# Helping People Through the Grieving Process

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# Disclaimer

This project focuses on the topics of terminal illness, death, and grief. If these are topics that you're sensitive to, please be aware.

# abstract

With my thesis, I wanted to explore ways to help people through the grieving process. Through research, I narrowed the topic down to communication within the family and grief after death from a terminal illness. More specifically, I focused on the communication between the family and the patient at the end of life and explored ways to use the remaining time in a way that could ease the grieving process.

In the case of a terminal illness, there is a brief opportunity to express love, appreciation, regret, and whatever else needs to be expressed to a loved one to create a sense of closure. However, as a society, we tend to avoid talking about the topics of death, illness, and grief. So when the time comes that a loved one is diagnosed with a terminal illness, people often don't know how to process that, how to communicate with their loved one in a way that is beneficial to both of them, and often they miss that opportunity and go into the grieving process regretting the things they didn't say.

My solution is an end of life activity that encourages people to explore their time spent together in a way that could bring a sense of peace and closure to the grieving process. It provides a starting point and structure for talking about memories, while co-creating tangible, visual representations of their memories that can be kept as keepsakes after the loved one's death.

Ultimately, family members must go on living after the death, and in doing so, they remember the final conversations and encounters from the end of life period for months, if not years, to come. Therefore, contact with loved ones at the end of life has the greatest and most lasting impact. [1]

# kokkuvõte

Oma lõputööga soovisin uurida võimalusi, kuidas aidata inimesi leinaprotsessis. Uurimuse käigus kitsendasin teemat perekonnasisesele suhtlusele ja surmaga lõppeva haiguse tagajärjel lahkunu leinamisele. Täpsemalt keskendusin pere ja patsiendi suhtlusele elu lõpus ning uurisin võimalusi, kuidas järelejäänud aega kasutada nii, et see võimaldaks leinaprotsessi hõlbustada.

Surmava haiguse korral on lähedastel võimalus lahkujale väljendada armastust, tunnustust, kahetsust ja muud, mida soovitakse kalli inimesega jagada, et tekitada lähedustunnet. Kuid ühiskonnana kipume siiski surma, haiguse ja leina teemadel rääkimist vältima. Seega, kui saabub aeg, mil lähedasel diagnoositakse surmav haigus, ei tea inimesed sageli, kuidas selle teadmisega toime tulla, ega kuidas kalli inimesega suhelda viisil, mis oleks mõlemale tähenduslik. Lisaks, tihti tuntakse kahetsust, et leina-eelsel ajal jäeti kasutamata võimalus olulisi mõtteid ning emotsioone väljendada.

Minu lahendus julgustab inimesi elu lõpus teostama tegevusi, et avastada ja kasutada koos veedetavat aega viisil, mis võimaldaks hiljem leinaprotsessi rahu ja leppimist tuua. Lisaks annab lahendus lähtepunkti ja struktuuri mälestuste jagamiseks, muutes need samaaegselt käegakatsutavaks ja visuaalseks kogumiks, mida pärast lähedase surma mälestusena alles hoida.

Lõppkokkuvõttes peavad pereliikmed pärast lähedase surma edasi elama ja seda tehes meenuvad viimased vestlused ja kohtumised eluperioodi viimastel kuudel, kui mitte aastatel. Seetõttu on kõige suurem ja püsivam mõju kokkupuutel lähedastega just elu lõpus. [1]

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CHAPTER 1

# introduction

# background

In certain cultures, people have traditions and customs that make them accept death as a natural and important part of life. When they lose someone, this mentality allows them to cope with the loss and in some cases even see it as a positive thing. [2]

In the West, we have distanced ourselves from death. It is a subject that people are afraid of and avoid talking about openly or perhaps even believe that talking about death invites it into our lives. [3] This avoidance is something that is also evident in funeral procedures, as we have "outsourced" this process to professionals and traditions that helped us with the grieving process (e.g. wakes) have become a thing of the past.

Indeed, a recent nationwide survey in the UK found that "almost 5 million people say they are too uncomfortable to talk about their own death at all, with almost 13 million UK adults saying they are uncomfortable, but would be willing to talk." while at the same time "91% of Brits have thought about their own mortality" and "a third (35%) think about their own mortality once a week or more." [4]

People who are grieving find little or no support from those around them, as most people do not know how to talk about the issue and help the griever. This leads to the grieving person feeling alone and isolated, unable to process their feelings and sometimes even leads to complicated grief (difficulty recovering from the loss and resuming their life).

The above provides an opportunity for us as designers to explore and find ways to encourage people to be more open to communicating and discussing these issues before or while they are grieving to help them through the grieving process.

# personal interest

I decided to research this topic for my thesis after reading “From Here to Eternity: Traveling the World to Find the Good Death” by Caitlin Doughty. In her book, she describes how she travelled to different places around the world to explore how other cultures experience death and mortality compared to the US. She also talked a lot about the fear of death and avoidance we have in the West and how this makes us unprepared for the loss of a loved one and affects our grief. [5]

This got me thinking about how I lost my dad as a teenager and how the culture we have around death may have affected my grieving process and made it harder for me to accept the loss. I remember, for example, friends and family at the funeral advising me to be strong from then on and put on a brave face to support my mother and siblings and not upset them further. I think this kind of advice shows the problem in our culture: we are raised to believe that avoiding a difficult subject, hiding our true feelings, and putting on a brave face will make the situation easier for everyone and we will eventually get through it. But in reality, it has the opposite result, as we all experience these extremely painful emotions, but choose to suffer in silence so as not to “bother” or “upset” our loved ones.

Therefore, I thought that my thesis would be a great opportunity to explore this topic to see what can be done to change this kind of mentality and how design thinking can provide a solution to such a challenging topic of contradictory nature. Of course, I realised that this can be an unsolvable problem, but I hoped to provide even the slightest relief to people experiencing the loss of a loved one through my research and solution.

# project goals

Through this thesis project I want to explore ways to encourage people to talk more openly about issues such as mortality, death, illness and bereavement.

I plan to achieve this by:

- Discovering opportunities through research where to intervene in the grief journey to offer a solution.
- Exploring different themes and solutions to the defined design challenge.
- Prototyping, testing and iterating my solution.

# personal goals

My personal goals, aside from applying the process and knowledge I was taught during my master's degree, are:

- To have thorough research on the topic.
- To let the research determine the development of my final solution in order to design something that makes sense and will be beneficial to my target audience.
- Create something that can be easily implemented.
- Use as little technology in my solution as possible.

# design approach

My design approach was based on the Double Diamond framework, which uses two diamonds to represent a process of exploring an issue more widely or deeply (divergent thinking) and then taking focused action (convergent thinking). [6] However, since my initial topic was quite broad, I went through the first diamond (discover and define) twice, once to find a specific area to focus on and once to define the design challenge/How Might We question. This led to an expanded version of the double diamond. (Figure 1)

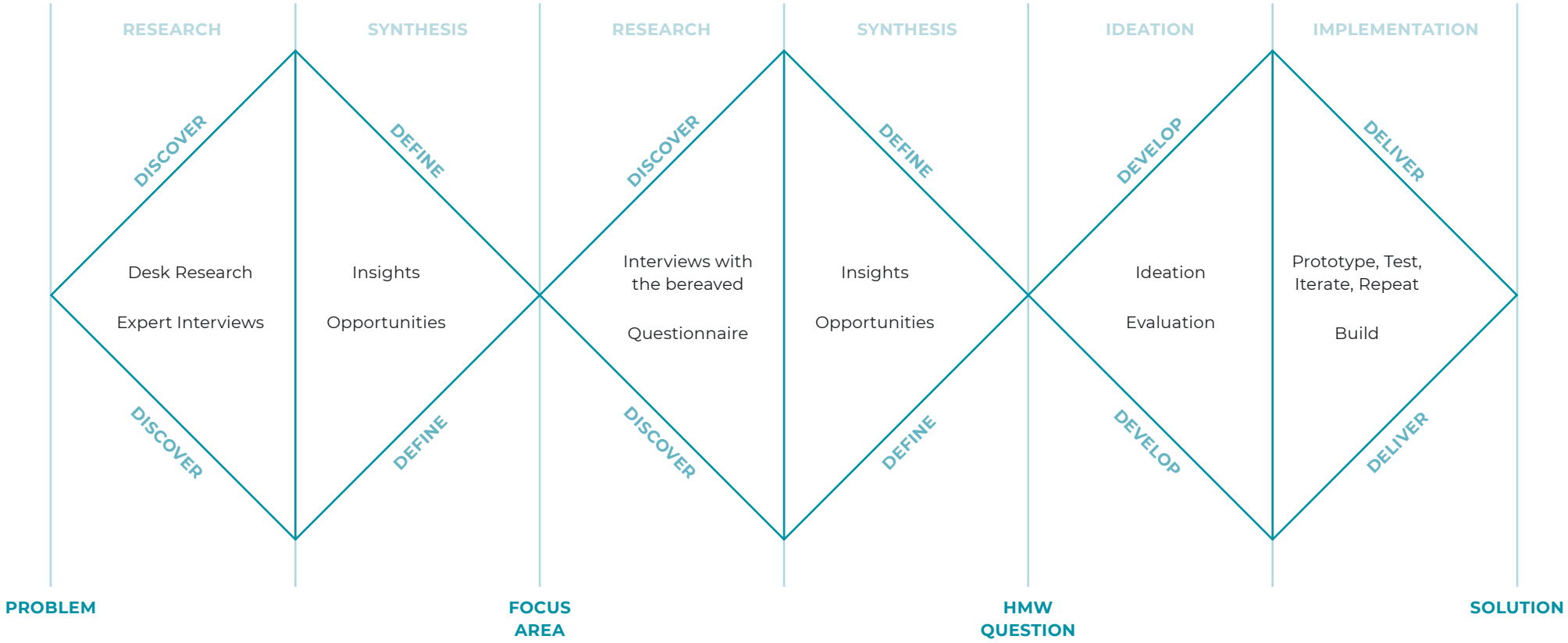



Figure 1: Expanded version of the double diamond

CHAPTER 2

# desk research

# overview

In October and November 2020, initial desk research was conducted by reading publications on grief, psychological theories, advice from health organisations on how to help grieving people, types of grief, existing design projects, etc. The initial aim was to find a more specific focus for the thesis, but as this topic is quite broad, there were a lot of areas of interest to potentially focus on.

Some of the potential areas of interest were:

- Death education
- Cultural perceptions of death
- Grief in difficult relationships (e.g., abusive parent/spouse)
- Grief after a long illness
- Complicated grief
- Grief after the death of a child
- Grief following suicide or substance abuse
- Family changes after a loss

The research familiarised me with the basic concepts and mechanisms of grief, and I also discovered some existing design solutions to the problem.

