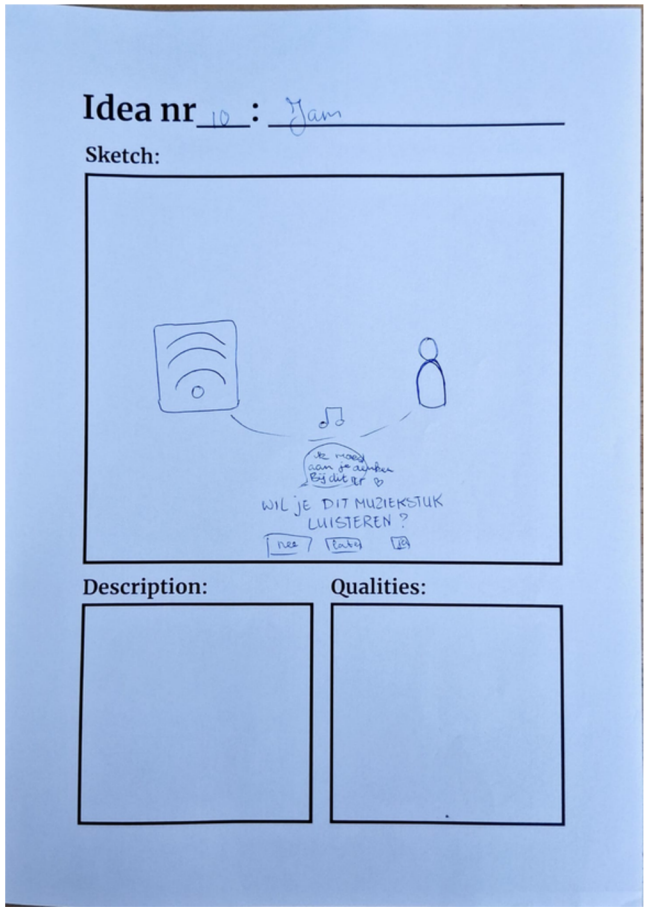
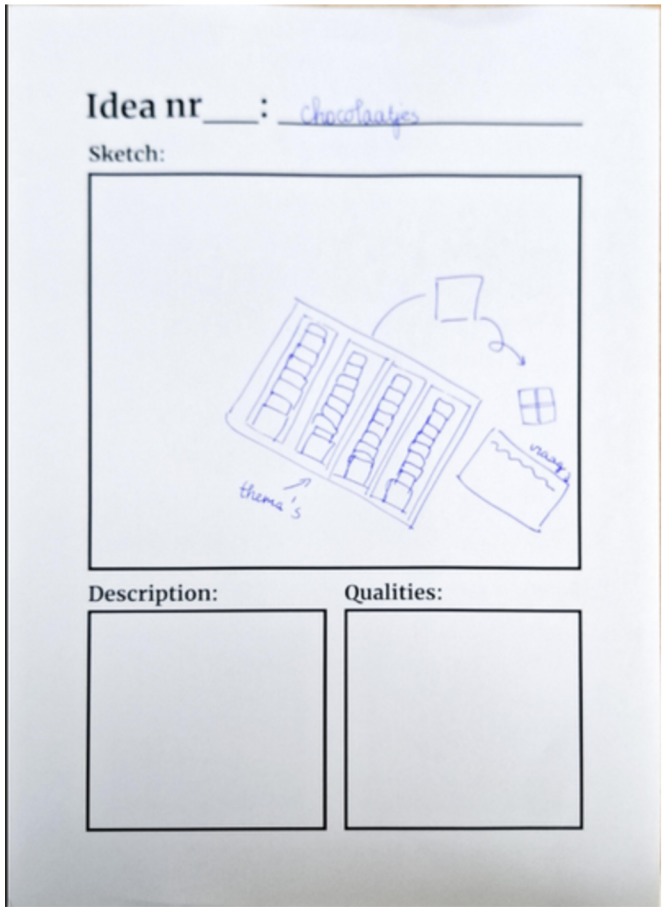


Figure 71. Ideas forms part 3





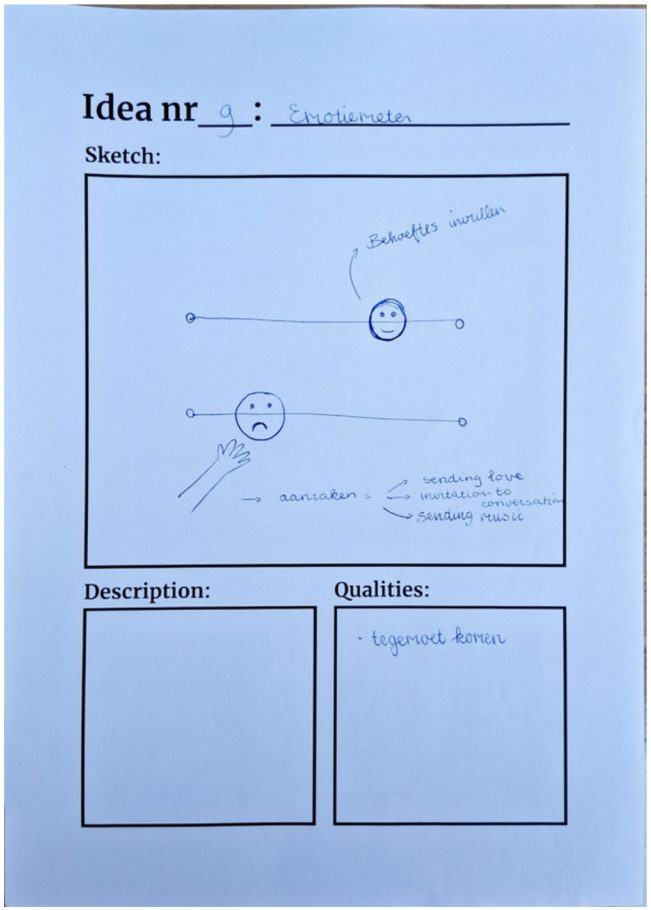
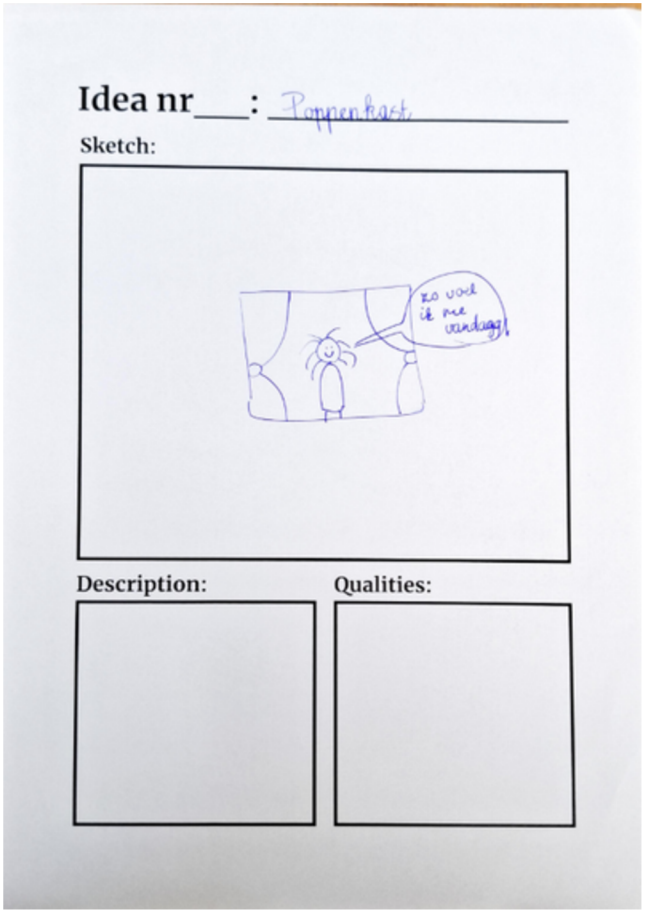


Figure 72. Ideas forms part 4



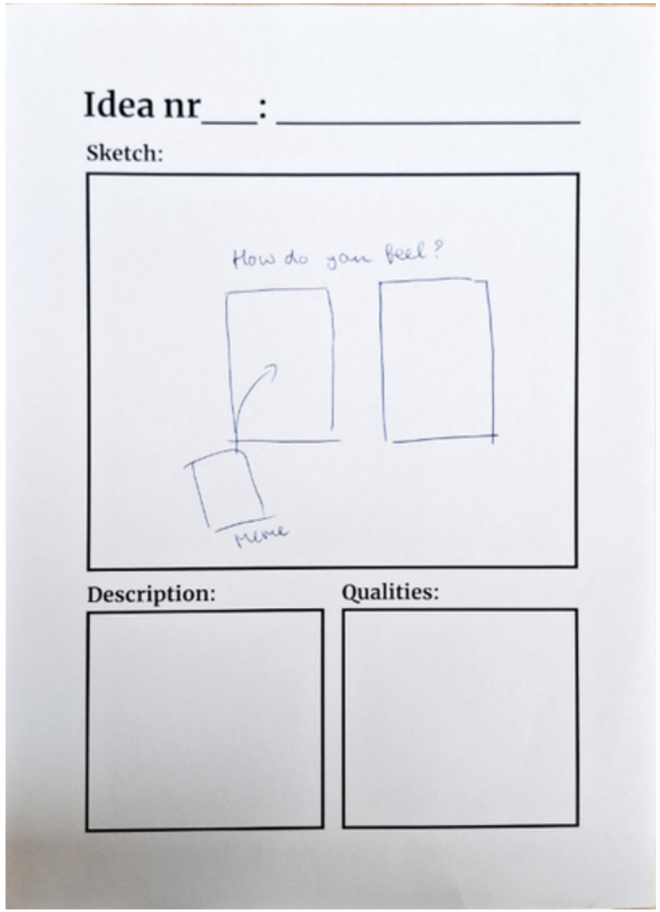


Figure 73. Ideas forms part 5

B.1.4. Positives & negatives concept directions

CONCEPT DIRECTION 1: TIME CAPSULE:

Qualities:

- Provides a meaningful and engaging activity and an opportunity to discuss end-of-life themes.
- Gives reassurance to the parent by leaving a legacy.
- Creates a tangible box of memories for the child.
- Establishes a physical place to return to for consolation.

Negatives:

- Nature is unpredictable; if the tree fails to grow or dies, it could have a negative emotional impact.
- Once the key is buried, it may not be possible to retrieve it.
- The tree is tied to a specific location, so if the family moves, they may have to leave the tree behind.

CONCEPT DIRECTION 2: MOSAÏC

Qualities:

- Provides a meaningful and engaging activity.
- Encourages open sharing of worries and fears.
- Allows participants to take their time and work at their own pace.
- Helps relieve emotional tension.
- Hands-on activity reduces pressure and facilitates conversation.
- Tangible mosaic artwork serves as a lasting reminder of the experience and connection.

Negatives:

- Breaking tiles could pose a safety risk.
- Some themes may not inspire meaningful conversation or might lack sufficient guidance.

CONCEPT DIRECTION 3: AI LIFESTORY:

Qualities:

- Provides the emerging adult with an opportunity to ask all their questions.
- Offers reassurance to the parent by leaving a legacy.
- Allows the parent to take their time and respond at their own pace.
- Produces a tangible book that fosters comfort, reflection, and connection.

Negatives:

- Use of AI may raise privacy concerns or worries.
- Limited direct, face-to-face communication between parent and child.
- The focus on the parent as the main character may make the child feel less included.

CONCEPT DIRECTION 4: MAILBOX:

Qualities:

- Provides opportunities for open and meaningful conversations.
- Gives participants autonomy to decide when they are ready to talk.
- Cards in the box evoke curiosity and invite discussion.
- Saved cards serve as tangible reminders of their bond and shared moments.

Negatives:

- Seeing that the other person wants to talk may create pressure to indicate readiness as well.
- If the other person is not ready to talk, it may lead to feelings of rejection.
- Conversations may be missed entirely if both participants are never ready at the same time, which could cause frustration.

Figure 74. Qualities and negative for concept directions.