# important terms

The literature points to several ways to define some of the key terms.
In my thesis project, I build on the following definitions:

**GRIEF**

“Grief is the normal and natural response to the loss of someone or something important to a person. It is a natural part of life. Grief is a typical reaction to death, divorce, job loss, a move away from family and friends, or loss of good health due to illness.” [7]

**BEREAVEMENT**

“When a person is bereaved it means that a loved one, or someone else important to them, has died. We tend to use the term ‘bereavement’ to describe the period after someone has died in which people who cared about them are grieving.” [8]

**END OF LIFE CARE**

“End of life care is support for people who are in the last months or years of their life. End of life care should help one live as well as possible until death and help to die with dignity.” [9]

**PALLIATIVE CARE**

“If one has an illness that cannot be cured, palliative care makes them as comfortable as possible, by managing their pain and other distressing symptoms. It also involves psychological, social and spiritual support for them and their family or carers.” [9]

**ANTICIPATORY GRIEF**

“Preparing for a loved one’s end of life or a major loss is what defines anticipatory grief. While it shares some commonalities with conventional grief, some symptoms are unique to anticipatory grief. Anticipatory grief can often be mixed in with hope that a loved one will live longer or survive their illness, while conventional grief signals that a loss has already occurred.” [10]

# design projects about grief

Initial research revealed that designers have already joined in the discussion of death and grief, with two recent theses by interaction designers on these topics standing out.

The first was the thesis project “KAIROS’’ by Fei Kwok at the Copenhagen Institute of Interaction Design. “KAIROS is an audio guided journaling companion that provides a safe space for the bereaved to express and explore their grief through writing.” [11]

The second was “Legacy: The Art of Saying Goodbye” from Agnes Sunyoung Yoon at MFA Interaction Design. “Legacy is an end-of-life guided journal that helps people leave words to their loved ones before it’s too late.” [12]

Other design projects include a Memorial Hub to “mourn the departed during the age of globalisation” [13], a social network for the deceased [14], a product that “allows you to say things that were left unsaid” [15], “a machine that shows social media mentions after you die.” [16]

There have also been a number of video games that have explored the themes of terminal illness, death, and grief. Some examples include “That Dragon, Cancer,” which is “an immersive narrative video game that retells Joel Green’s 4-year fight against cancer” [17], “I Am Dead”, a puzzle adventure game about exploring the afterlife [18], “Spiritfarer®”, a management game about dying [19], and “When The Past Was Around”, which is “an adventure point-and-click puzzle game about love, moving on, letting go, and the joy and pain of everything in between.” [20]

CHAPTER 3

# expert interviews

# overview

To narrow down the topic, four interviews were conducted with experts, who relate to the topic in different ways, to learn from their experiences and find out what they think are the biggest pain points.

**KSENIA**

Ksenia works as an elementary school teacher in Cyprus and has a PhD in psychology. She has been teaching children about death, loss and grief for twenty years. She also offers seminars for teachers and parents on Death Education.

**ANNIKA**

Annika has been a pastor in Estonia for fifteen years. She also works part-time as a chaplain in a children's hospital. Over the past ten years she has raised awareness about stillbirths and created a support system for families who lose their baby at birth.

**CAROLYN**

Carolyn is a Volunteer Service Manager from the USA who is responsible for the grief support programme at Galilee Palliative Care Centre in Greece.

**KONSTANTINA**

Konstantina, a Greek psychologist with expertise in anxiety, depression and panic attacks, who has worked with the Greek Association of Cancer patients KEFI.

# interview goals

Hear the opinions and experiences of the experts

Seek their point of view, not textbook answers

Find out if they have defined "types of people" or "types of behaviours"

Find a focus for the thesis

## conducting the interviews

First, the interview goals were established and, based on these, broader themes to be addressed were defined and the interview questions for each theme were developed.

The questions served as a guide and were not strictly followed, as it was best to conduct semi-structured interviews to get the experts' thoughts and opinions on this sensitive topic. [21] This approach was also ideal because of the different experiences and backgrounds of the interviewees. This allowed for flexibility in the research while providing a structure to ensure certain topics were covered in each interview.

Three interviews were conducted online because of location and/or COVID-19 constraints. One interview was conducted in person. The interviews were between 40 minutes and one hour long.

# analysis of the interviews

Three of the four interviews were recorded and transcribed. One participant did not want the interview recorded, so detailed notes were taken during the conversation.

After reviewing the transcripts and notes, the themes and key words of each interview were highlighted. Notes and quotes were added next to each theme, and parts that stood out the most were also highlighted. A brief reflection on each interview was then written, describing key discoveries and observations. (Figure 3)

For further reflection and processing of the interviews, illustrations were created based on quotes from the experts. In this way, important parts of the interviews were visualised and it was easier to draw connections between different findings. (Figures 2A & 2B)

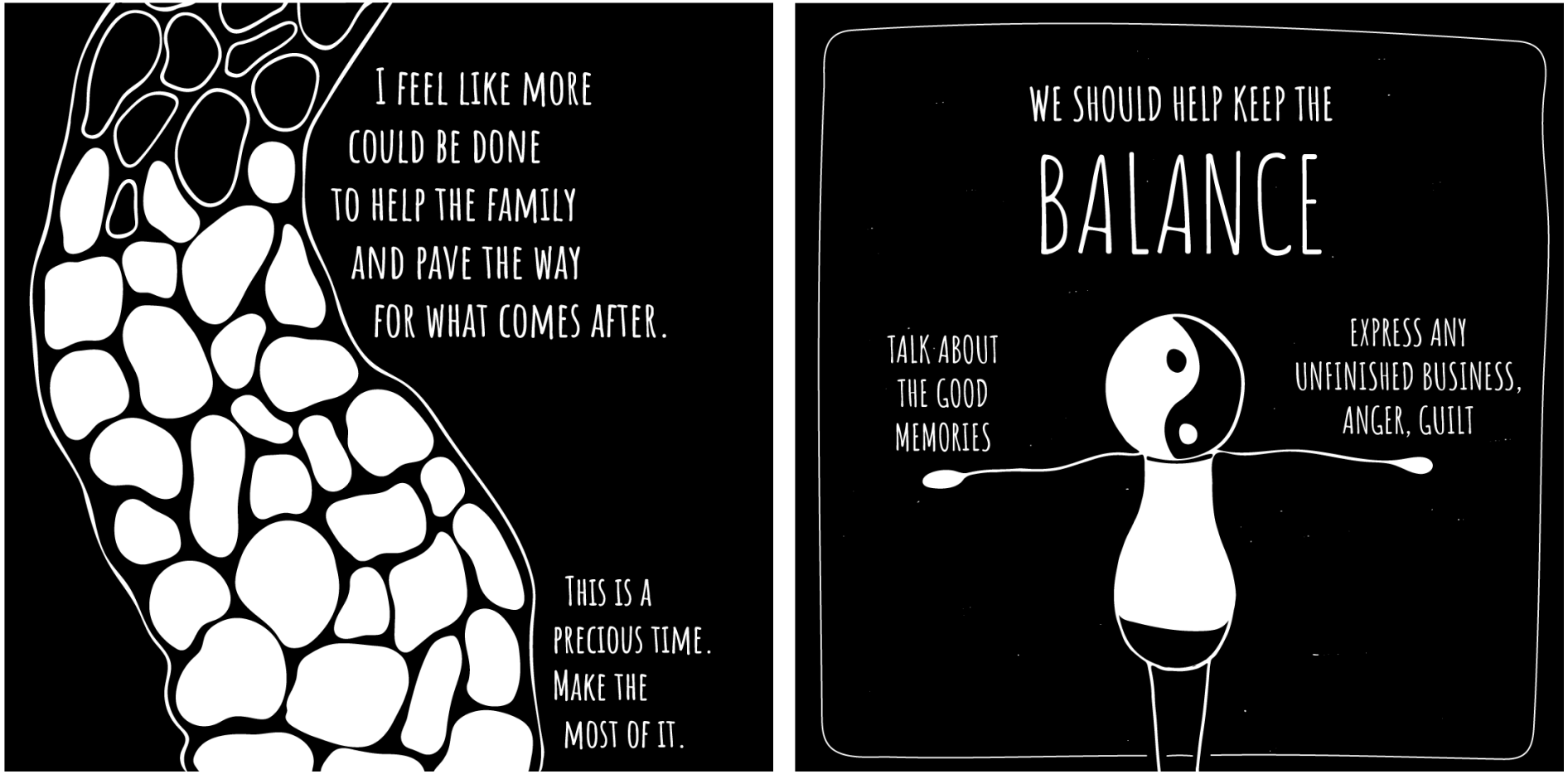
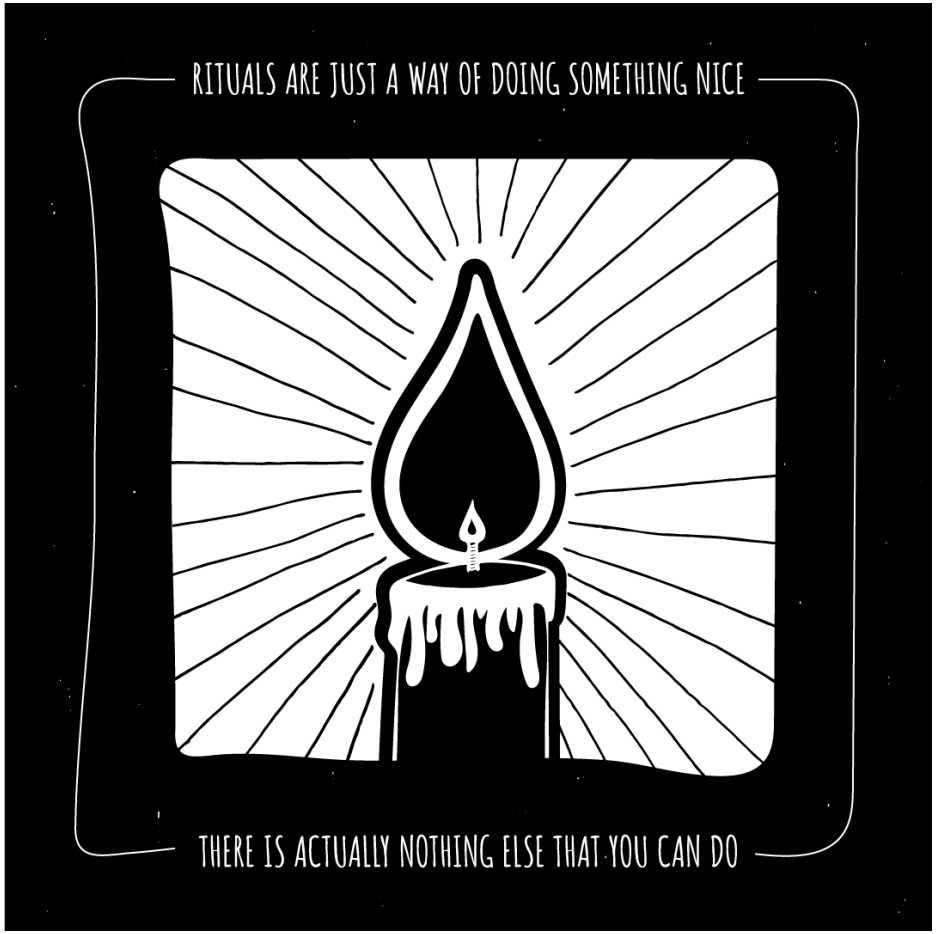