B.2.1. First prototype and test : Mosaïc

BRAINSTORM

Brainstorming was done on how to improve the concept: Mosaïc (See page 69). Different themes and presentation methods were explored to encourage meaningful conversations. A timeline was also created to visualize how users might interact with the concept over time. This lead to changes to the concept.

Key changes from the first concept version include:

- Material choice: Premade mosaic stones were selected instead of tiles for safety reasons, removing the need to break tiles manually.
- Conversation prompts: Questions or words are presented as conversation starters, each paired with a colour representing one of four themes : spiritual, psychological, physical, or social.
- Memory box design: The mosaic artwork is placed on top of a box, transforming it into a memory box where users can store personal memories. The transparent lid allows participants to write words on the back of the tiles during discussions, making them visible when the box is opened.
- Light feature: A light is integrated into the box, creating a ritual element , turning on the light allows it to shine through the mosaic artwork.
- Gold glue: Gold glue is used to fill the mosaic artwork, inspired by the Japanese art of Kintsugi, where repairs are highlighted to express that there is beauty in what has been broken (Risner, 2022).

PROTOTYPE

A first prototype was created (see Figure 76). It includes a box with a transparent lid, four bags of mosaic tiles in colours corresponding to the four themes, a light, markers, and gold glue.

For this prototype, each theme is accompanied by a different method of presenting its subthemes to observe variations in user interaction during testing:

- A card with subthemes
- Three cards divided into past, present, and future
- Cards with questions
- An audio message introducing the theme



Figure 76. Prototype V1

TESTING

The first test round was conducted with a mother and her daughter. Together, they explored the themes and created the mosaic artwork collaboratively (See figure 77 & 78).

INSIGHTS

- The audio message feels somewhat intrusive and takes participants out of the moment.
- A clearer instruction on how the concept works is missing.
- Participants appreciated having something tangible to hold, which helped support engagement.
- The light feature was well received: “This way, the memories shine out of the box.” -Emerging adult participant
- Participants expressed a desire for personalisation, such as choosing the central motif instead of the butterfly.
- The tiles provided a comforting, tactile element, allowing fidgeting and reducing the pressure of maintaining eye contact.
- Subthemes successfully prompted conversation and follow-up questions, though they sometimes lacked sufficient guidance.
- Question cards offered more direction but left less room for personal interpretation.
- The tiles were too small, and the marker ink bled through the glue, making the text difficult to read.
- Participants preferred using premade tiles over breaking them: “Breaking tiles takes away from the softness.”
- Both participants indicated they would use the box to store personal memories. The mother mentioned she would write a letter to her daughter to place inside.
- Blind question cards sparked curiosity, participants were eager to discover what the next question would be.
- Humour was naturally used during the process.



Figure 77. Test 1



Figure 78. Test 1: outcome

B.2.2. Second prototype and test : Blocks

BRAINSTORM

Based on the insights gained from the first test, an additional brainstorming session was conducted to refine the concept (See figure 79).

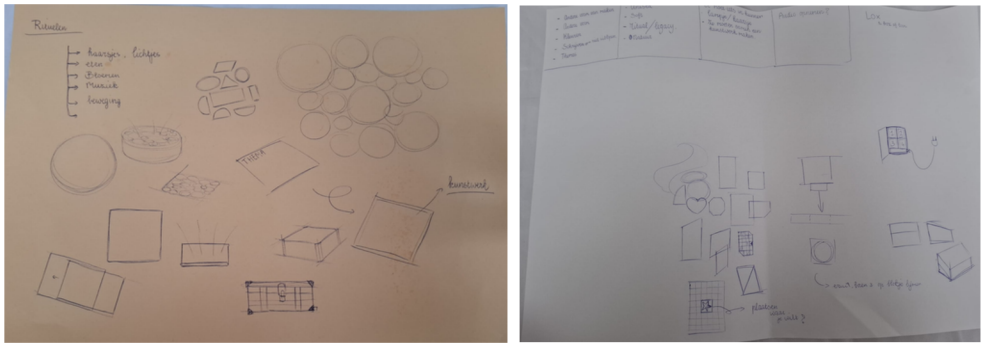


Figure 79. Brainstorming

KEY CHANGES:

- Introduced wooden blocks and more neutral colours to create a different aesthetic and simplify the creative process. This method is also more accessible than the mosaic approach.
- Decided to present the themes in sealed envelopes to evoke curiosity and a sense of discovery.
- Established a set order for exploring the themes.
- Chose to include both word cards for open discussions and question cards for more structured guidance.

PROTOTYPE

A new prototype was developed (see Figure 80). It consists of a base on which the wooden blocks can be placed. Each block features a small circular area at the bottom where users can draw or write words inspired by the corresponding questions or subthemes.
Each theme is stored in its own envelope, containing an instruction card as well as question and subtheme cards.



Figure 80. Prototype V2

See Figure 81 for the instruction cards and Figure 82 for examples of the question and subtheme cards.



Figure 81. Instruction cards V2

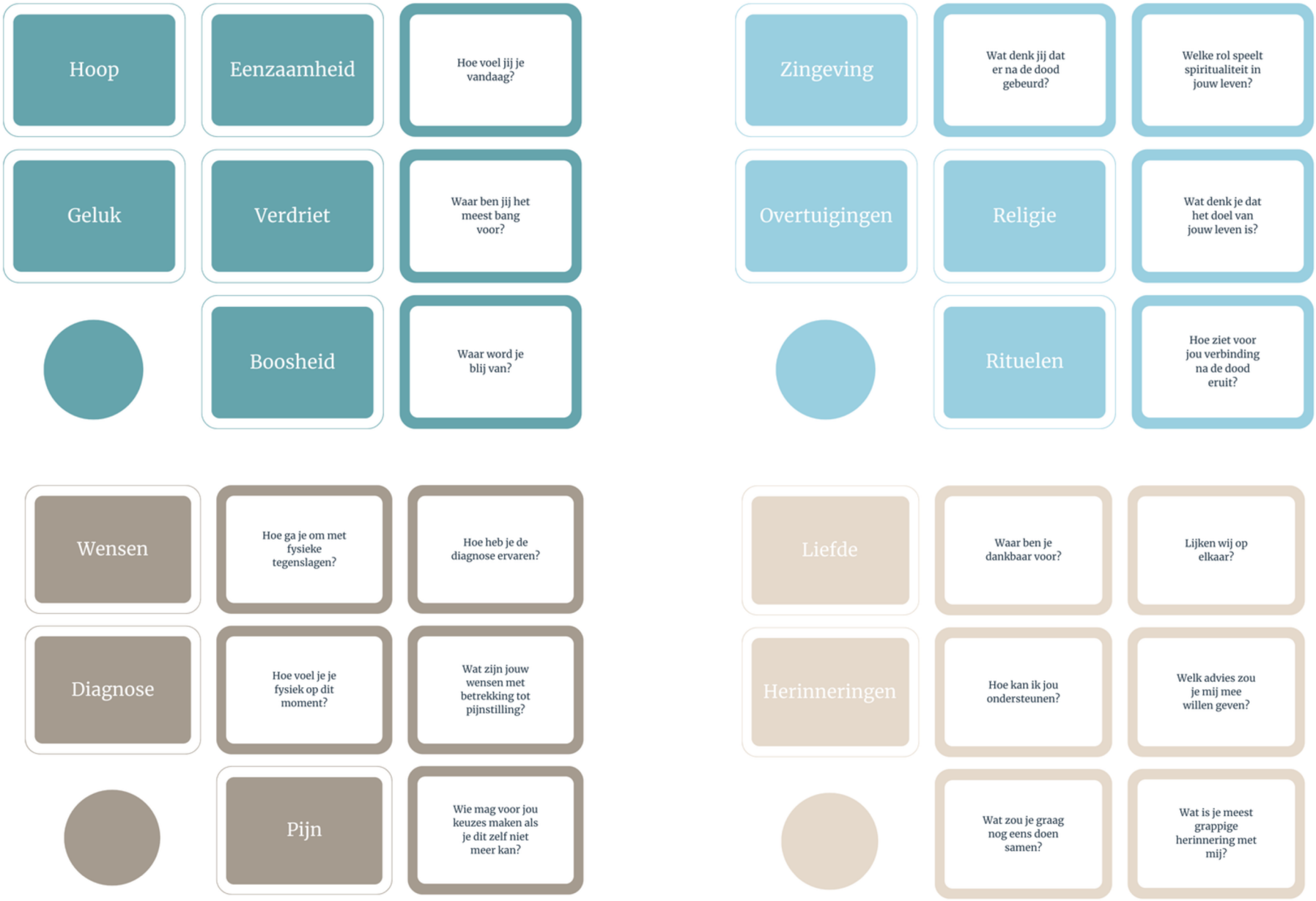


Figure 82. Question and subtheme cards V2

TESTING

The second test round was also conducted with a mother and her daughter (See figure 83 & 84).

INSIGHTS

- The placement of the blocks held personal significance for participants , the most meaningful ones were placed in the centre.
- There was insufficient creative freedom; the circular areas on the blocks were too small, and the wooden surface made drawing difficult.
- The subtheme cards were largely ignored. Participants found them unclear and lacking in guidance, and were unsure how to use them.
- Having one envelope per theme effectively evoked curiosity.



Figure 83. Test 2





Figure 84. Outcome test 2

B.2.3. Third prototype and test : Plates

BRAINSTORM

With the insights gained from the first test, another brainstorming session was conducted to further develop the concept.

KEY CHANGES:

- Introduced a new method of creation to make the process more engaging and flexible.
- Provided a larger surface for participants to write and draw, allowing for more expressive input.
- Added example questions on a single card for each theme to offer clear guidance.
- Placed subthemes on puzzle-shaped pieces, so that participants' drawings and writings could easily connect back to a specific theme.

PROTOTYPE

A new prototype was created (see Figure 84). Each theme includes a set of shapes with a subtheme written on the front. For each theme, there is also a card containing instructions and example questions (see Figure 85).
Participants are invited to write or draw on the back of each shape, guided by the subthemes and questions. Once all themes are completed, the shapes can be assembled into a collective artwork, placed between two transparent plates. In this way, the artwork can be viewed from the front as a visual composition, while the reflections and conversations written on the back remain visible from the other side.



Figure 84. Prototype part theme physical.

Voorbeeldvragen:

Verdriet: Ben je vaak verdrietig?

Hoop: Wat geeft jou hoop in het leven?

Boosheid: Waar kan jij echt boos om worden?

Geluk: Wanneer ervaar jij geluk?

Blijheid: Waar wordt jij blij van?

Eenzaamheid: Voel jij je weleens eenzaam?

Angst: Waar ben je het meest bang voor?

Druk: Wanneer ervaar jij druk?

Voorbeeldvragen:

Communicatie: Ben je tevreden met hoe wij met elkaar communiceren?

Herinneringen: Wat is jouw meest grappige herinnering aan mij?

Liefde: Welke rol speelt liefde in jouw leven?

Gelijkenis: Waarin vind je dat we op elkaar lijken?

Ondersteunen: Hoe kan ik jou ondersteunen op moeilijke momenten?

Dankbaarheid: Waar ben je het meest dankbaar voor?

Advies: Welk advies zou je mij mee willen geven?

Trots: Ben je trots op mij?

Voorbeeldvragen:

Doelen: Wat denk je dat het doel is van jouw leven?

Zingeving: Wat maakt voor jou dat het leven zin heeft?

Rituelen: Wat voor een ritueel zou je voor mij blijven uitvoeren?

Religie: Welke rol speelt religie in jouw leven?

Overtuigingen: Welke overtuigingen begeleiden jou door het leven?

Na de dood: Wat geloof jij dat er na de dood gebeurd?

Verbinding: Hoe ziet voor jou blijvende verbinding eruit?

Spiritualiteit: Welke rol speelt spiritualiteit in jouw leven?

Voorbeeldvragen:

Pijn: Hoe is het vandaag met je pijn?

Wensen: Wat zijn jouw wensen met betrekking tot pijnstilling?

Keuzes: Wie mag voor jou keuzes maken als je dat zelf niet meer kan?

Vermoeidheid: Heb je veel last van vermoeidheid en wat doet dit met je?

Diagnose: Hoe heb je de tijd rondom de diagnose ervaren?

Ziekenhuis: Hoe ervaar je de ziekenhuisbezoeken?

Hulpmiddelen: Hoe sta je tegenover fysieke hulpmiddelen?

Behandelingen: Wanneer is het voor jou klaar met behandelingen?

Figure 85. Example questions per theme

TESTING

The third test round was conducted with a father and his son to explore whether gender influenced the interaction and experience with the concept. See figure 86 for the outcomes.

INSIGHTS

- Participants found it difficult to begin, as it was not immediately clear what they were expected to do.
- The shapes were still too small to comfortably draw on.
- Some of the questions were challenging, as they encouraged reflection on topics participants were not used to discussing.
- The pair used more humor during the activity, possibly as a way to manage initial awkwardness (which may also have been influenced by the researcher's presence). Despite this, there were genuine moments of connection, such as one placing a hand on the other's shoulder.
- Participants mentioned they might use the concept if it were recommended to them, but they would not initiate its use independently.

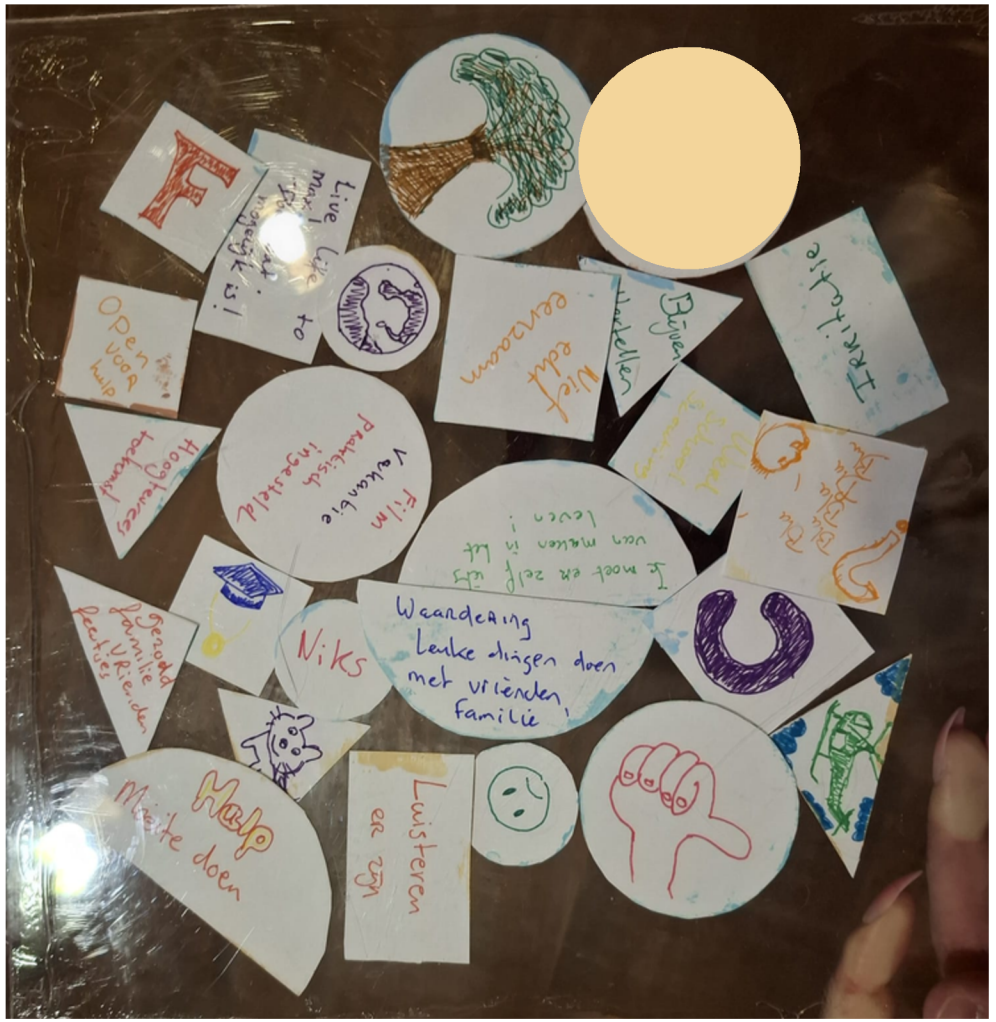


Figure 86. Outcome test 3

B.2.4. Iterating Mosaic

BRAINSTORM

Based on the insights from previous prototypes and test rounds, the decision was made to return to the first prototype. Although this version still requires refinement, it appeared to function in the most logical and meaningful way. The inclusion of the box element also gives the concept an extended purpose, it continues to serve as a memory box even after the artwork is completed.

That said, the concept still needs significant development. Considering the insights gained from earlier tests, a fresh start was made through extensive brainstorming and iterative prototyping. During this phase, many smaller aspects of the concept were tested in a formative way, asking participants directly for their impressions for example, "What do you think about this?"

ADDITIONAL RESEARCH / INSPIRATION

This phase of brainstorming began with further exploration into rituals and acts of remembrance to inspire new directions for the design.

ALTARS

An altar can be described as "a raised structure or place that is used for sacrifice, worship, or prayer" (Britannica Editors, n.d.).
However, as CHANI (n.d.) notes, "an altar is a place to honor, well, anything."

Altars can take many forms, they vary in size, colour, and composition, and can be either abundant and expressive or minimal and sober in design (see Figure 87 & 88).



Figure 87. Abundant altar
(Emelio Sánchez Hernandés via Pexels via canva.com)



Figure 88. minimal altar
(Katrin Bolovtsova via Pexels via canva.com)

DIA DE LOS MUERTOS

The main inspiration for this concept is Día de los Muertos in Mexico, which translates to "Day of the Dead." During these days, people honour their loved ones who have passed away through joyful remembrance and symbolic rituals.

OFFRENDAS

A central element of Día de los Muertos is the ofrenda, an altar created in homes or cemeteries to honour deceased loved ones. Ofrendas can have one or several levels, though the most common design features three tiers, representing heaven, earth, and the underworld (The Grace Museum, n.d.).

FLOR DE MUERTO

The symbolic flower of Día de los Muertos is the marigold, also known as flor de muerto. Marigolds are used to decorate ofrendas and graves. Their strong scent are believed to guide the spirits of loved ones back to the world of the living. (The Grace Museum, n.d.).

CELEBRATION

For Mexicans, Día de los Muertos is above all a celebration. Although it centres around death, it is not a sombre occasion. People sing, dance, attend parties and parades, and wear colourful costumes (Ward, 2025). It is a beautiful example of how a community transforms grief into joyful remembrance.



Getty Images (FG Trade Latin) via canva.com



Rom creator via canva.com



Gettyimages (Francesca Casillas) via canva.com



Magenta via canva.com

Figure 89. A colourful impression of the dia de los muertos.

BRAINSTORM

During the previous tests, it became clear that words and themes carry different meanings for different people. Terms such as psychological and spiritual evoke particular associations or energies, and participants often had preconceived feelings about them. For example, spirituality was sometimes perceived as too abstract or vague, making it difficult for participants to connect with.

To address this, the decision was made to replace the original four themes, Spiritual, Psychological, Physical, and Social, with three new ones: Past, Present, and Future. The original themes are now woven through these three temporal stages as subthemes. By avoiding the use of the more "loaded" words, potential biases and assumptions are reduced, allowing for broader and more open conversations.

This change also meant that the concept would now consist of three main conversations, and the question sets were redesigned accordingly to align with this new structure.

Another focus of the brainstorming phase concerned the box and its aesthetics. The new goal was to design a concept where the user can view both the created artwork and the contents of the box simultaneously. Several sketches were made exploring different possibilities, including boxes with fully removable lids and boxes with drawers that can be pulled out and displayed.

The visual style of the box was inspired by the vibrant aesthetics of Día de los Muertos. The design aims to be playful and altar-like, incorporating elements like flower petals. The development of this aesthetic direction can be seen in Figure 90 & 91.

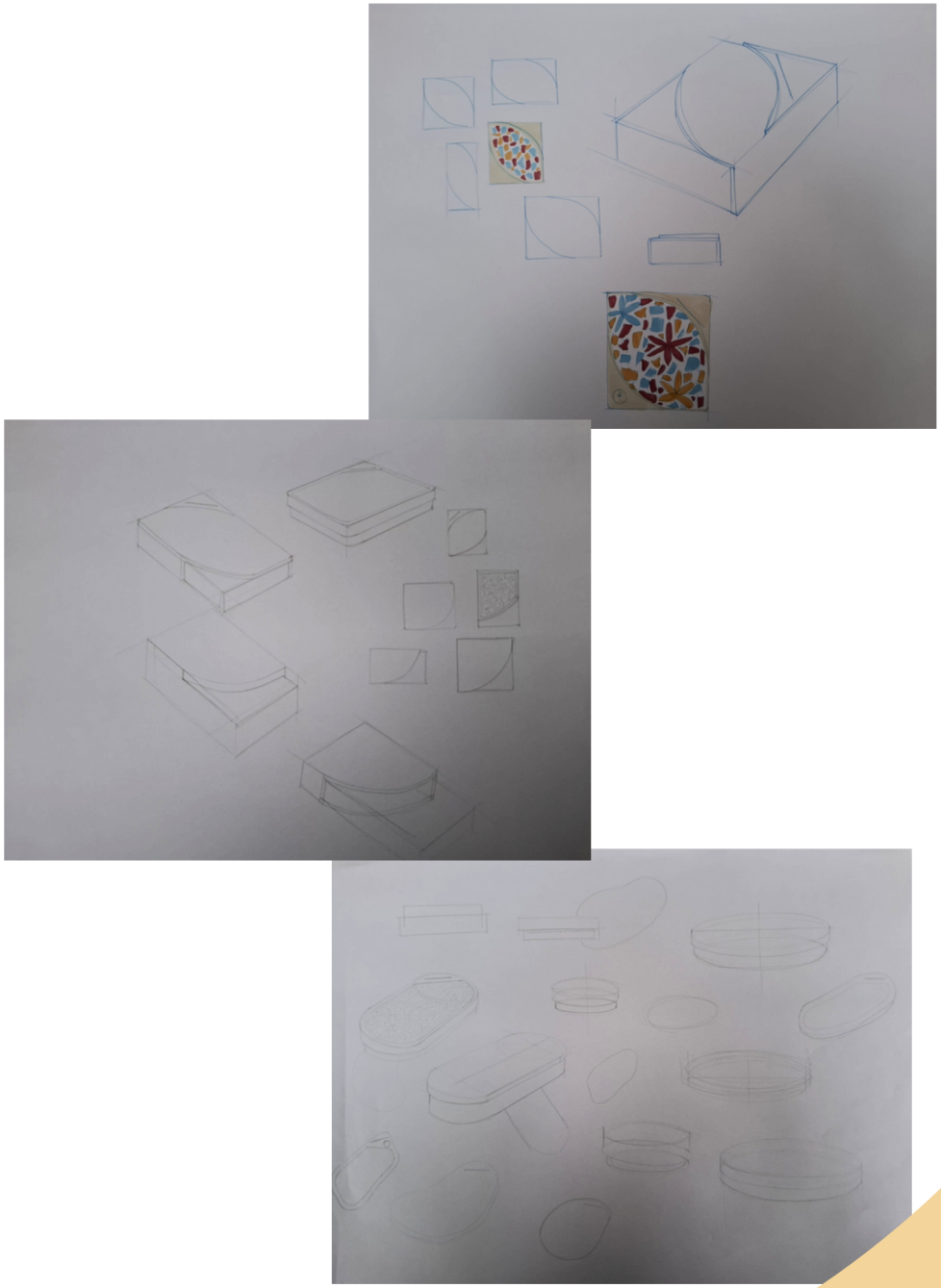


Figure 90. Sketching new aesthetics











Figure 91. Prototyping for Aesthetics

MOSAÏC LEAFS

The decision was made to use mosaic flower petals as the main tiles within the concept. Each question card is accompanied by a flower petal tile, on which users can write a summarizing word that captures the essence of their conversation. These petals are then placed onto the box, gradually forming a collective mosaic.