Figure 2A: Examples of illustrations based on quotes from the experts



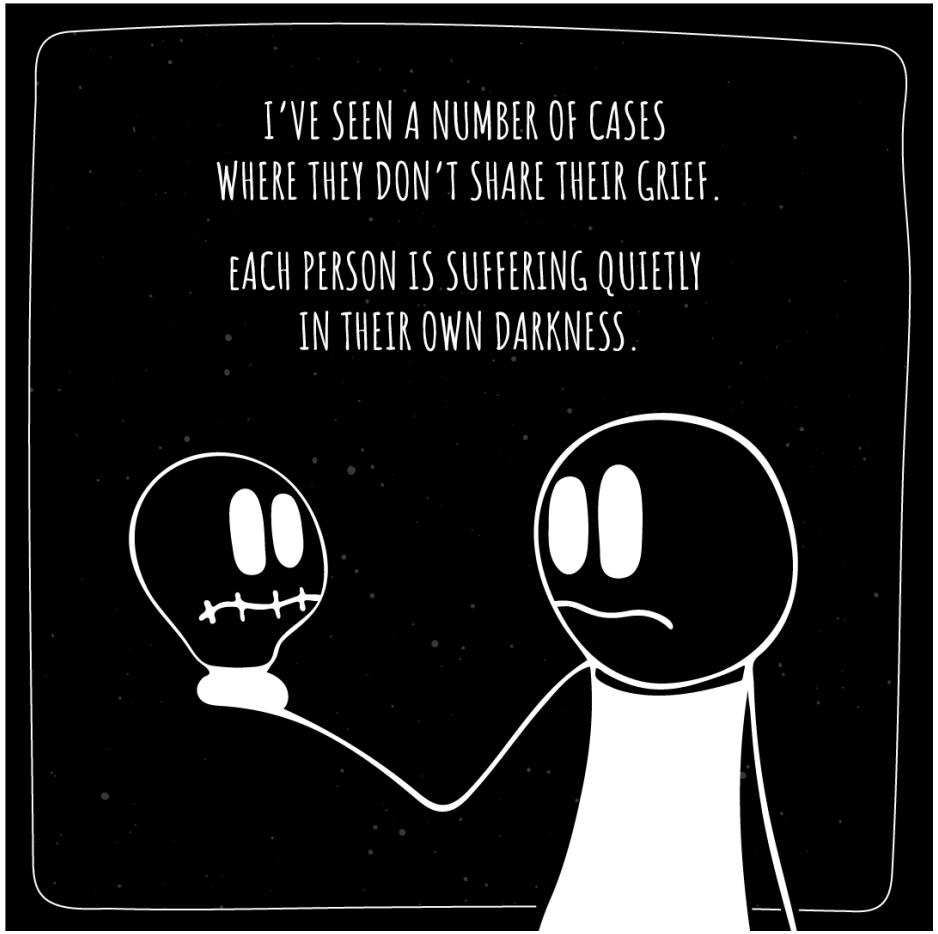




Figure 2B: Examples of illustrations based on quotes from the experts

Figure 3: Analysis of the expert interviews

# insights

After completing the analysis, four themes stood out strongly, appearing in all or most of the interviews.

INSIGHT 1

## The key to coping with grief is to express everything one feels

This point came out in every interview and everyone agreed that this is the key to a healthy grief recovery. Having someone to talk to and feel safe to express any feelings, especially the negative ones like anger, depression or despair, is very important. Below are some quotes from the experts that highlight this point.

*"The heart of bereavement support is talking and listening. Developing a relationship of trust so that the person can open up and share the things that are really simmering inside."*

**Carolyn, volunteer service manager**

*"When I tell people what I do for a living I try to then change the topic, but people almost always return to it and start telling me their stories. You can see that they need to share. They don't have questions (as opposed to children), they just need to share."*

**Ksenia, death educator**

*"I force them (the family) to come together and talk. Talk through what they have inside: their gratefulness, their thankfulness, their bitterness, their feeling of guilt. It's good for them. For me, it takes five times more time."*

**Annika, pastor**

*"As therapists, we should help keep the balance. Create a space to express any unfinished business, anger or guilt. We should talk about the bad, it is not blasphemy, but also talk about the good memories. Not only good or bad. Holistic."*

**Konstantina, psychologist**

INSIGHT 2

## People tend to avoid expressing their feelings to their family or loved ones

Sometimes people feel that they have to appear strong for their family or loved ones and therefore do not express to them what they are going through.

*"I think I've seen a number of cases where they don't share their grief. Each person in the family is suffering quietly in their own darkness."*

**Carolyn, volunteer service manager**

*"I see how people say crazy things like "Children don't understand about death". So they don't tell them what happened or take them to the funeral. Even if they are teenagers. We really harm them when we don't let them see death as a normal process of life. The problem is in grownups, not in children, the grown-ups are afraid of death, not the children."*

**Annika, pastor**

*"We pressure ourselves to appear strong and happy. We can't interfere with what the family decides, but if you hide things it will come out in some way later."*

**Konstantina, psychologist**

*"Some people just have trouble expressing difficult feelings. Some are just trying to protect each other or they don't want to burden their relatives. But if you share it kind of lessens everybody's burden in most cases."*

**Carolyn, volunteer service manager**

INSIGHT 3

## It helps people to know that what they feel is normal

Grief is accompanied by intense and painful feelings. Many people think that what they are experiencing is not normal and that something is seriously wrong with them. Just knowing that this is something that everyone goes through helps a lot.

*"You go through stages with extreme feelings, but they are not necessarily problematic. By definition, grief is a hard process, but it is normal. Most of the times it simply helps knowing that what they are feeling is normal, that this is happening to others."*

**Konstantina, psychologist**

*"Grieving for somebody that we lose is a very natural process, there's nothing pathological about it. Often you feel like there's something desperately wrong with you when you're going through it. And the truth is that you need support. It just doesn't necessarily need to be professional support."*

**Carolyn, volunteer service manager**

INSIGHT 4

## There is an opportunity to help people prepare for what comes next

In the case of a terminal illness, the grieving process usually begins with the diagnosis. Although it is a difficult time for both the patient and those close to them, it is also an opportunity to prepare for what comes next and express whatever we need to express.

*"This is a precious time. Make the most of it. Say the things you want to say. This is the time to ask for forgiveness, to say thank you, to say I love you. There's a sense of closure, there's a sense of peace."*

**Carolyn, volunteer service manager**

*"In these cases (terminal illness) both caregivers and patients need support. It's important to talk as usual, open up any issues and talk about them. But these discussions should be done with a correct approach: carefully and respectfully. The caregiver needs support to open up issues with respect."*

**Konstantina, psychologist**

*"I feel like more could be done to help the family and to also pave the way for our role (bereavement support). I think there needs to be a little more groundwork laid before the death of the patient."*

**Carolyn, volunteer service manager**

CHAPTER 4

# defining the focus

# narrowing down the topic

The above findings from the expert interviews helped narrow down the topic. There was a very interesting contrast between the fact that the key to coping with grief is to express everything one feels (insight 1) and that people tend to avoid expressing their feelings to their family or loved ones (insight 2). These opposing insights can provide a powerful opportunity to intervene.

Also, the unique opportunity (compared to other types of death) that terminal illnesses provide by giving families some time to pave the way for the grieving process (insight 4) seemed to be an area worth exploring.

### Communication within a family or with their loved ones

By encouraging people to communicate with their loved ones, all members will benefit from expressing themselves (insight 1). By seeing that others are having a similar experience, they will also understand that what they are experiencing is normal (insight 3).

### Deaths after long illness

explore if there is a way to use the time before the patient's death to support the grieving process (insight 4).

**Finally, the interviews helped define cases that will not be part of the scope of this project:**

- Death of children
- Death by suicide, addictions, or cases where there is an abusive relationship
- Death education from parents to their children
- Sudden death (e.g., car accident, heart attack)

# focus area

**Group A**

People who have a loved one with a terminal illness

**Group B**

People who are grieving the loss of a loved one due to a terminal illness

**Group C**

People who have overcome their grief over the loss of a loved one due to a terminal illness

# target audience

## defining the target audience

In the case of deaths caused by terminal illnesses, the grief journey begins with the diagnosis, as people grieve in response to the anticipation of death (anticipatory grief). However, this does not mean that it is easier or less painful for the bereaved when the patient dies. The normal grieving process begins when the actual death occurs. [22]

This fact created two distinct groups in the target audience. A third group was defined, which is people who have overcome their grief, and whose reflections on their experiences could be very insightful.

With this in mind, the target audience was divided into three groups and the final target audience would be decided after conducting user research, finding a point of intervention, and developing a point of view.

CHAPTER 5

# qualitative research

# overview

After learning from the experts how they perceive people's grief, it was time to talk to people and learn how they actually experience grief. So the next step was to conduct qualitative research through interviews with the bereaved and a questionnaire.

# research goals

Obtain a holistic understanding of how grief develops over time

Gain empathy and insights from people's experiences

Find pain and gain points

Identify specific opportunities and moments in the grief journey to intervene with a solution

Define the design principles, point of view, and HMW

**Interview goals for people who have a loved one with a terminal illness (Group A) or are grieving the loss of a loved one due to a terminal illness (Group B)**

- Listen to their experiences
- Find out what helps/doesn't help them
- Whether they share what they are going through
- How they handle the situation (with their family)
- How they handle(d) the situation (with the patient)
- Find inspiration

**Interview goals for people who have overcome their grief over the loss of a loved one due to a terminal illness (Group C)**

- Listen to their experiences
- Find out what helped/didn't help them overcome grief
- Relationships - where they affected, where they alone?
- What they learned from the experience
- Find inspiration

# interview goals

# interviews with the bereaved

## Defining the interview goals and questions

As the target group was divided into three groups who were at different stages of the grief journey, different interview goals and questions were defined for each group.

The interview questions for each group were created using the same procedure as for the expert interviews. Thus, broader topics were defined to be covered and the questions were created based on them. Again, due to the personal and diverse nature of the topic, semi-structured interviews were conducted to cover the broader topics while providing the flexibility to skip or add questions based on the respondents' answers and experiences.

Once the questions were created, feedback was provided by a psychologist and people who were part of the target group to ensure that nothing inappropriate or potentially harmful was asked. Based on their feedback, some slight adjustments were made before proceeding with the interviews.

## Recruiting interviewees

Interviewees were recruited through grief support groups on platforms like Facebook and Reddit to find people living in different locations who may lack support and communication and seek it elsewhere. This resulted in four interviews. (Figure 4)

To find additional participants, people were contacted who could potentially put me in touch with people in the target group. This resulted in one additional interview and a total of five interviews with bereaved people.

Figure 4: Recruiting interviewees

## Conducting the interviews

In total, five people were interviewed (four with online interviews and one in written form). All interviews were conducted online due to location and/or COVID-19 constraints. Interviews lasted an average of half an hour.

| | |
|---|---|
| **ATHENA** | Athena is from Greece and lost her parents in December 2020 |
| **MISA** | Misa lives in France and lost her mum in April 2020 |
| **JULIE** | Julie is from Pennsylvania and lost her mum 4 years ago |
| **JESSICA** | Jessica is from Kansas and lost her dad 11 years ago |
| **MARY** | Mary is from Estonia and lost her dad when she was a teenager |

## Analysis of the interviews

The analysis of the interviews was conducted in a similar way to the expert interviews. All interviews were recorded and transcribed. The transcripts were analysed to reveal themes and keywords, and an affinity map was created for each interview, in an attempt to find common themes across all of them. The parts that stood out the most were also highlighted and a short reflection was written for each interview describing the key discoveries and observations.

# Insights

After completing the analysis, four themes stood out strongly, appearing in all or most of the interviews.