An exploration of scale was conducted to determine the most suitable tile and box dimensions (See figure 92). This investigation was inspired by and based on flower petal mosaic tiles from Mozaïektegeltjes & Zo.



Figure 92. Use of flower leafs as mosaïc tiles.

CARDS

An additional exploration focused on the presentation and design of the question cards (See figure 93). It was decided that the cards should continue to be presented in envelopes, maintaining an element of curiosity and discovery. However, each envelope now clearly indicates the theme of the card, providing participants with some guidance.

The cards were also designed to include:

- Space for writing and drawing, allowing users to record and preserve their conversations.
- A dedicated area for the mosaic tile.

Finally, the aesthetic design of the cards was carefully aligned with the overall style of the box (See figure 94 & 95).

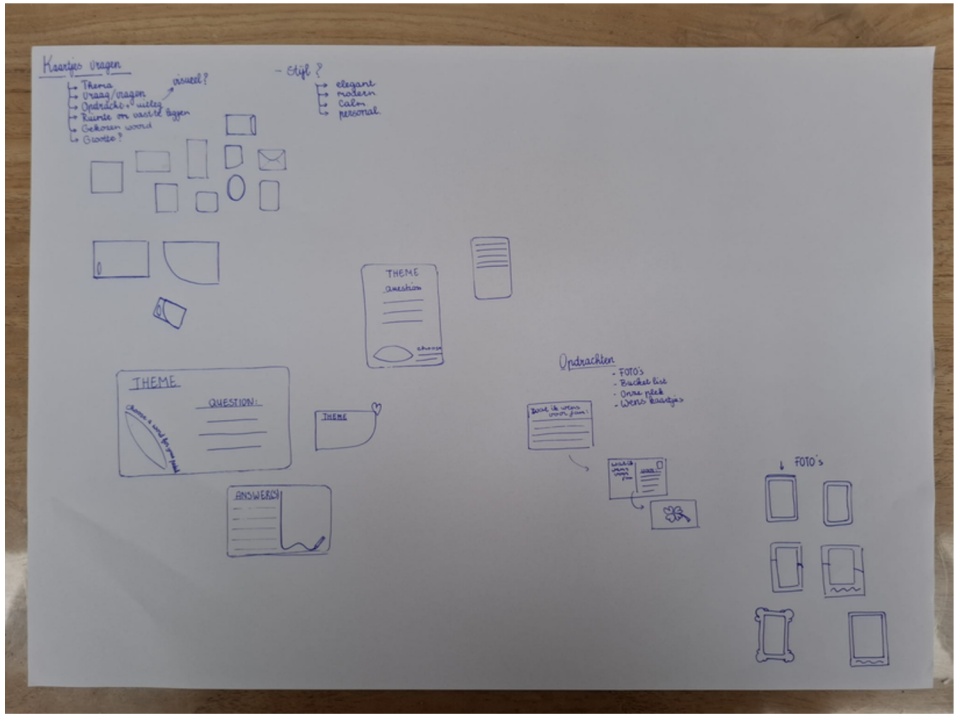


Figure 93. Brainstorm card presentation



Figure 94. Prototype card presentation

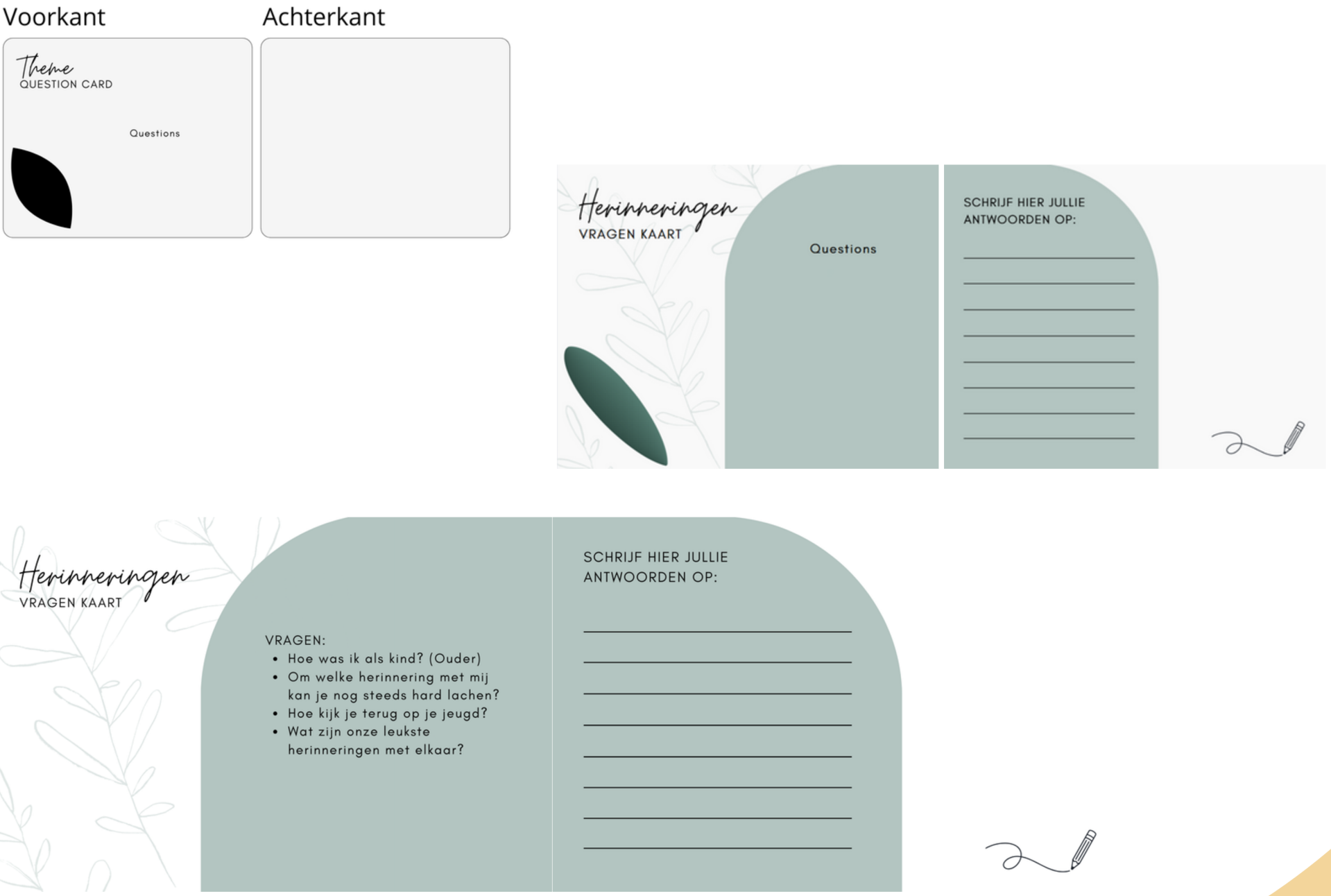


Figure 95. Online prototypes card presentation

COLOUR AND TEXTURE ANALYSIS

The interior of the box will be lined with fabric. An exploration was conducted to determine the most suitable fabric type and colour (see Figure 96). In parallel, different types of wood and mosaic tile colours were evaluated (see Figure 97 & 98), experimenting with multiple combinations to assess their effects (see Figure 99).

Through this process, various combinations of wood, tile colours, and fabric were tested to identify the most harmonious pairing (see Figure 100). The final choice was a medium-light wood paired with suede fabric. Six mosaic tile colours were selected, allowing participants to create personalized combinations based on their preferences. To unify the aesthetics, the fabric lining shares the colour of one of the chosen mosaic tiles, visually connecting the interior with the overall design.

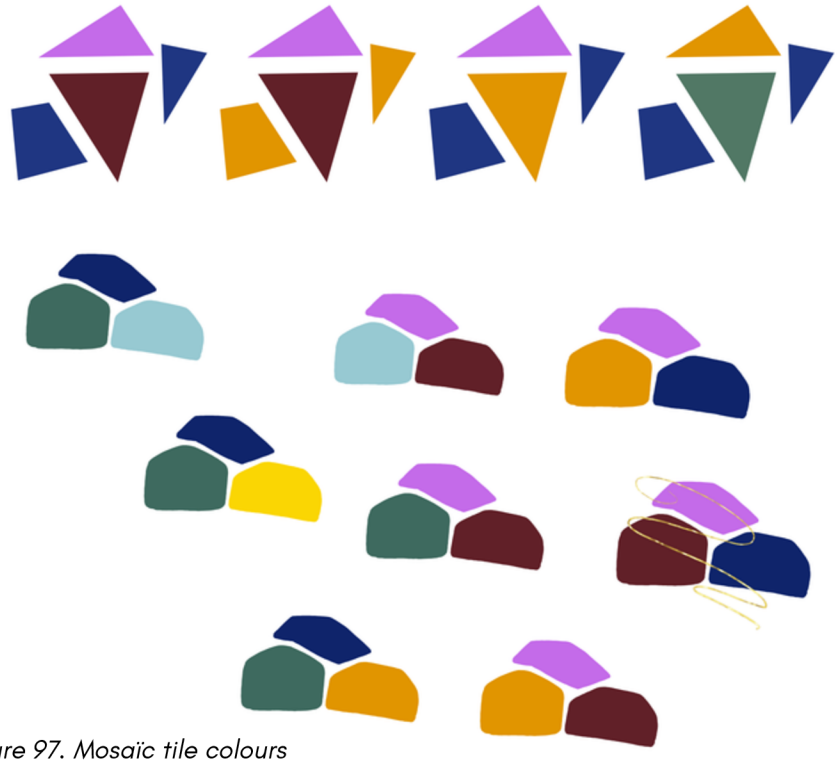


Figure 97. Mosaïc tile colours

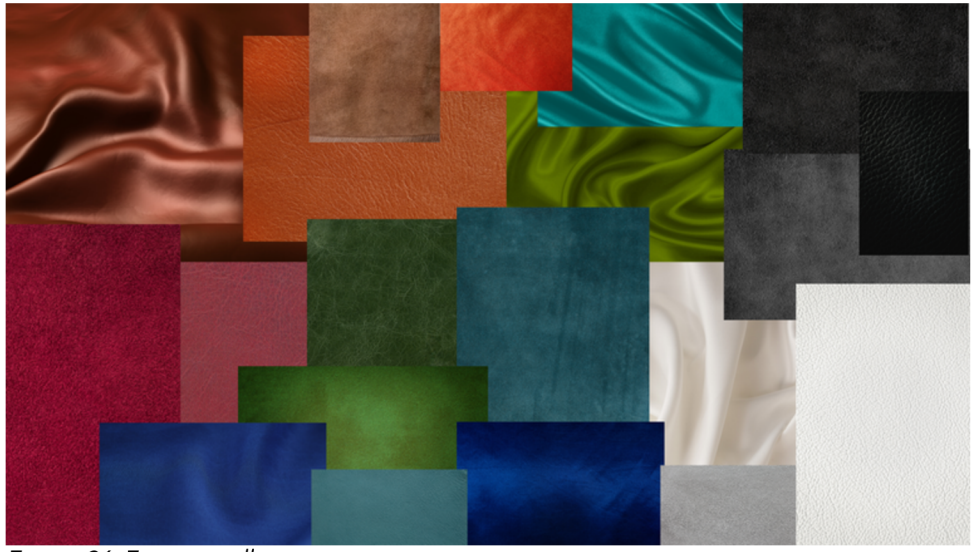


Figure 96. Texture collage



Figure 98. Wood collage

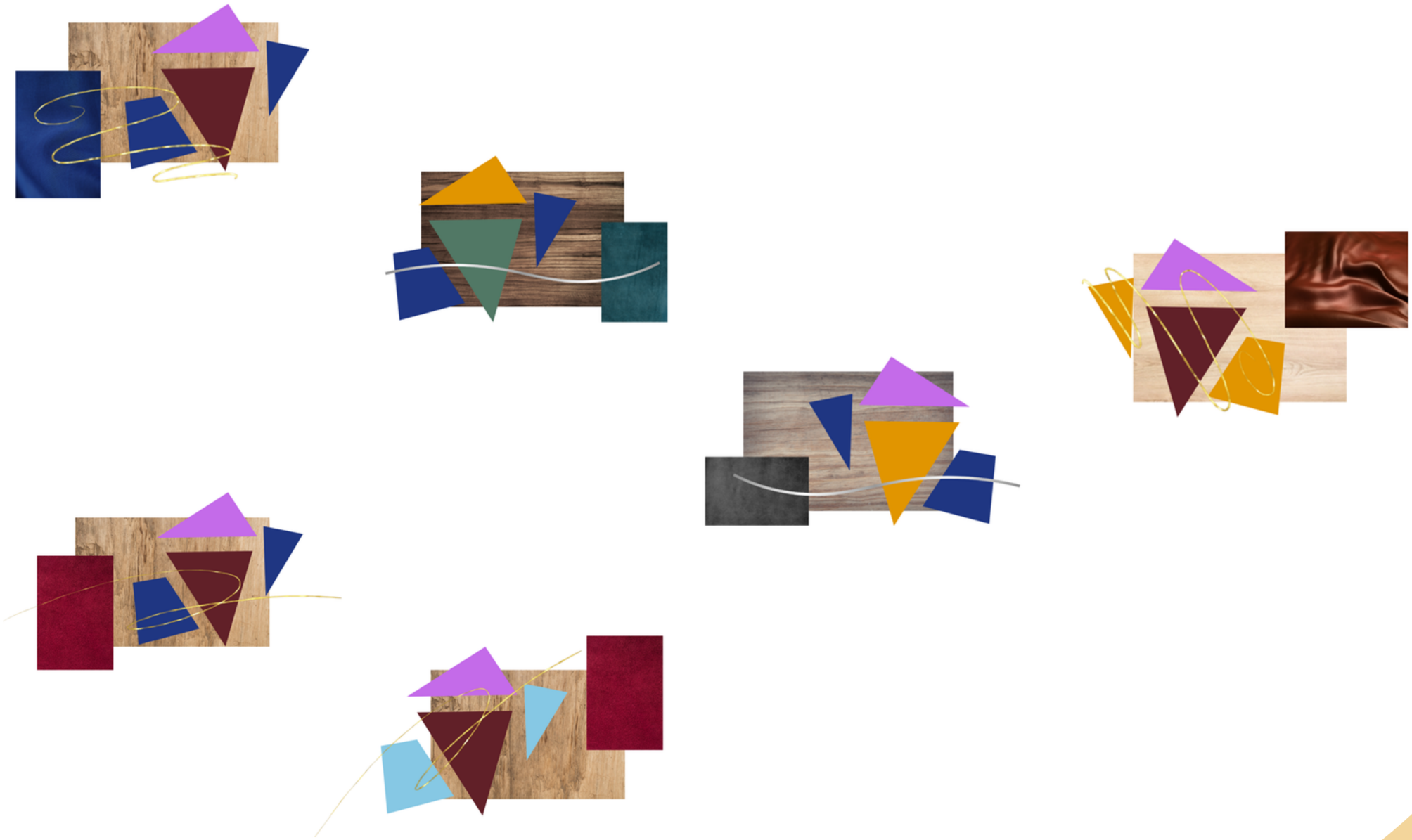


Figure 99. Colour and texture combinations V1



Figure 100. Colour and texture combinations V2

QUESTIONS

The presentation of questions on the cards was carefully reconsidered, particularly with respect to the "energy" of words. The goal was to create questions that were direct yet gentle, encouraging meaningful conversation without feeling confrontational.

A set of themes was selected thoughtfully to guide the conversations (see Figure 102).

During an interaction with ChatGPT (see Figure 101), additional insights emerged regarding question presentation. This led to the idea of introducing assignments alongside questions. Assignments could provide an active, experiential dimension, as performing an activity may elicit emotions or memories that can then be discussed.

Based on formal communication and themes, a set of assignments was developed. For each theme, there are four subthemes with questions and two assignments (see Figure 103). This structure was chosen to cover a broad range of topics while keeping the total amount manageable and not overwhelming for participants.



Mooi!
Hier zijn de voorbeeldvragen herschreven naar **speelse, korte triggers** voor op kaartjes.
Zo kun je ze tijdens het maken makkelijk voorlezen of laten trekken zonder dat het als een "interview" voelt.

Fysiek

1. *De geur van...*
2. *Een plek waar ik me thuis voelde*
3. *Ons leukste samen-doe-moment*

Gevoel

4. *Trots op jou toen...*
5. *Een klein gebaar met grote waarde*
6. *Zo voelt onze band*

Figure 101. Interaction with ChatGPT (OpenAI, 2025).

Past

Memories
As a child
Feelings

Unfinished business
Regret
Finishing

Illness process
Diagnosis
Treatment
Social

Gratitude

Present

Communication
Support
Avoidance

Feelings
Sadness
Anger
Loneliness
Hope
Happiness
Love
Pain

Future

Wishes
Physical
Social
Spiritual

Advice
Milestones
Life

After death
Beliefs
Connection
Rituals

Meaning
Goals
Motto
View on life

Figure 102. Set of themes

PAST

Question 1:

What was I like as a child?
Which memory of me still makes you laugh out loud?
How do you look back on your childhood?
What are a few of our happiest memories together?

Question 2:

If you could turn back time, would you do things differently?
What have you learned a lot from?
Are there things you need or want to finish?

Question 3:

What was it like for you to receive the (news of the) diagnosis?
How have you experienced the illness process so far?
What have you struggled with (or are still struggling with)?

Question 4:

What are you grateful for in your life?
What are you grateful to me for?

Assignment 1:

Grab some old photos of you together.
Are there photos that make you happy? Or emotional?
Are there photos that make you laugh? Can you see your bond clearly in certain photos?
Choose the most special photo of you together and keep it safe in the provided sleeve. You can also place it on the lid of the box so you can keep looking at it.

Assignment 2:

Go together to a place you loved being together. If you can't go there physically, try to create an image of it by talking about it, looking at photos, or gathering objects connected to that place. Did you always bring the same snack or the same drink there? Bring that along and imagine being in that place together again. What made this spot special? What was so nice about it? How did you feel when you were there?

PRESENT

Question 1:

How can we support each other?
How can I help you when you're having a hard time?
What can I do to make things a bit easier for you?
What makes you feel a bit better when you feel down?

Question 2:

Are there things you want to share with me?
Do you like the way we communicate with each other?
Which questions could I ask you more often?
How can I help you express yourself?

Question 3:

How are you feeling today?
What are things you are afraid of?
Are you ever sad or angry?
In which moments do you struggle, and when do you feel good?
At what moments do you experience hope and/or happiness?

Question 4:

How would you describe yourself?
How would you describe me?
In what ways are we alike?
What is your best quality?

Assignment 1:

Are there songs that mean something to you? Songs that remind you of each other? What is your favorite song? Which song touches you every single time?
Each of you choose a song (or several) and listen to them together.

Assignment 2:

Take a photo together. Have someone else take it or take a selfie. You can print it and keep it safe in the provided sleeve.

FUTURE

Question 1:

Who is allowed to make decisions for you if you are no longer able to do so yourself?
What are your wishes regarding the end of life and the funeral?
Which wish would you like to fulfill?

Question 2:

What advice would you like to give me?
How did you experience important milestones (e.g., a relationship, getting married, buying a house, getting a job, having a child), and what tips would you give me based on them?

Question 3:

What are your beliefs regarding death?
Does religion play a role for you?
How do you see connection after death?
What kinds of rituals do you perform to remember someone?
How would you do that for me?

Question 4:

Do you have goals you would like to achieve?
What gives your life meaning?
What do you think is the purpose of your life?
According to which motto do you live?

Assignment 1:

Write your wishes for each other on the corresponding cards. You may read them aloud to one another and give each other the card. But you can also keep the card for a later moment or choose not to share your wishes.

Assignment 2:

Create a bucket list of three things you would like to do together. These can be big or small activities. Write the items on the provided bucket list sheet.

Figure 103. Questions and assignments per theme.

PROTOTYPING

The prototype was constructed using a combination of laser-cutting, hand assembly, and finishing techniques (See figure 104):

- The wooden components and acrylic plates were laser-cut, then assembled, sanded, and painted.
- The interior lining was created with a sewing machine, then glued and nailed into the box. Fiberfill was added between layers to achieve a soft, cushioned interior.
- The cards were printed, glued together, and cut to their final shape.
- The logo was applied to the box using gold foil.

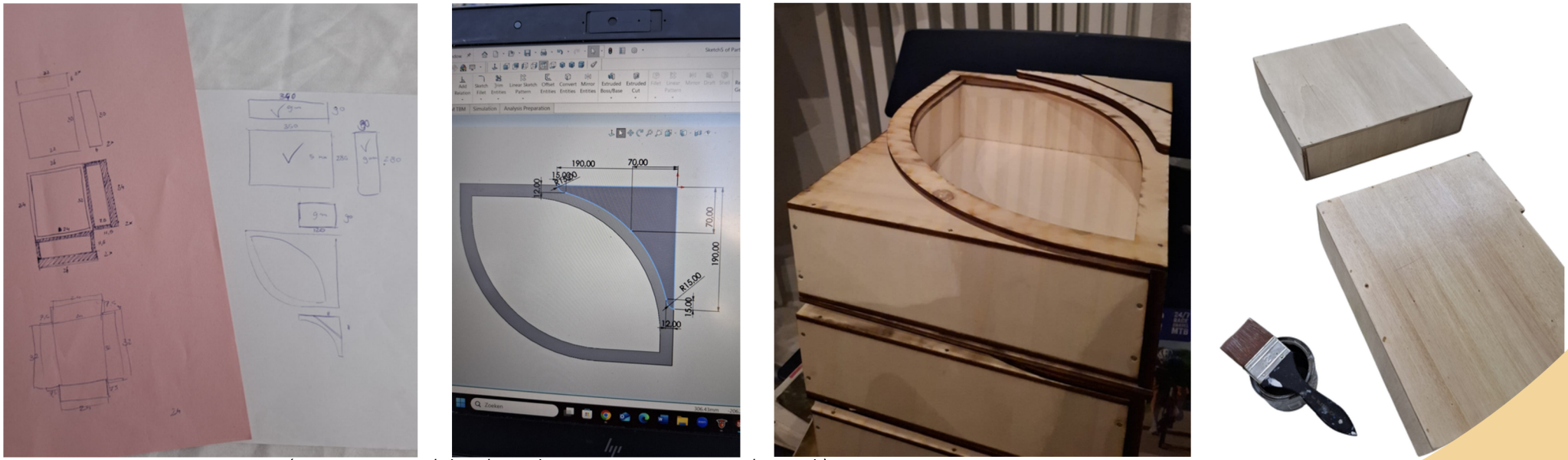


Figure 104. Prototyping pictures (on paper, in Solidworks and creating prototypes with wood.)

NAME AND LOGO

Two potential names were considered for the concept:

- Leafe - a combination of Leaf, Leave, and Lief (Dutch for “sweet”).
- Fier - meaning “proud” in Flemish, and inspired by Vieren, which means “celebrating” in Dutch.

Following formal communication and feedback, the name Leafe was selected for the concept.

A visual exploration was then conducted to develop a suitable logo. Initial designs were considered too harsh, so a completely different approach was explored, resulting in the final logo (See Figure 105 & 106).