INSIGHT 1

## There is no “one solution to suit them all”

When asked how they cope with grief and what they find helpful, responses varied between participants. This was somewhat expected, but it was interesting that some activities really helped certain participants, but the same activities didn’t work at all for others. So, even if an activity has a “proven” positive effect on grief recovery, that doesn’t mean it will work for everyone.

> *“I preferred talking to my journal rather than to share everything with friends because you can’t take it back if you’re having a bad day or dark thoughts and I’m not very comfortable with this.”*
>
> **Misa**

> *“Everyone says writing helps. But you only write when you are in a bit of a better mood. I don’t know how to deal with it when I am going through the thoughts.”*
>
> **Athena**

INSIGHT 2

## (Lack of) Closure

This point came across clearly in almost all of the interviews. The interviewees who had the opportunity to say goodbye to their loved ones mentioned that they received a sense of closure that helped them in their grieving process. In the opposite cases, the lack of closure was something they struggled with.

*"I had an opportunity to say goodbye, to have closure with that. I don't even remember what I said. I really more remember the feeling. That it just felt really peaceful."*

**Jessica**

*"I just wish she would have let me in and advocate for her... I struggle because I don't have closure."*

**Julie**

INSIGHT 3

## It's all about who you talk with

Everyone had someone to talk to about what they were going through and felt safe to share their feelings with. It was important that these people could really relate to them, genuinely care about them and support them. There were also some instances of trying to talk to people who did not relate to them and in most cases the interviewees felt disconnected from those people and hurt.

*"It really helped having genuine people who cared... Even if I didn't reply they would message me because they were sitting in pain for me and caring."*

**Athena**

*"I tried to go to a grief support group at my church. It was horrific. A bunch of widowers told me to find a grief support group where I "fit". I remember coming home and just bawling my eyes out."*

**Julie**

*"We've talked a lot with my best friend about grief. We're both familiar with it. It's nice to have somebody that knows what you're talking about as you go through it... My partner doesn't understand, he grieves in a different way. Grief is the kind of thing that either you get or you don't. And either you really get it or you really don't"*

**Jessica**

*I like to keep to myself a lot, I just find it very exhausting telling every friend every detail. But I have one friend that I actually told everything because she would always make the effort of calling me regularly. That friend definitely saw me evolve"*

**Misa**

INSIGHT 4

## Keeping the memory alive

This point came up in a variety of ways, such as sharing memories with their children, looking at photos and videos, listening to music, or scrapbooking. But the point was that they were looking for ways to keep the memory of their loved one alive.

*"I try to listen to the music my mum or my dad listened to. It's hard but I try to do it... I try watching videos or photos cause I don't want to avoid this but it is hard. It almost brings them alive for me and it's the only thing that helps me in the moment."*

**Athena**

*"Remembering your loved one is so important. I love sharing stories with my children and keeping her memory alive."*

**Julie**

## Challenges

The people interviewed had very different experiences, and although certain insights were discovered, the highly personal and multidimensional nature of the problem made it difficult to generalise.

Another problem was that people who had a loved one with a terminal illness (Group A) were not represented in the results, as the interviews were conducted with people who were currently grieving (Group B) or had overcome their grief (Group C).

At this point, it was realised that even conducting a few additional interviews would not be sufficient, as a large number of responses were needed to safely reach conclusions and to obtain responses from all three groups of the target audience.

Therefore, a questionnaire was created to find more participants and to understand people's journey and experiences of grief.

# questionnaire

## Overview

The questionnaire was developed based on the findings from the expert and user interviews and contained both quantitative and qualitative questions. The questions led to different response scenarios depending on the situation (Figure 5), based on the structure of the interviews, and were tested prior to release with 3 people who had personal experiences that were relatable.

The questionnaire was sent out in 25 groups on Facebook and Reddit for grief or caregiver support, ran for a week and received 33 usable responses. The average age of the participants was 34 years old, 72.8% were female, 21.2% male and 6% other/no reply. Regarding the target group 42.4% (14) had overcome their grief, 39.4% (13) currently were grieving and 18.2% (6) had a loved one with a terminal illness.

The quantitative questions were used to create a statistical analysis of the responses, while the qualitative questions were analysed with an affinity map and the creation of a timeline to show how grief evolves over time. The combination of quantitative and qualitative questions resulted in an insightful data set.

In general, the qualitative responses were consistent with the insights gained from the user interviews and were therefore validated.

Overall the questionnaire goals were the same as the interview goals, with some additions

Gather more responses to have a better understanding of people's journey and experience with grief

Have more responses to safely reach conclusions

Obtain responses from all three groups of the target audience

Validate the insights from the user interviews

# questionnaire goals

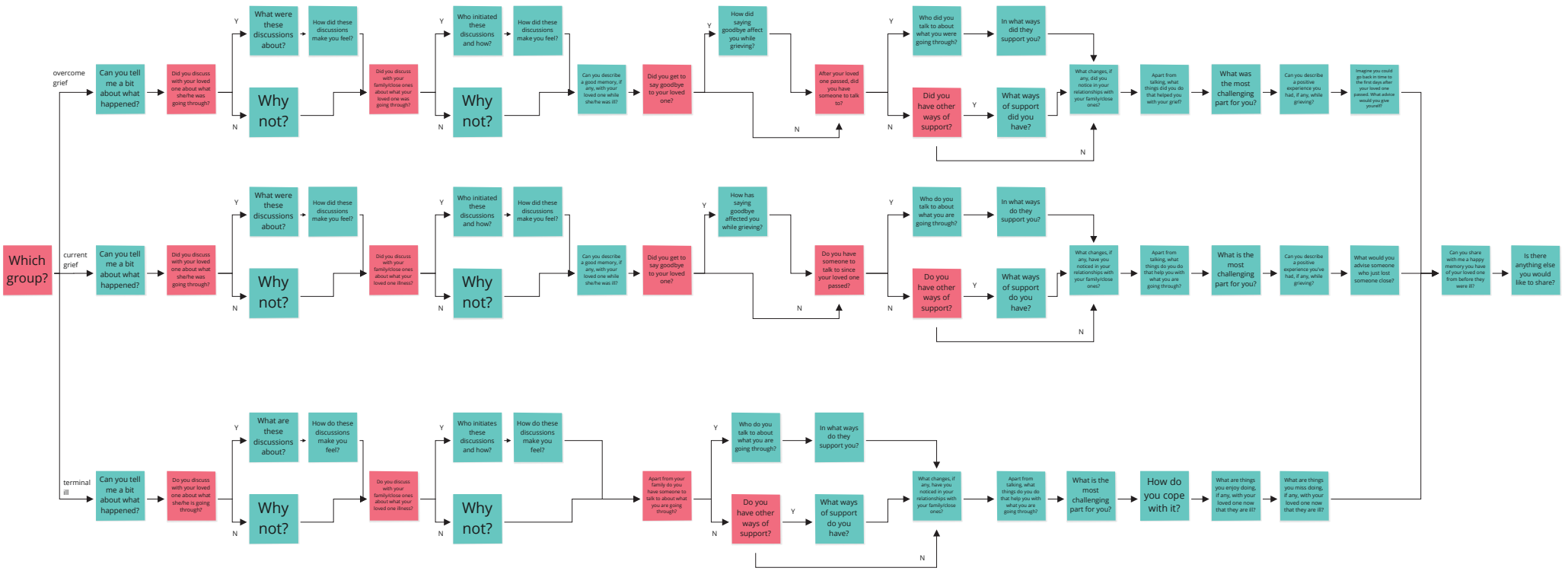



Figure 5: Structure of the questionnaire

# Combination of quantitative & qualitative data

When the qualitative and quantitative responses were juxtaposed, certain issues and opportunities for intervention became apparent. For example, it revealed how many people talked to their loved ones about what they were going through, but also what they talked about, how it made them feel, or why they avoided that conversation. This created a better understanding of the numbers and in certain cases led to the identification of problems that were not very obvious at first sight.

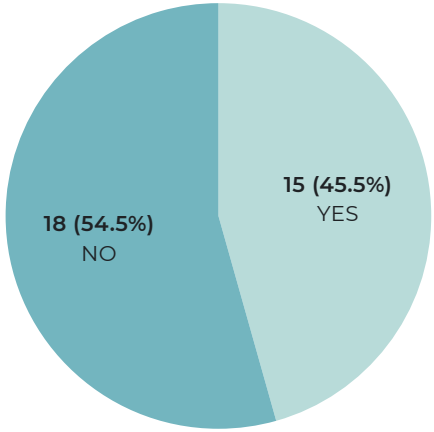
One example is that 84.8% of respondents said that they had talked to their family/close ones about their loved one's illness, which at first glance does not seem to be a problem, but when one looks at what they talked about, almost all of the responses were about facts and/or treatment.

Some of the data that was gathered is presented in the following pages.

# Data about communication while loved one is ill

*SUM = 33 (All groups)*
*In the qualitative data some participants had more than one response.*

Did/do you discuss **with your loved one** what they were going through while they were ill?




**What they talked about (for YES answers)**

Feelings (6) | End of life wishes/treatment (6) | Optimistic discussions (4) | Avoiding talking about death (3) | Difficult (3) | Realistic (2)

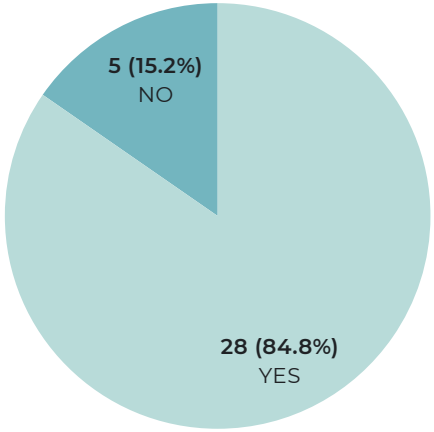
**How they felt from talking (for YES answers)**

Sad (5) | Comfortable (4) | Helpless (4) | Awkward (3)

**Why they didn't talk (for NO answers)**

Patient couldn't communicate (4) | Patient avoided it (4) | Sudden (3) | Scared/Not knowing what to say (3) | False hope (2)

Did/do you discuss **with your family/close ones** about your loved one's illness?




**What they talked about (for YES answers)**

Facts & treatment (11) | Support (5) | Upsetting/stressful (5) | Short (2)

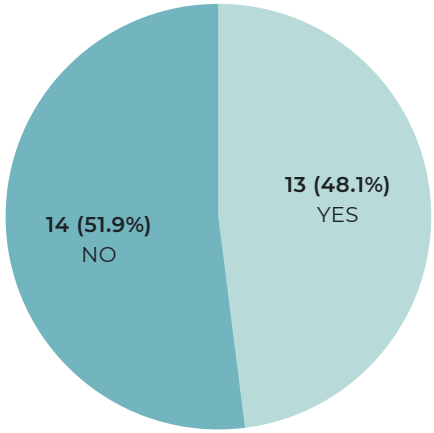
**How they felt from talking (for YES answers)**

Sad (6) | Worried (4) | Hope (3) | Comfort (3) | Prepared (3) | Alone (3) | Nothing (2)

## Data about saying goodbye

*SUM = 27 (People who are currently grieving or have overcome grief)*

Did you get the chance to say goodbye to your loved one?