Leafe

Figure 105. Final logo

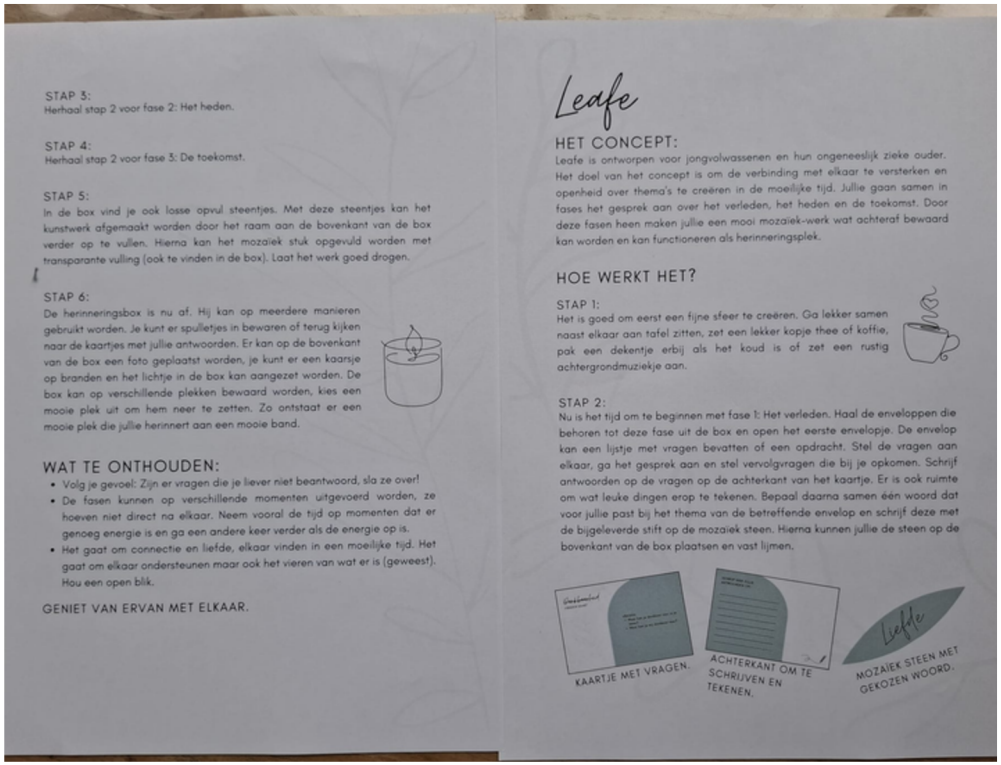


Figure 106. Logo with gold foil on wood

B.2.5. Testing Leafe V1

PROTOTYPE

The first prototype of Leafe was created (see Figure 108). This prototype included a manual to guide users through the interaction with the concept (see Figure 107).



STAP 3:
Herhaal stap 2 voor fase 2: Het heden.

STAP 4:
Herhaal stap 2 voor fase 3: De toekomst.

STAP 5:
In de box vind je ook losse opvul steentjes. Met deze steentjes kan het kunstwerk afgemaakt worden door het raam aan de bovenkant van de box verder op te vullen. Hierna kan het mozaiek stuk opgevuld worden met transparante vulling (ook te vinden in de box). Laat het werk goed drogen.

STAP 6:
De herinneringsbox is nu af. Hij kan op meerdere manieren gebruikt worden. Je kunt er spulletjes in bewaren of terug kijken naar de kaartjes met jullie antwoorden. Er kan op de bovenkant van de box een foto geplaatst worden, je kunt er een kaarsje op branden en het lichtje in de box kan aangezet worden. De box kan op verschillende plekken bewaard worden, kies een mooie plek uit om hem neer te zetten. Zo ontstaat er een mooie plek die jullie herinnert aan een mooie band.

WAT TE ONTHOUDEN:

- Volg je gevoel: Zijn er vragen die je liever niet beantwoord, sla ze over!
- De fasen kunnen op verschillende momenten uitgevoerd worden, ze hoeven niet direct na elkaar. Neem vooral de tijd op momenten dat er genoeg energie is en ga een andere keer verder als de energie op is.
- Het gaat om connectie en liefde, elkaar vinden in een moeilijke tijd. Het gaat om elkaar ondersteunen maar ook het vieren van wat er is (geweest). Hou een open blik.

GENIET VAN ERVAN MET ELKAAR.

Leafe

HET CONCEPT:
Leafe is ontworpen voor jongvolwassenen en hun ongeneeslijk zieke ouder. Het doel van het concept is om de verbinding met elkaar te versterken en openheid over thema's te creëren in de moeilijke tijd. Jullie gaan samen in fases het gesprek aan over het verleden, het heden en de toekomst. Door deze fasen heen maken jullie een mooi mozaiek-werk wat achteraf bewaard kan worden en kan functioneren als herinneringsplek.

HOE WERKT HET?

STAP 1:
Het is goed om eerst een fijne sfeer te creëren. Ga lekker samen naast elkaar aan tafel zitten, zet een lekker kopje thee of koffie, pak een dekentje erbij als het koud is of zet een rustig achtergrondmuziekje aan.

STAP 2:
Nu is het tijd om te beginnen met fase 1: Het verleden. Haal de enveloppen die behoren tot deze fase uit de box en open het eerste envelopje. De envelop kan een lijstje met vragen bevatten of een opdracht. Stel de vragen aan elkaar, ga het gesprek aan en stel vervolgvragen die bij je opkomen. Schrijf antwoorden op de vragen op de achterkant van het kaartje. Er is ook ruimte om wat leuke dingen erop te tekenen. Bepaal daarna samen één woord dat voor jullie past bij het thema van de betreffende envelop en schrijf deze met de bijgeleverde stift op de mozaiek steen. Hierna kunnen jullie de steen op de bovenkant van de box plaatsen en vast lijmen.

KAARTJE MET VRAGEN.

ACHTERKANT OM TE SCHRIJVEN EN TEKENEN.

MOZAÏEK STEEN MET GEKOZEN WOORD.

Figure 107. Manual Leafe V1



Figure 108. Prototype V1

TESTING

The prototype of Leafe was tested with a mother and her son (See figure 109 & 110). They explored all the cards of the concept and began creating their mosaic artwork. Due to time constraints, they only had the opportunity to glue down the mosaic leaves themselves; the remaining tiles were arranged and glued by the designer according to the participants' preferences. See figure 111 for the outcome.

INSIGHTS

- Overall, the concept was experienced positively.
- The concept was not perceived as particularly lighthearted.
- For some questions, it was unclear who the intended respondent was.
- Participants appreciated discussing the past, enjoying it alongside conversations about the future.
- Certain aspects of the interaction were not immediately clear, such as the ability to take the stone from the card; however, participants explored the process and found their own way to complete the tasks.
- The letters on the cards were small, making them difficult to read.



Figure 109. Test Leafe V1 - 1



Figure 110. Test Leafe V1 - 2







Figure 111. Outcome test Leafe V1

B.2.6. Changes to leafe after test

BRAINSTORM

An exploration was conducted to make the presentation of the card sets more aligned with the overall aesthetic and emotional tone of the concept (See figure 112 & 113). It was decided to present the sets in a gift-like format, using ribbons and title cards. This approach creates a more personal and caring experience for the user.



Figure 112. Exploring way of presenting sets of cards. Part 1.



Figure 113. Exploring way of presenting sets of cards. Part 2.

BAGS

As recommended, bags were created using the same suede fabric as the box lining to hold the mosaic filler stones and additional materials. This ensured that all components matched the overall aesthetics of the concept (see Figure 114).

WRITING WITH GOLD FOIL

The titles on the envelopes and small cards were applied using gold foil. This not only gives a luxurious and refined feel but also ensures that the writing is consistent and visually cohesive across all materials (see Figure 114).



Figure 114. Bags for additional materials and writing in gold foil.

QUESTION CARDS

The wording on the cards was updated to clarify who should answer each question. Instead of simply stating (Parent), the text now reads “Ask the question to the parent” (see Figure 115), making the instructions more explicit.

Additionally, the font size on the cards was increased, addressing readability issues identified in previous testing (see Figure 115).



Figure 115. Old versus new cards

MANUAL

The manual was refined to better align with the overall aesthetics of the concept. Additional illustrations were added to clearly demonstrate how the concept works, improving participant understanding (See figure 116 & 117).

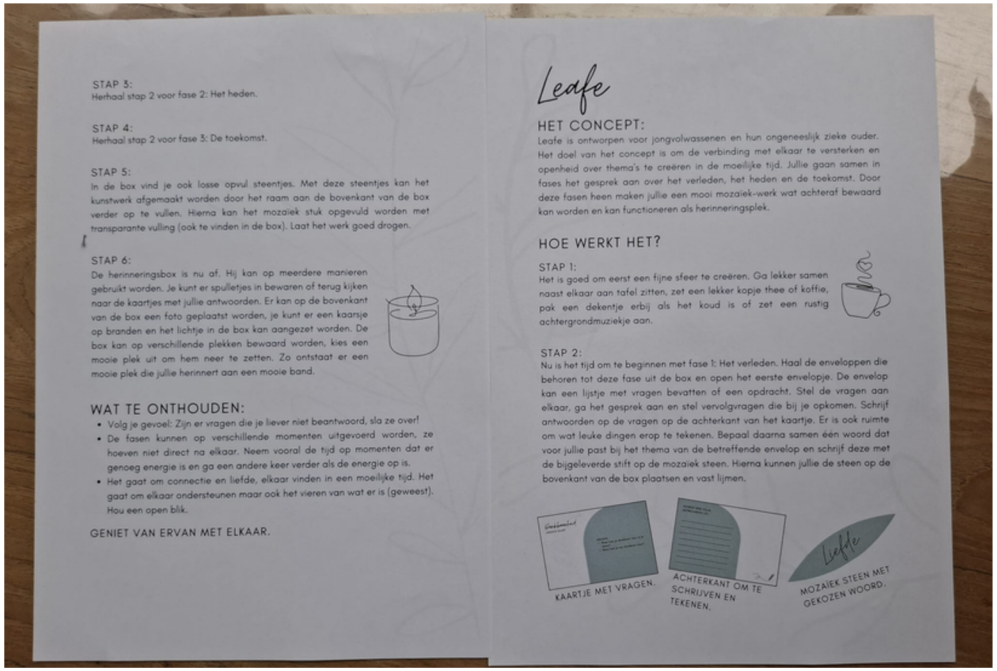


Figure 116. Manual leafe v1



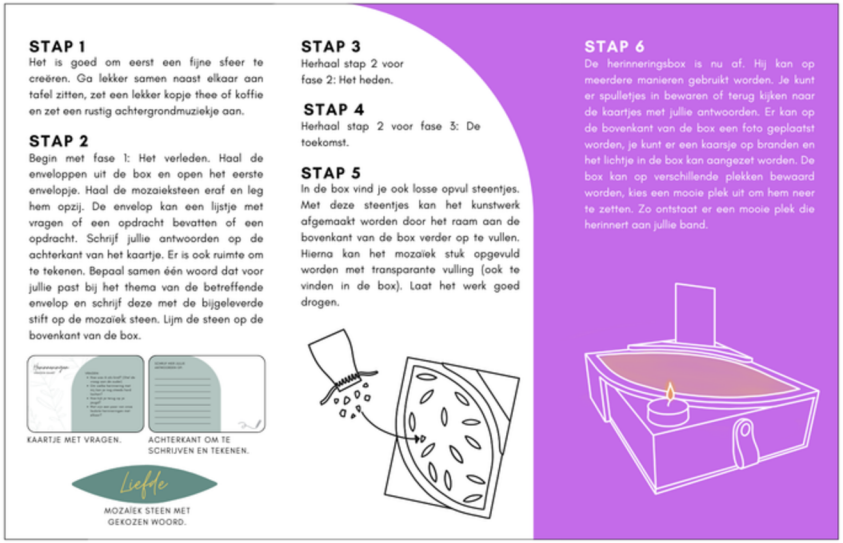


Figure 117. Manual leafe v2

Appendix C

DELIVER

OVERVIEW

C1. Final concept Leafe

C.1.1. Manual

C.1.2. Cards Leafe

C2. Evaluation

C.2.1. Questionnaire - Evaluation

INTRODUCTION

This appendix contains additional materials related to the final concept. It includes a larger version of the manual in C.1.1. and all question cards included in the concept in C.1.2.. Additionally, the questionnaire used for the final evaluation is provided in C.2.1..