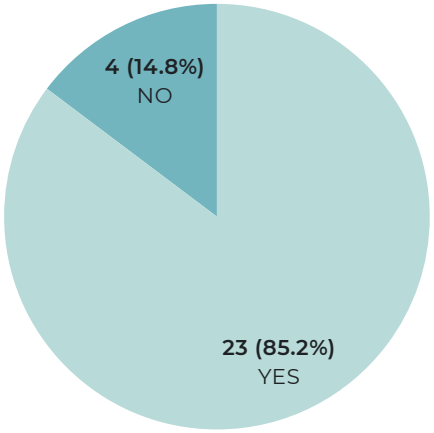

**How did it affect the grieving? (for YES answers)**

Helped grieving process (7) | Saying goodbye wasn't the hardest part (3) | Mixed feelings (2) | Made grieving harder (1)

## Data about communication after loved one passed

*SUM = 27 (People who are currently grieving or have overcome grief)*
*In the qualitative data some participants had more than one response.*

After your loved one passed, did you have someone to talk to about what you were going through?




**Who they talked to (for YES answers)**

Friends (7) | Sister (5) | Family (5) | Therapist (4) | Significant other (3) | Parent (3) | Preffered being alone (2) | Internet (2) | Support group (1)

**How they were supported (for YES answers)**

Listening (12) | Emotional support (4) | Practical support (3) | Sharing memories (3) | Sharing grief (2)

# Pains & Gains

Some of the questions in the questionnaire served to understand the pains and gains people have while their loved one is ill or while they are grieving. These themes were collected to get a better understanding of where to intervene (pains) and find elements that could be used in the solution (gains).

## Pains

**Most challenging part**

Absence (9) | Related to illness (6) | Uncertainty (5) | Firsts (4) | Pointles present/future (4) | Moving forward (3) | Lack of guidance/advice (2) | Existential crisis (2)

**What they miss most while loved one is ill**

Doing things together (5) | Expressing emotions (5)

## Gains (Happy Memories)

**While loved one was ill**

Doing things together (9) | Expressing love (5) | Family time (2) | Humour (2) | No good memories (2)

**Things they enjoy doing with loved one while ill**

Talking (3) | Quality time (3) | Doing things together (2)

**While grieving**

Closeness (7) | Nothing positive (3) | Sign from deceased (3) | Relief (2) | Relating to others (2)

# outcome

Through qualitative research, a deeper understanding of the evolution of grief over time, as well as people's experiences, pains, and gains, emerged. In addition, several opportunities and moments were identified to intervene with a solution.

The information gathered helped develop the point of view, define the design principles, and figure out the How Might We question, as described analytically in the following chapter.

CHAPTER 6

# ideation

# point of view

The point-of-view template provided by the Interaction Design Foundation [23] was used to uncover and structure the key findings from the questionnaire data and the research as a whole. These helped define the design principles and frame the design challenge.

POINT OF VIEW 1

## Not taking advantage of the time remaining

**Group:**
People who have a loved one with a terminal illness (Group A)

**Need:**
Guidance in how to use this time as a “window of opportunity”

**Insight:**
People tend to ignore the odds of death and what the doctors tell them. They feel like somehow they will be the exception and their loved ones will survive. So they tend to discuss optimistically and avoid facing reality until it is too late. It’s important to not remove hope from people, but also to encourage them to use this time in a manner that will bring them closure and peace.

POINT OF VIEW 2

## Uncertainty and lack of guidance

**Group:**
People who have a loved one with a terminal illness and people who are grieving (Group A and B)

**Need:**
Help to know what to do or say

**Insight:**
During this time they are facing a new reality, need to adapt to this situation quickly and are dealing with a lot of painful and stressful emotions. All this makes them uncertain about how to deal with their day-to-day lives, how to support their loved ones, what to say to them. They feel out of control and uncertain about the present and the future. It seems like just knowing where to start or having some sort of structure would help provide the guidance/assurance they seek in these times.

POINT OF VIEW 3

## Lack of balance between negative and positive emotions

**Group:**
People who have a loved one with a terminal illness and people who are grieving (Group A and B)

**Need:**
Help finding balance

**Insight:**
Most people said they talked with the patient and/or family, but these conversations created mostly negative feelings (sad was the one that stood out in both cases, followed by worried, stressed, helpless, awkward, and alone). It makes sense that these feelings will be prominent in this situation, but we could find a way to balance them out by creating room for positive emotions. Some people mentioned that sharing stories about their loved ones, spending quality time with them and doing activities led to positive emotions like support and comfort. The aim shouldn't be to block out the negative emotions, as these are important to express, but create a balance between negative and positive.

POINT OF VIEW 4

## Support from people who understand them

**Group:**
People who have a loved one with a terminal illness and people who are grieving (Group A and B)

**Need:**
To share their feelings with people who get them

**Insight:**
Almost everyone mentioned that the best way they felt supported was by talking to someone who gets them. This wasn't necessarily their family or a large group of people. It usually was one or a few people who understood what the person was going through, mostly because they had also been through a similar experience. But this wasn't the only factor. It came up a lot that, because people don't grieve in the same way, it was important to find a person who grieves similarly with them. Some people sought support and got shot down because the person or group wasn't going through their experience similarly, and they ended up feeling hurt, unsupported, and alone. When finding the right person though, offers them a sense of support and belonging that ultimately helps them process their feelings and overcome their grief.

POINT OF VIEW 5

## Need to create time and space for deeper moments while loved one is ill

**Group:**
People who have a loved one with a terminal illness (Group A)

**Need:**
To be encouraged to have deep discussions/moments

**Insight:**
About 50% of the people said they talked with the patient and almost everyone spoke with their family/close ones. These discussions were mostly factual about the treatment or end of life wishes. A lot of these discussions were optimistic or avoiding reality, on the one hand, to be supportive to the patient and on the other because most were in denial. Discussions were also difficult in some situations. In general, it seems that a lot of people have a hard time having deeper conversations in this situation, they don't want to think that the patient will die and want to seem optimistic and supportive so they end up losing the opportunity to say whatever they need to say before it is too late. It makes sense that discussions about treatment and practical aspects of the illness will be in the spotlight, but we must also make space for these deeper moments (not necessarily discussions) because those who "took advantage" of this time said that those moments gave them a sense of closure and peace that helped them when grieving.

# design principles

“Design principles are value statements that describe the most important goals that a product or service should deliver for users and are used to frame design decisions.” [24]

The design principles derived from the research.

# design principles

PRINCIPLE 1

## Make it familiar

In experiencing illness, loss, and grief, there is much uncertainty and distressing feelings. Therefore, the solution should feel familiar, safe and simple so as not to create additional stress.

PRINCIPLE 2

## Provide structure but keep it flexible

People are looking for structure and some kind of guidance, but at the same time the solution should be flexible to adapt to each person's experience, needs and story.

PRINCIPLE 3

## Create a feeling of safety

Communication needs to be respectful in order to achieve a positive outcome for everyone involved. Creating a sense of safety is important for conversations to have that outcome.

PRINCIPLE 4

## Celebrate life

At the end of life, most conversations revolve around treatment, end of life wishes and practicalities. The solution should encourage finding time between all these practical aspects to celebrate the person's life, their journey and their legacy.

PRINCIPLE 5

## Allow verbal and non-verbal expression

People find it easy to communicate in different ways. Some may be good at verbal communication while others prefer to write, paint, etc. Allowing options for both can help improve communication and expression.

# how might we

HMW ("How Might We") questions "are short questions that launch brainstorms" and "fall out of the point-of-view statement or design principles as seeds for ideation." [25]

First, 3-5 HMW questions were created for each POV, resulting in 22 HMW statements. To decide which HMW to proceed with, I asked from people who knew my process and findings and/or were part of my target audience to vote on the HMW statements they preferred. Twelve people (including myself), with up to three votes each, voted individually on the statements (Figure 6). The poll ended in a tie (four votes each) between two statements:

1. How Might We make the end of life a celebration of life?
2. How Might We create empathy and better communication between family members who grieve in different ways?

Each of these statements focuses on a different part of the grief journey, the first when the loved one is at the end of life and the second after they have passed away. The first statement was chosen after reflecting on previous choices and what was discovered during the research.

The two main factors that helped in the HMW decision were:

1. The previous decision to narrow the topic to deaths caused by terminal illnesses, and the fact that this provides a window of opportunity for communication and closure that is unique and not available with other types of deaths.
2. Insights from the research, which highlighted that there is a major problem with communication at the end of life that provides a solid opportunity to meaningfully intervene and offer a solution.

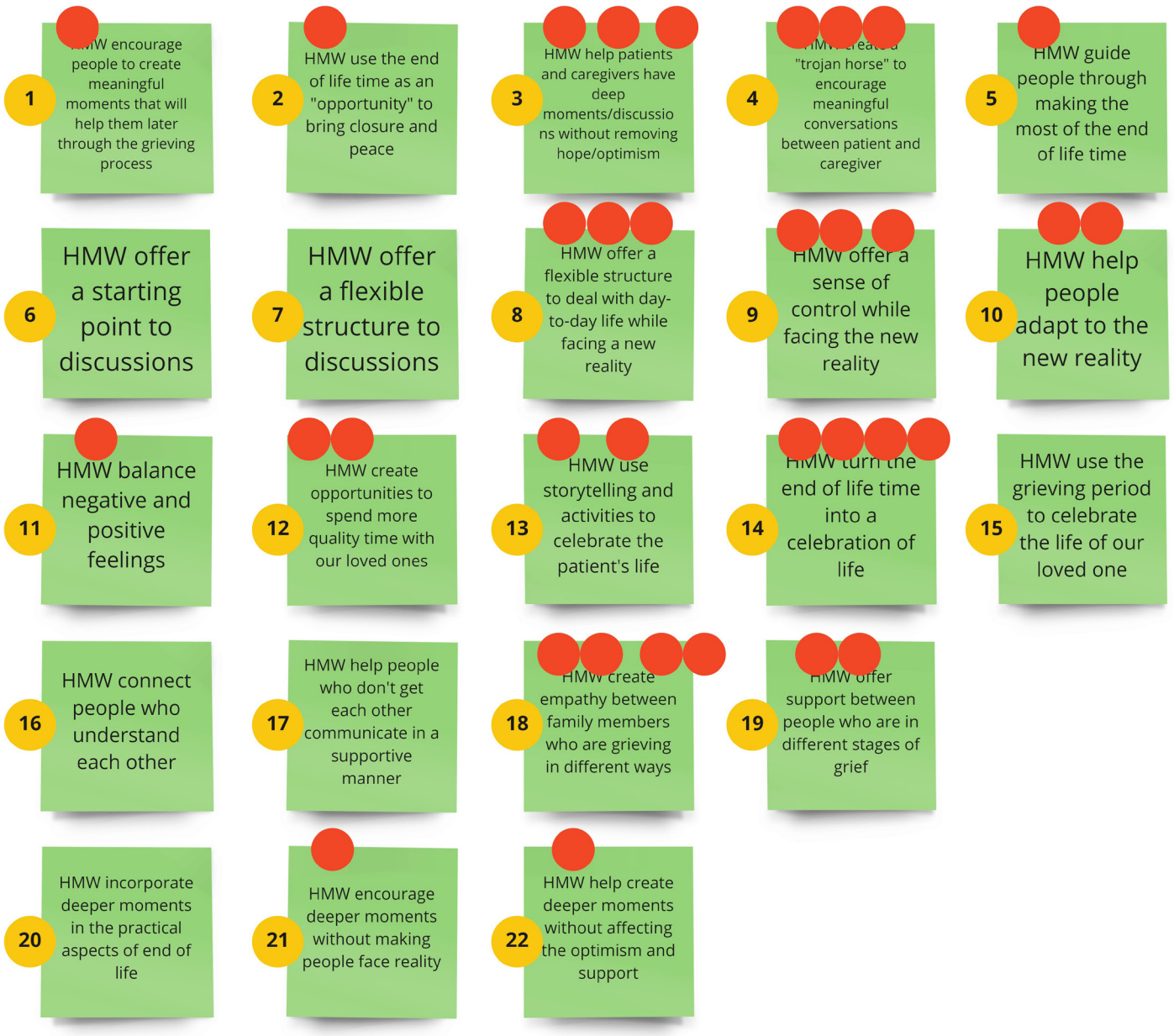



Figure 6: HMW voting

The term “celebration of life” seemed to confuse people because everyone had a different understanding of the term. So the HMW statement was reworded to provide clarity and a common understanding.

This resulted in the final design challenge, which was used to brainstorm and come up with solutions:

How Might We help people who have a loved one with a terminal illness **make the most** of the time they have left so that there is a **sense of closure** in their grieving process?

# exploring solutions

## Brainstorming

Some designer friends who also participated in the HMW vote were invited to participate in the brainstorming session. The target audience, key findings, design principles, and final HMW were introduced to them so they could get a good understanding of the problem we were trying to solve. Then we set a timer and individually wrote as many ideas as we could think of on post-it notes. When the time was up, one by one we presented our ideas to the group and taped them to the wall. Once all the ideas were presented, we grouped them into themes.

The five themes that came up were:

1. Doing activities together
2. Sharing and creating memories
3. Wish list/last wishes
4. Travel
5. Giving something back to the community

# Further ideation

The themes and some ideas that came up during brainstorming were used as a starting point for ideating with sketches to come up with concrete solutions. Several ideas came up, but I wanted to explore what would happen if an element of randomness was introduced into the ideation process.

To add this element of randomness, the mash-up ideation technique was used, in which you “pick two broad, unrelated categories... and list as many elements of these two experiences as you can in two minutes”. Then you “combine items from the two lists to ideate as many new products, services, or experiences as you can”. [26]

For the mash-up ideation elements of life (e.g. friends, work, vacations) and elements of parties (e.g. invitations, balloons, cake) were listed. Again, different ideas came up, but this technique was used again, this time with categories that related to the problem and what needed to be addressed. So on one side there were elements of how to make the most of life, and on the other side there were elements of how to communicate. A third column was added where “types” of solutions (e.g. service, virtual, physical, ritual, etc.) were listed (Figure 7). This led to more focused ideas while still having the element of randomness.

Figure 7: Mash-up ideation

# Outcome

Going through the various ideas that came out of the ideation sessions and using the design principles narrowed down the options to three possible solutions. In order to decide which solution to pursue, the opinions of the experts and individuals interviewed during the qualitative research were sought.

# initial concepts

The main goal of the solutions that came up were to create a time and space for people to safely and creatively explore their time spent together, while creating physical representations of their memories that can be kept as keepsakes and help through the grieving process.

CONCEPT 1

## Association Card Game & Memory Book

A game played with an illustrated deck of cards. Each player lays down a card and must think and communicate a memory he associates with it. It is a tool to encourage communication and to share and create memories with your loved ones. At the end of each game, they can choose their favourite memories to add to a memory book.

CONCEPT 2

## Art Classes

Each class has a different theme that gets them discussing and thinking so they can work together to create a piece of art based on their memories, feelings and experiences. At the end of each class, they get to keep their creation.

CONCEPT 3

## The Book of Life

Family and friends share memories, stories, photos, videos, etc. (possibly via a digital platform) of the person with the illness. These are used to create a physical album that is given to the patient who can see their life through the eyes of others. After the album, there is space for the patient to reflect and write their own perspective and stories.

**Find out:**

How people feel about these ideas

What concerns or questions they might have

Whether they would undertake these activities

If they thought these activities could help bring closure

Which idea related to them the most

# prototyping goals

# prototyping

To proceed with developing the final solution, the ideas had to be presented to get feedback. To this end, a high-fi prototype of an imaginary palliative care website was created that featured activities offered to terminally ill patients and their families/loved ones (Figure 8)

The link to the prototype was sent to the experts and individuals interviewed, explaining what the website was about and asking them to click through the different activities in any order to learn more about them. Each activity had its own page with a description of the activities and photos so they felt like real, existing activities.

[Click here to view the prototype]

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# Activities

We believe that this time is an opportunity for you and your loved ones to have open, honest discussions that can deepen your relationships and help bring a sense of peace and closure.

We know that these discussions are sometimes hard to initiate. So, we have created certain activities you can do together to encourage you to **explore your time spent together in a safe space and creative manner,** while at the same time creating **physical representations** of them.

## The Association Game & Memory Book

Play this game with your loved ones to revisit your memories and capture them in time by creating a visual representation of them together.

Find out more

## Art Classes

We offer art classes for you and your loved ones. Each class has a different theme for you to explore and create art based on your memories, feelings, and experiences.

Find out more

## The Book of Life

We help you gather stories, photos, and memories about your life from your loved ones and create your book of life out of them. You can also add your own memories and stories.

Find out more

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Figure 8: Prototype of landing page

After people read through the activities, they were asked to fill out a short questionnaire. For each activity, they were asked three questions based on the “three questions for effective feedback” [27] and one additional question so they could add any other thoughts they wanted to share:

1. What did you like about this activity?
2. What do you think I can do better or differently?
3. What do you think I should remove?
4. Any other thoughts you would like to share.

Then they were asked for overall feedback on the ideas with the following questions:

1. In which order did you view the three activities? Was there any reason for viewing them in that order?
2. If these activities existed, which ones (if any) would you have liked to have done with your loved one? (if you have more than one activity please list them in the order you prefer them from favourite to least favourite, if you don’t have any please briefly let me know why)
3. Do you think these activities could help people have closure?
4. If these activities existed now, would you like to do them with your family/close ones as a way to share your stories/feelings about your loved one? Why/why not? Which ones would you do?
5. Any other thoughts you would like to share.

# feedback & validation

The Test Capture Matrix [28] was used to evaluate the feedback received. One grid was created per idea and one for general feedback on overall direction and solutions. Each grid had four sections, top left for positive feedback, top right for negative feedback/concerns, bottom left for questions or areas that were not clear, and bottom right for ideas or suggestions that came up. (Figure 9)

it's a good way of making new memories

it can involve more than one or two people at a time

it's simple

grants access to younger ones

It would help you focus on something other than illness

I would play the game with my mum's family now, I think it could be fun!

the journal is something they can carry with them for the rest of their lives

I like the idea of sharing memories and revisiting them together

Just doing these things together, sharing memories etc... that's a time I wish I would have had with my family before my mom passed

verbal expression is the fastest medium of sharing

I think the association game is such a great idea because it would make you make you and your loved ones playing smile as you remember special moments you spend together

It's hard to smile when you are losing someone you love and I feel that with this activity would help you to grow together and in a way that takes your mind off of what you are going through even if only for a brief time

not sure about the journal part

I'd kind of feel obliged to participate for the sake of having the final product

if I took part in activities like these with a terminal loved one, I wouldn't be as spontaneous as I'd like

can we really capture a memory on a piece of paper?

people may have other forms of expression they are more comfortable with

playing the game might be sad

It depends on the circumstances/people if the solutions would work or not

why not include also a voice recorder?

I think you could also play it and focus on someone who has passed

I really think that this game could be beneficial to all families with or without someone who is sick

make the journal optional

Figure 9: Test capture matrix for the association card game & memory book idea

# Insights from the feedback

### Feedback from the target group

1. Liked the idea of sharing memories and reliving them together with their loved one.
2. Found that the activities were a good way to make new memories.
3. Liked that they created something together to keep as a keepsake.
4. Concerned that they might lack spontaneity and feel like an obligation.
5. The fact that you are doing these activities because your loved one is dying could make the activities feel tragic or sad.
6. Concern was expressed that people have different ways of expressing themselves and the solution should take this fact into account.
7. Mentioned that the success of the activities and whether they help provide closure and comfort during the grieving period will depend greatly on the circumstances (e.g., nature of the illness) and/or existing relationships and dynamics within the family (e.g., if the family has a hard time expressing their feelings, these activities might help them open up).

### Feedback from the experts

1. They mentioned that the HMW statement is a very interesting and an important area to explore, as not much has been done for this topic.
2. They believe that the solutions are valid and can possibly help bring closure and work through grief, depending on the situation (as above - nature and duration of illness, existing relationships and dynamics).

# choosing the solution to move forward with

From the feedback received, all three solutions seemed to be valid directions to pursue. The aspects that people liked and the concerns they had applied to all ideas. There seemed to be a slight preference for the Association Cards & Memory Book. The feedback provided a lot of insight that could be used to develop the final solution.

The Art Classes were discarded because people had concerns about having different needs and ways of expressing themselves. This solution would be very specific to people who like art and feel this is a good way to express themselves.

Then the Book of Life was eliminated because it does not promote the communication aspect between the family and loved one as much as the Association Cards & Memory Book. Getting back to the design principles, the solution had to encourage both verbal and nonverbal communication. The Book of Life strongly promoted the nonverbal aspect while not focusing on the verbal.

Therefore, the Association Cards & Memory Book solution was chosen because it aligned well with the design principles and provided room for customization and versatility to solve the problems that arose from the feedback.

CHAPTER 7

# end of life communication

# current situation

To see how the solution fits with products or activities that already exist in the end of life industry available resources and what has been done so far in this area were analysed.

All information and resources focused heavily on the practical aspects of dying and helping patients plan their affairs and final wishes. Resources for planning one's own funeral [29], end of life planning checklists [30], and workbooks for sharing end of life care wishes [31] were easily found.

There was some advice on how to talk about illness and any fears [32] and how to talk about death and dying [33]. But these did not seem as structured as the advice given for the practical aspects (for example, there were no checklists or workbooks) and also focused on how to help people talk about death rather than using this time to create a sense of closure.

Suggestions for activities that could possibly create a sense of closure were found on hospice websites. One hospice suggests talking about one's memories, laughing, and asking the patient questions about their life [34]. Another suggests playing games together or helping the patient write letters to loved ones [35]. Mayo Clinic mentions that encouraging the loved one to talk about his or her life helps to "affirm that the person's life mattered and that they will be remembered." [36]

These were along the lines of my solution, but seemed to require a lot of effort from the patient and caregiver to make these activities a reality. There was also a lack of structure and guidance, for example how does one even decide what to put in their memory book or where do they start talking about their life? People feel "awkward and ill at ease when faced with the opportunity for communication at the end of life" because "communication is a skill that takes practice and, in general, people have no experience with communication at the end of life" [3]. The above solutions did not seem to address this problem.

# legacy making activities

## Overview

Legacy making activities “help individuals, families and caregivers review the life of a dying person, and may produce a meaningful project that serves as a living memory after the individual’s death.” [37]

“Examples of legacy-making activities include memory books, hand molds, songwriting, artwork, photographs, and videos. While some children’s hospitals offer such activities to pediatric patients, legacy-making has received little empirical attention.” [38]

End of life communication is equally important for the terminally ill person and the family, but it is only since 2004 that research on end of life communication has focused on the family members. Prior to this the focus was on the patient’s perspective [1]. So this is a relatively new direction and not supported by much research.