C.1.1. Manual

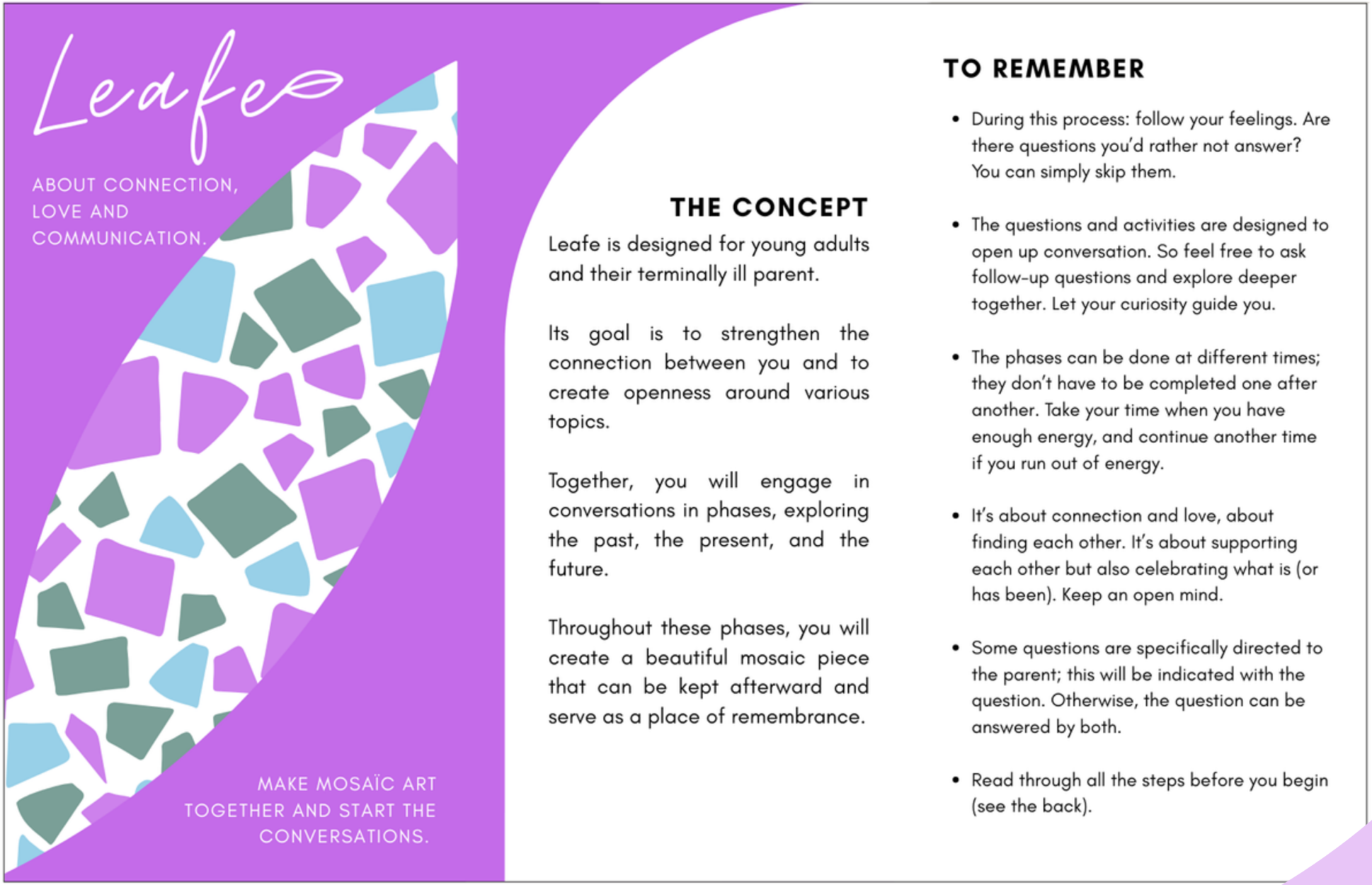


Figure 118. Manual Leafe front

STEP 1

It's good to first create a comfortable atmosphere. Sit together at the table, enjoy a nice cup of tea or coffee, and put on some gentle background music.

STEP 2

Start with Phase 1: The Past. Take the envelopes out of the box and open the first one. Remove the mosaic tile and set it aside. The envelope may contain a list of questions or an activity. Write your answers on the back of the card. There is also space to draw.
Together, choose one word that represents the theme of the envelope and write it on the mosaic tile using the provided marker. Glue the tile onto the top of the box.



CARD WITH QUESTIONS

BACKSIDE TO WRITE AND DRAW



MOSAÏC TILE WITH CHOSEN WORD

STEP 3

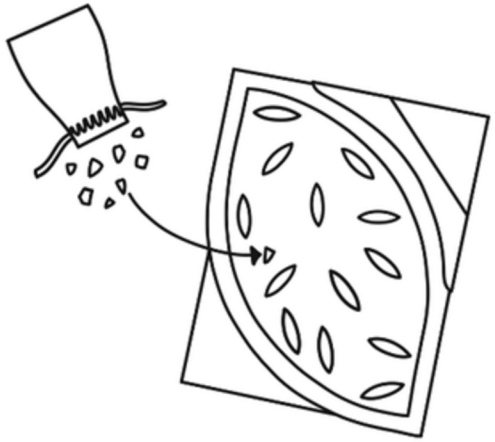
Repeat step 2 for
Phase 2: The present.

STAP 4

Repeat step 2 for phase 3: The future.

STEP 5

In the box, you will also find loose filler stones. You can use these stones to complete the artwork by filling in the window on the top of the box. After this, the mosaic can be filled with the transparent filler (also included in the box). Allow the piece to dry thoroughly.



STEP 6

The memory box is now complete. It can be used in multiple ways. You can store items inside or look back at the cards with your answers. A photo can be placed on top of the box, you can light a candle on it, and the light inside the box can be turned on. The box can be kept in different places, choose a special spot to display it. This creates a beautiful place that reminds you of your bond.

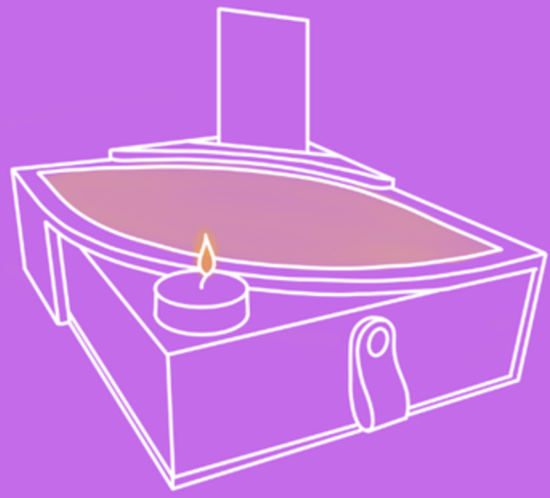


Figure 119. Manual Leafe Back

C.1.2. Cards Leafe

CARDS PHASE 1: THE PAST



Figure 120. Cards Phase 1

CARDS PHASE 2: THE PRESENT



Figure 121. Cards phase 2

CARDS PHASE 3: THE FUTURE

After death
QUESTION CARD

QUESTIONS:
- What are your beliefs regarding death?
- Does religion play a role for you?
- How do you see connection after death?
- What kinds of rituals do you perform to remember someone?
- How would you do that for me?

Wishes
QUESTION CARD

QUESTIONS:
- Who is allowed to make decisions for you if you are no longer able to do so yourself?
- What are your wishes regarding the end of life and the funeral?
- Which wish would you like to fulfill?

Meaning
QUESTION CARD

QUESTIONS:
- Do you have goals you would like to achieve?
- What gives your life meaning?
- What do you think is the purpose of your life?
- According to which motto do you live?

Advice
QUESTION CARD

QUESTIONS:
- What advice would you like to give me?
- How did you experience important milestones (e.g., a relationship, getting married, buying a house, getting a job, having a child), and what tips would you give me based on them? *(Ask this question to the parent.)*

I wish for you...
ASSIGNMENT CARD

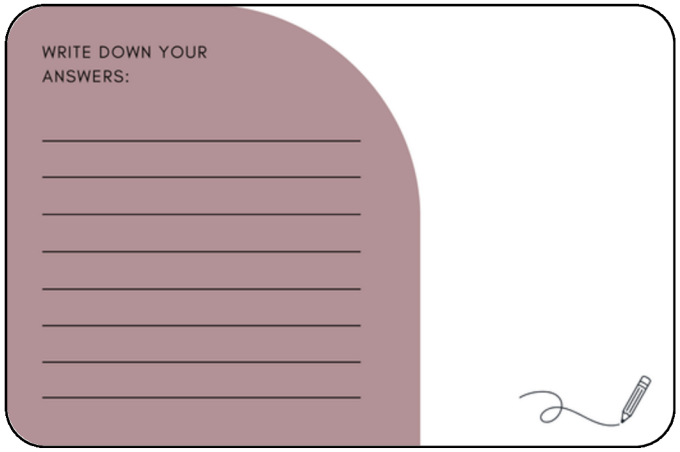
Write your wishes for each other on the corresponding cards. You may read them aloud to one another and give each other the card. But you can also keep the card for a later moment or choose not to share your wishes.

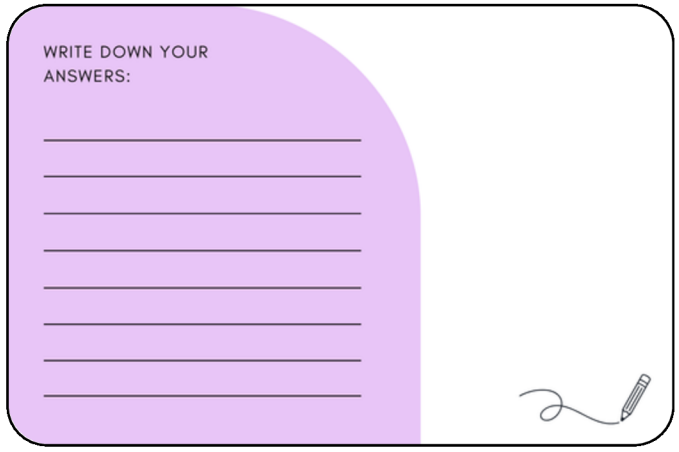
Bucketlist
ASSIGNMENT CARD

Create a bucket list of three things you would like to do together. These can be big or small activities. Write the items on the provided bucket list sheet.

Figure 122. Cards phase 3

BACKSIDE CARDS





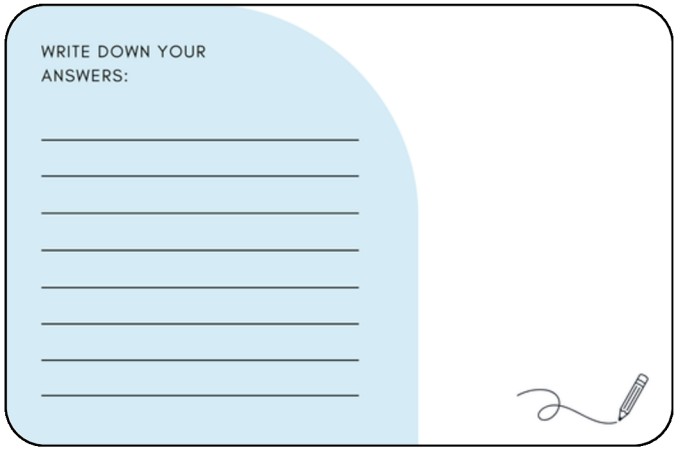


Figure 123. Backside cards

EXTRA CARDS FOR CHALLENGES

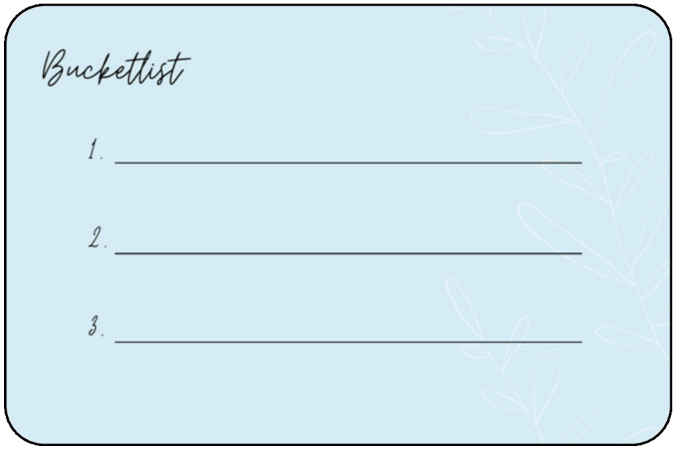
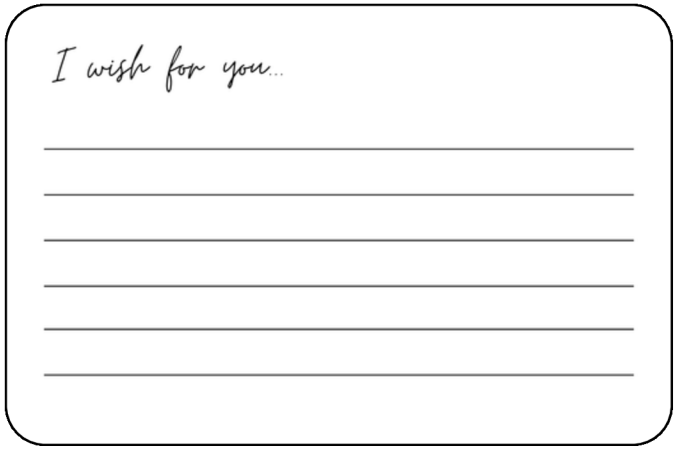