However, the research that has been conducted suggests that legacy building activities improve family communication and do not create feelings of discomfort when participating in them [39].

They also help families to move on and grow from the experience, and can “decrease individuals’ fear of the death process and help change the culture of silence and uncertainty surrounding death.” [3]

Legacy activities can also influence family members’ perceptions of how they experience death, whether it was a ‘good death’ or a ‘bad death’, as these perceptions are influenced by certain factors including how they interacted with the patient during the end of life. [1]

“These undertakings were never intended as “legacy,” were not designed to address impending death or the continuation of familial bonds. Instead, they arose organically as opportunities to learn a new skill, connect with friends and family during a hospitalization or illness, or even express a quirky sense of humor. Each, like life itself, was a constant active process of connecting, creating, and narrating a human experience.” [40]

## Current pain points

Although, as mentioned above, end of life communication is important for both the patient and the family, and the benefits can be very effective in creating a sense of closure and supporting the grieving process, there are still some issues that need to be addressed.

A survey on the topic of legacy making activities conducted in children's hospitals across the U.S. revealed four main areas that need improvement. There is a need for more research, activities should be offered earlier in the course of illness, staff need to be trained and encourage these activities more, and there needs to be more flexibility in the variation of activities to make them more individualised. [38]

Another problem is that these conversations can be overwhelming for both the family and the patient. Thus, questions arise such as how to start these conversations, what to (not) talk about, who should lead the conversations, and so on. This uncertainty can lead to the family feeling intimidated by the task or avoiding it altogether [1]. The current legacy making activities don't seem to address these issues.

# summary

The desk research on end of life communication confirmed the findings from the expert and qualitative research, namely that using the end of life as an opportunity to communicate with the loved one plays an important role in the later experience of grief. Sharing memories and stories and co-creating a tangible version of them has been shown to provide a sense of closure and also create a better end of life experience for patients and families.

It also confirmed the feedback received on the solutions that the activities need to be flexible and varied so that they are very individual to the needs of each situation and therefore have the positive effect they aim for.

Finally, it drew my attention to certain issues such as whether and how medical staff are involved in this activity and that end of life communication can be quite stressful and daunting, so the solution should try to remove some pain points that exist there.

CHAPTER 8

# concept development

# overall activity

The overall activity consists of two parts: the association card game and the memory book. The association card game is used as a way to start conversation and revisit memories and the memory book is used to capture these memories in time by creating a physical representation of them.

The whole activity is designed keeping flexibility in mind. It is best if there are two or more participants, but it could even be done individually (e.g. the patient uses the cards for inspiration and completes the memory book alone). Another option could be playing the game together and completing the book alone. It can adjust to what the participants feel comfortable with and prefer.

The activity has been designed to be done at the end of life of a person as a way to help the patient and families talk about their time spent together and create a tangible representation of it that can be kept as a keepsake after the patient passes. However, it could also be done after the passing of the loved one as a way for the family to remember and talk about the memories they have.

It can be done in an end of life facility or in the home depending on where the patient spends his/her last days. The involvement of the medical staff is minimum. They could introduce the activity to the family but apart from that it will be easy and simple to use without supervision or assistance.

# association card game

## Why a game

During ideation, ideas were generated keeping in mind activities families enjoy doing together, and one was playing games. In fact, a survey conducted in the US in 2018 showed that 49% of participants play games with their family one or more times a week and 32% play games one or more times a month [41]. Another study conducted by Hasbro showed that 91% of participants said that “playing games gives their family’s mood a positive boost” and “96% of families who play games together say that they feel closer.” [42] Therefore, playing games is something familiar to many families and is associated with positive feelings and memories, creating a sense of safety.

The above could help address a major pain point of end of life communication, which is feeling overwhelmed and stressed by it or not knowing how to approach it. Communicating through a game could make end of life communication less overwhelming by doing it in a way they are familiar with, and help people approach the conversations with a positive mindset.

# Development

To develop this concept, games that are used to promote communication were researched. There are many conversation-starter card games that are used in a different context to help people get to know each other better in early or later stages of a relationship, or just to have a fun time at friend or family gatherings. Some examples are Big Talk [43], unCURATED [44], and We're Not Really Strangers [45] which all aim to spark meaningful conversations.

There are some games that use pictures or illustrations instead of words, such as "What do you meme?" which combines picture and text cards [46], or Dixit, which is not a conversation starter game, but uses illustrations that allow players to use their imagination to interpret the cards [47].

I decided to use illustrations that would connect the players to their memories as it seemed like a good way to create some structure (what to talk about, how to start) while allowing flexibility, for example, by not asking specific questions. Illustrations could open up endless possibilities for discussion because people will see and associate things very differently based on their experiences and may subconsciously create associations that bring up issues and memories they may not have known they needed to talk about.

Finally, the game's engaging interaction loop (Figure 10) was created to describe how the game keeps the player engaged by providing a solution to their objective, challenging them in an interesting/motivating way, and providing an outcome that appeals to them emotionally.

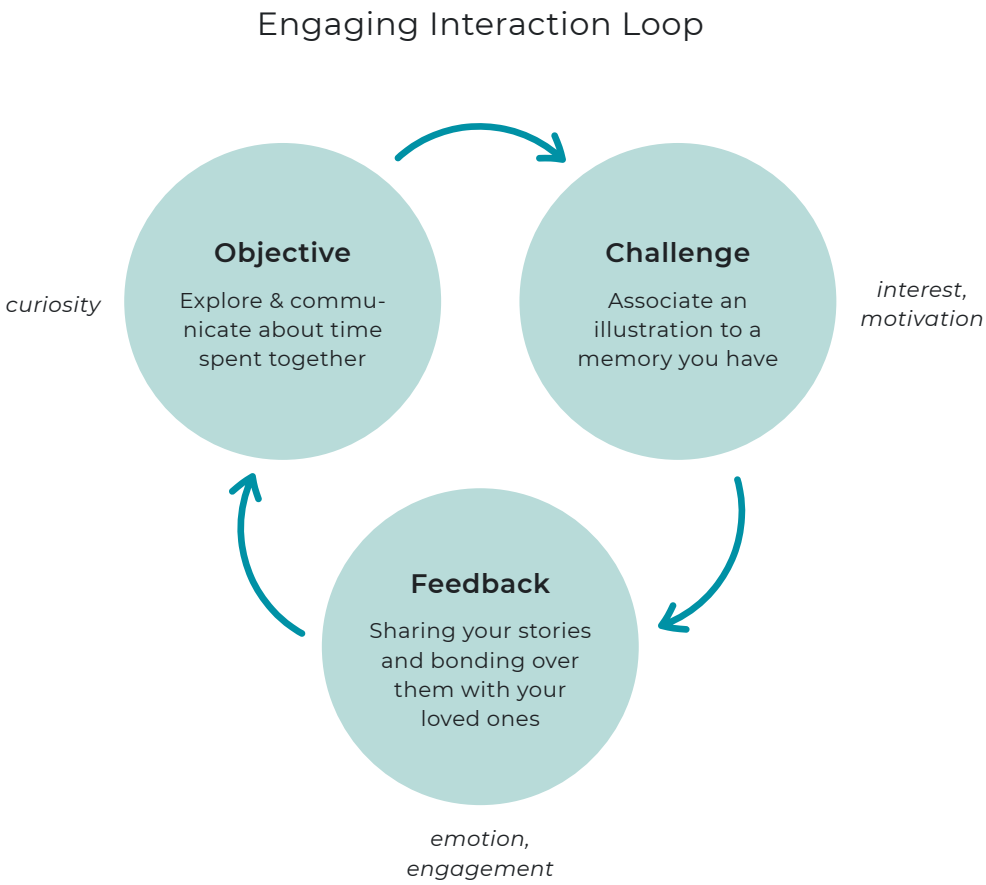



Figure 10: Game's engaging interaction loop

## Illustrations

To find the subjects of the illustrations, I went back to user research. The user interview and questionnaire participants had been asked to share happy memories they had of their loved one. Their responses were used as inspiration for the illustrations on the cards.

As a starting point for developing the illustrations, certain themes that came up frequently were used, such as nature, the ocean, travel, or more specific memories. Quick sketches were made that served as a guide for the final illustrations. (Figure 11)

For the style, I wanted the cards to be simple and almost childlike to reinforce the feeling of safety when playing. On each card, certain shapes and colours repeat to create a sense of harmony and calmness.

A limited colour palette was used to give the cards a sense of consistency and mainly shades of blue were used, which have a calming and relaxing effect. Shades of pink, which create feelings of intimacy and affection, and yellow, which evokes a sense of warmth, were also used.

Figure 11: Quick sketches to guide the final illustrations

## Game rules

Some research on game development and mechanics was conducted, and the possibility of making the game more challenging or adding gamification elements, like rewards and point systems, was considered. Ultimately, it was decided to keep the game as simple as possible, as the goal was to encourage communication and reduce the complexity and uncertainty that comes with end of life communication. Keeping points or adding unnecessary elements could lead to a more complex game that might discourage people from playing if they already have a lot of negative feelings.

Looking at the conversation starter games mentioned earlier, it was also noticeable that they stay away from complexity and added elements. Players just pick a card and have a discussion with the others based on that.

At this stage, an expert interview was conducted with a game designer to discuss the further development of the concept. We discussed how to structure the introduction and game rules and what to do when a player brings up an issue that the other player(s) do not want to discuss or that might be distressful. They suggested researching Nordic live action role playing games that often deal with sensitive topics and have developed certain techniques to deal with this later issue.

After contacting two more gaming experts who specialise in this type of games, two safety cards based on the “Kutt” and “Brems” safewords [48] in combination with the tap-out safety technique [49] were designed to help people indicate if a topic is sensitive to them.

The introduction to the activity and the rules of the game have their own cards. This way, it’s easy for players to get familiar with the game, and have handy single cards to guide them in whatever activity they are doing. They can disregard the cards that are not relevant to them at the moment.

# memory book

## Why a memory book

The purpose of the memory book is to co-create a visual representation of life and time spent together with your loved one. Through this activity, the patient and family create new memories while reminiscing about existing ones, and they create a tangible artifact of the person's life.

The association game can be used as a starting point to decide what to include in the book. After the game, participants can choose their favourite memories that they have shared and add them to the book. Creating the book could also be an individual activity, depending on whether people do not feel comfortable creating it together or if there are physical limitations.

As the research has shown, "the combined treatment components of life review and engagement in pleasant events, targeting meaning-based coping, may improve patients' and caregivers' communication and emotional aspects of quality of life". [39]

# Development

From the research, it became apparent that people have different ways of expressing themselves and therefore there must be diversity in the way they record their memories. Therefore, more options needed to be added.

Of course, people can write, draw, and so on in the memory book. They could also add audio with the use of audio chips, similar to birthday cards with sound, which can record audio with a short duration (about 2 minutes). With the use of envelopes, small tangible objects can be added to the memory book related to the memories or notes/letters to be read in the future (e.g. on a special occasion such as a birthday or anniversary). (Figure 12)

In summary, the memory book can be filled with:

- Anything that is in written form ( text, poems, lyrics, recipes, etc.)
- Photos, magazine clippings, etc.
- Small tangible objects
- Letters or notes to be read in the future
- Audio recordings

This creates a flexible, modular system that adapts to participants' preferences, but still creates enough structure so they don't feel lost or stuck.