Figure 124. Bucketlist card



Figure 125. Wishing card



PICTURE SLEEVES

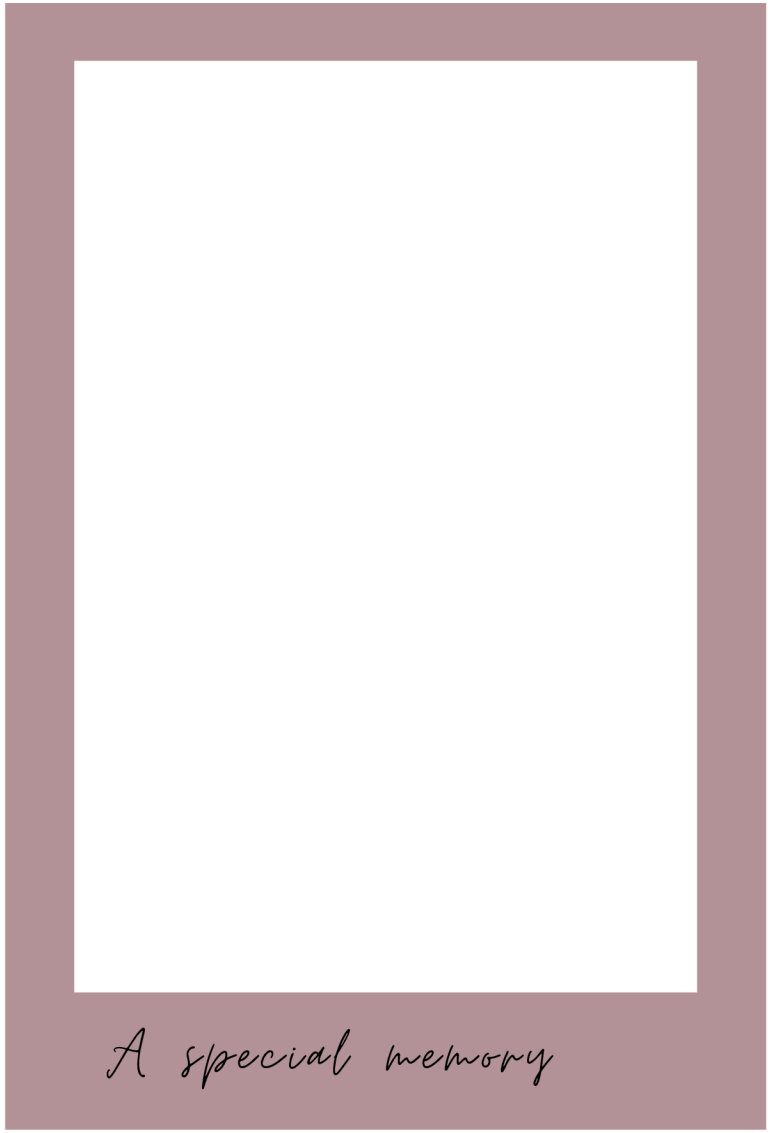


Figure 126. Picture sleeve phase 1

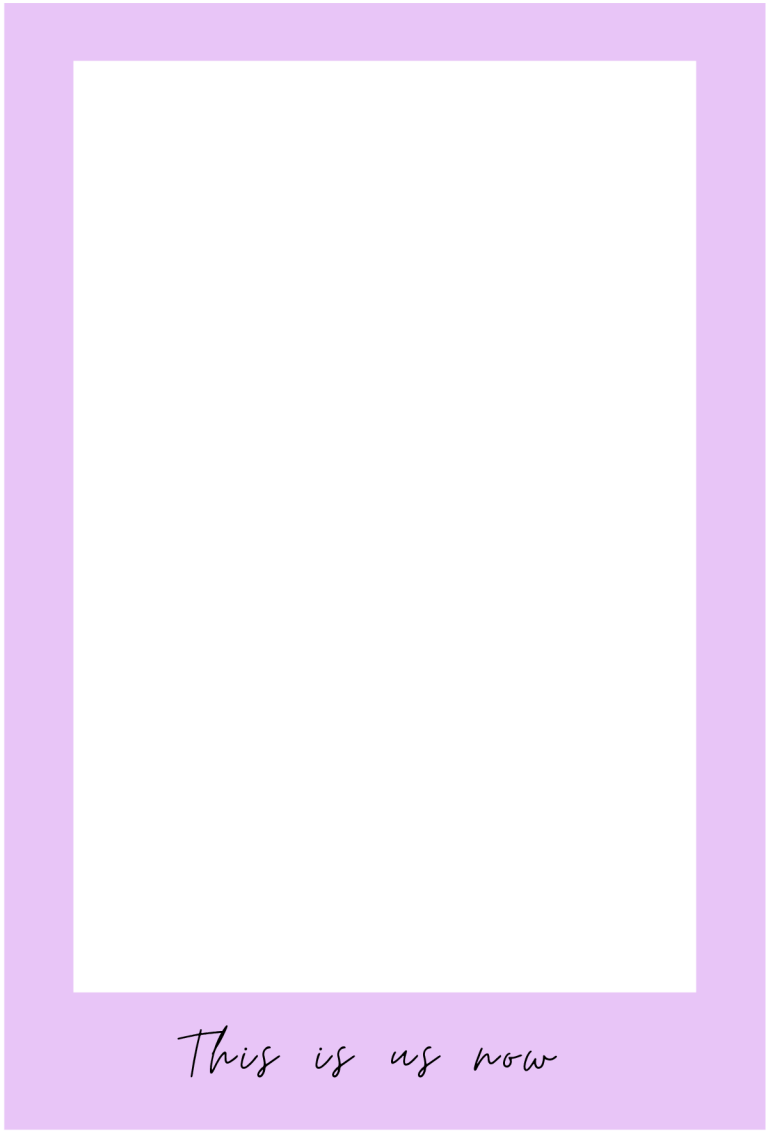


Figure 127. Picture sleeve phase 2

C2.1. Questionnaire - Evaluation

LAATSTE TEST: VRAGEN LIJST

Dit formulier bestaat uit 9 onderdelen met ieder een verschillend thema. Bij elk thema horen een aantal vragen. Ik wil je vragen om rustig de tijd te nemen om de vragen te beantwoorden. Het doel van deze vragen is om erachter te komen hoe je het concept: Leafe hebt ervaren. Bij sommige vragen staat een schaal (oneens-eens, Likert-scale) waarin je kunt invullen tot in hoeverre je het eens bent met de stelling. Als je een vraag niet wilt/kan beantwoorden kun je hem gewoon overslaan. Het is belangrijk dat je de lijst alleen invult. Gelieve niet overleggen. Alvast bedankt!

THEMA 1: ALGEMEEN:

1. Wat vond je fijn aan het concept?

2. Vond je iets niet fijn aan het concept?

3. Hoe kijk je terug op het proces?

4. Zou je iets veranderen aan het concept, zo ja, wat?

5. Nu jullie kunstwerk af is, wat ga/zou je ermee doen?

THEMA 2: ESTHETIEK:

Het uiterlijk van het concept is aantrekkelijk:

Geheel oneens	Oneens	Neutraal	Eens	Geheel eens
○	○	○	○	○

1. Hoe voelde de uitstraling van de box en onderdelen voor jou?

Figure 128. Evaluation questionnaire part 1

2. Vind je het uiterlijk van het concept samenhangend?

3. Tot in hoeverre past het uiterlijk van het concept bij jou en je interieur?

4. Hoe voelde de texturen van de verschillende materialen voor jou?

5. Ben je tevreden met het eindresultaat?

THEMA 3: BEGELEIDEND:

De interactie met het concept was begeleidend:

Geheel oneens	Oneens	Neutraal	Eens	Geheel eens
○	○	○	○	○

1. Was het snel duidelijk hoe het concept werkt?

2. Voldeed de handleiding als genoeg uitleg over hoe het concept werkt?

3. Heb je de kaartjes met vragen en opdrachten ervaren als begeleidend?

Figure 129. Evaluation questionnaire part 2

4. Had je het gevoel dat er genoeg ruimte was voor je eigen input tijdens de gesprekken?

5. Gaf het concept genoeg houvast of voelde je je weleens verloren tijdens het proces?

THEMA 4: VERBINDEND:

De interactie met het concept was verbindend:

Geheel oneens	Oneens	Neutraal	Eens	Geheel eens
○	○	○	○	○

1. Hoe voelde de verbinding tussen jullie tijdens en na de gesprekken?

2. Heeft dit concept invloed gehad op jullie verbinding, zo ja, hoe?

THEMA 5: VERKENNEND:

De interactie met het concept was verkennend:

Geheel oneens	Oneens	Neutraal	Eens	Geheel eens
○	○	○	○	○

1. Heb je nieuwe dingen kunnen ontdekken tijdens het proces?

2. Voelde je jezelf open om te exploreren tijdens het proces?

Figure 130. Evaluation questionnaire part 3

3. Lukte het om vervolgvragen te stellen?

THEMA 6: LUCHTHARTIG:

De interactie met het concept was luchthartig:

Geheel oneens	Oneens	Neutraal	Eens	Geheel eens
○	○	○	○	○

1. Voelde de interactie weleens zwaar, zo ja, wanneer en waarom?

2. Voelde de interactie weleens ongemakkelijk, zo ja, wanneer en waarom?

3. Hoe luchthartig waren de gesprekken ten opzichte van eerdere moeilijke gesprekken?

4. Was er ruimte voor humor tijdens het proces?

THEMA 7: COMFORTABEL:

De interactie met het concept was comfortabel:

Geheel oneens	Oneens	Neutraal	Eens	Geheel eens
○	○	○	○	○

1. Hoe comfortabel waren de geprekken ten opzichte van eerdere moeilijke gesprekken?

Figure 131. Evaluation questionnaire part 4

2. Tot in hoeverre voelde je je comfortabel om de vragen te stellen en beantwoorden?

3. Heb je je oncomfortabel gevoeld tijdens het proces, zo ja, wanneer en waarom?

THEMA 8: NIEUWSGIERIG:

De interactie met het concept was nieuwsgierig makend:

Geheel oneens	Oneens	Neutraal	Eens	Geheel eens
○	○	○	○	○

1. Wat maakte je nieuwsgierig tijdens het uitvoeren van het proces?

2. Welke onderwerpen maakte jou het meest nieuwsgierig?

3. Is je nieuwsgierigheid naar bepaalde thema's gestegen door het concept?

THEMA 9: AFSLUITEN:

Kun je de interactie met het concept omschrijven in 3 woorden?

Hoe vond je het om dit te doen met je ouder/kind?

Wil je nog iets kwijt?

DANKJEWEL!

Figure 132. Evaluation questionnaire part 5