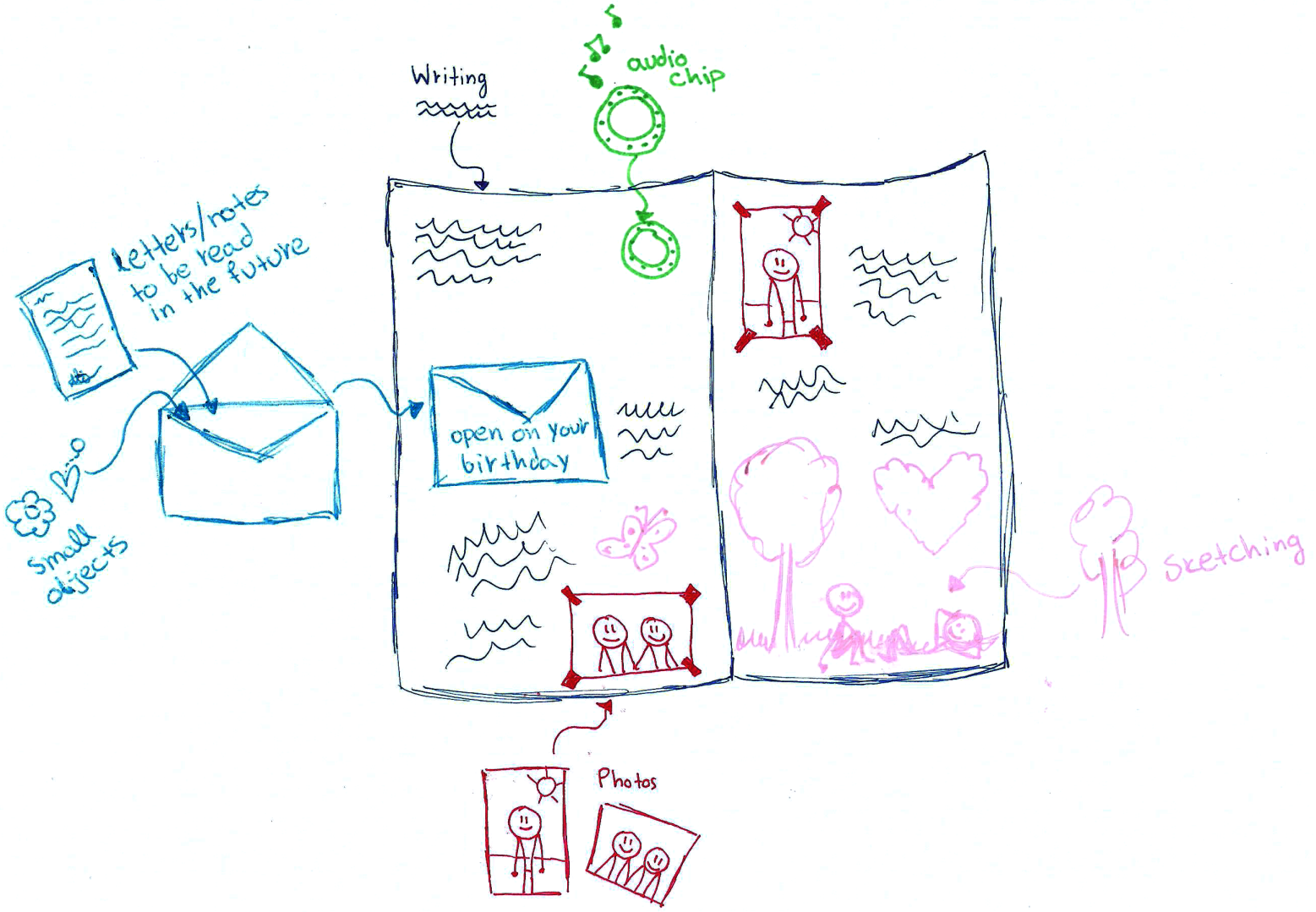



Figure 12: Sketch of memory book

CHAPTER 9

# testing & validation

# overview

The concept was tested in a variety of ways to test different aspects of the activity. Due to the limitations of Covid 19, it was not easy to test with the intended target group (people who have a loved one with a terminal illness - Group A). The game was tested with one person from Group A. In addition, the overall concept was tested with five people who had recently lost a loved one to a terminal illness (Group B) and two experts.

Furthermore, I wanted to test the functionality of the game (whether the rules are understandable, whether the game is fun, whether the illustrations encourage storytelling, and so on). To do this, I tested the gameplay with eight people who had either recently lost a loved one and used the game to share memories of their loved one, or the players had a long-standing relationship and used the game to share their memories.

# testing the concept

## Testing the concept with the intended target audience

The game was tested by a person who had recently learned that their grandmother had terminal cancer. The family gathered at the grandmother's house to celebrate Mother's Day and played the game, which resulted in sharing memories and discovering stories they had not known before, and overall very positive emotions. The memory book started spontaneously in digital form, as they began sharing photos and memories in their family group chat later that day. (Figure 13)

> *"Her childhood memories are the strongest associations in her mind. It's such a powerful feeling to be a part of her life before I was born, and to listen to her stories - bits and pieces that we hadn't taken the time to talk about before..."*

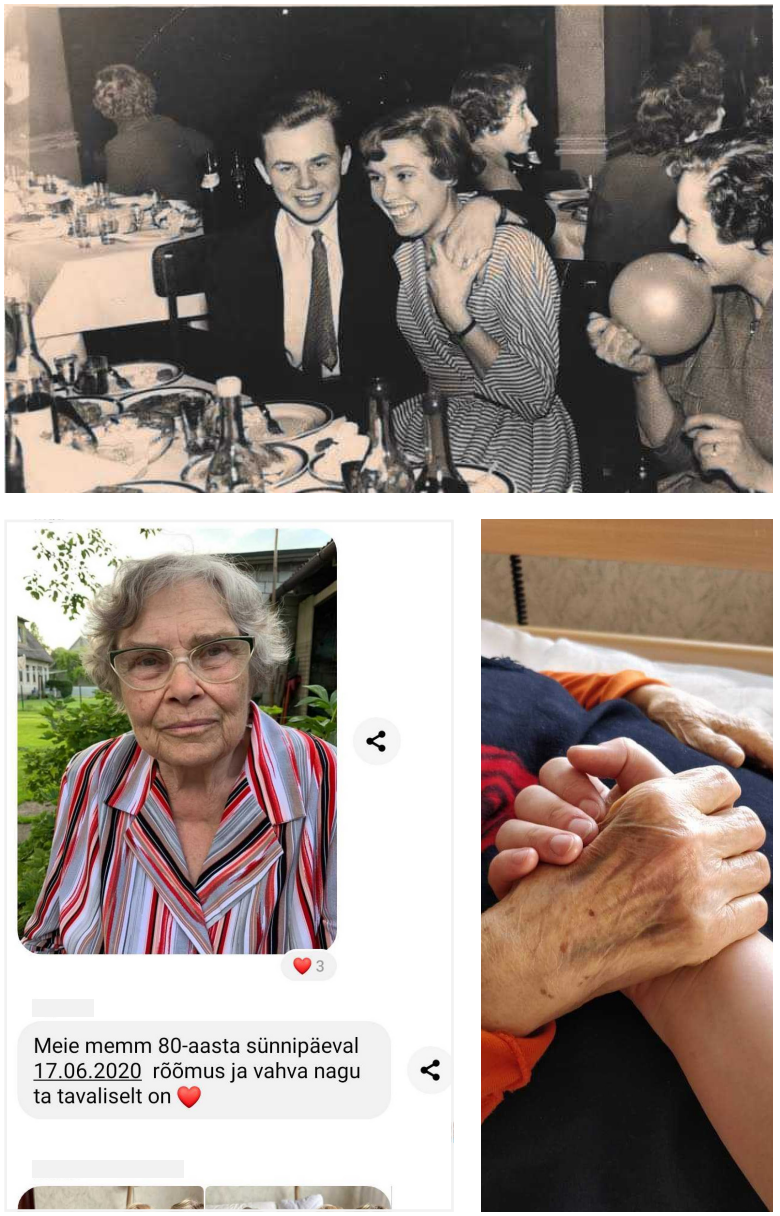



Figure 13: Images from the spontaneous memory book

# Testing the concept with people who recently lost a loved and experts

The concept was further tested with five people who recently lost a loved one due to a terminal illness. A prototype of a landing page (Figure 14) was created presenting the activity, describing what it was and why it was created. Similar to the earlier testing to decide upon a solution, participants were asked what they liked, what could be done better/differently, what could be removed and anything else they wanted to add and the feedback was evaluated with the Test Capture Matrix. (Figure 15)

On the whole, people liked the idea and especially the purpose, functionality and customization options, as well as the look and feel. Concerns were expressed by one person about whether the game would take away hope and that the gameplay approach might feel a little too light given the circumstances. One person suggested that more options for the memory book (and in particular adding videos) could encourage spotineity and help people express themselves better.

Furthermore, the concept was tested with two experts. The feedback was very positive and they expressed their interest in making this activity a reality.

[Click here to view the prototype]

Figure 14: Prototype of landing page

I love the emphasis you put on the importance of having open and honest conversations during this time: I had never thought about how these conversations actually needed to take place.

These cards give comfort just by playing a game. I like how each card has images that take every person to different memories!

The idea is very good, because you will inevitably feel afterwards that you should have inquired and asked more.

The color palette and general “mood” of the document are very peaceful and enjoyable, which is important for the purpose they serve.

I like that you included safety cards for a respectful conversation.

I really like the emphasis you put on the customisation aspect of the game, of course each story is going to be different, so to be able to tailor each session to each need is great; well done.

The audio or written option makes the game much more accessible to those who maybe are sight or hearing impaired - great point for inclusivity.

It looks amazing! I love the soft colors, they are very calming and the illustrations are amazing. I love the safety cards. What a great idea! I wouldn’t remove or change anything. I think it is perfect!  Well done!

I don’t want to act very logically (drawing, writing). I feel like options are missing to express myself.

It feels like by playing this game I am taking away the hope that perhaps it can get better. As if I am giving up or announcing the end.

The game approach feels a bit too light given the heaviness of the topic.

The lack of options in the memory book might not encourage spontaneity and people might not be totally free expressing themselves.

I actually think the idea is very good, but perhaps you should think more about the positioning.

I’d love to have the option to record voice or add very short movies.

Figure 15: Test capture matrix

# testing the gameplay

The gameplay was tested by eight people, whether they were part of the target group or not, as I wanted to be present and observe the game while it was being played. (Figure 16) Since I wanted to test the functionality of the game, it was not necessary for the people to be part of the target group. The individuals who tested it either used the game to share memories of a loved one they had lost or had longstanding relationships and used the game to share their memories.

Overall, people seemed to understand the rules, enjoyed the game and visualisation of the memories, and could easily make associations. The cards sparked storytelling and encouraged people to remember and share their memories.

Two things stood out to me that could be improved. The first was that the memories shared were rather random, so there were no photos they could add to the memory book. The second was that sometimes a player would discuss their memory, but it would not lead to a discussion.

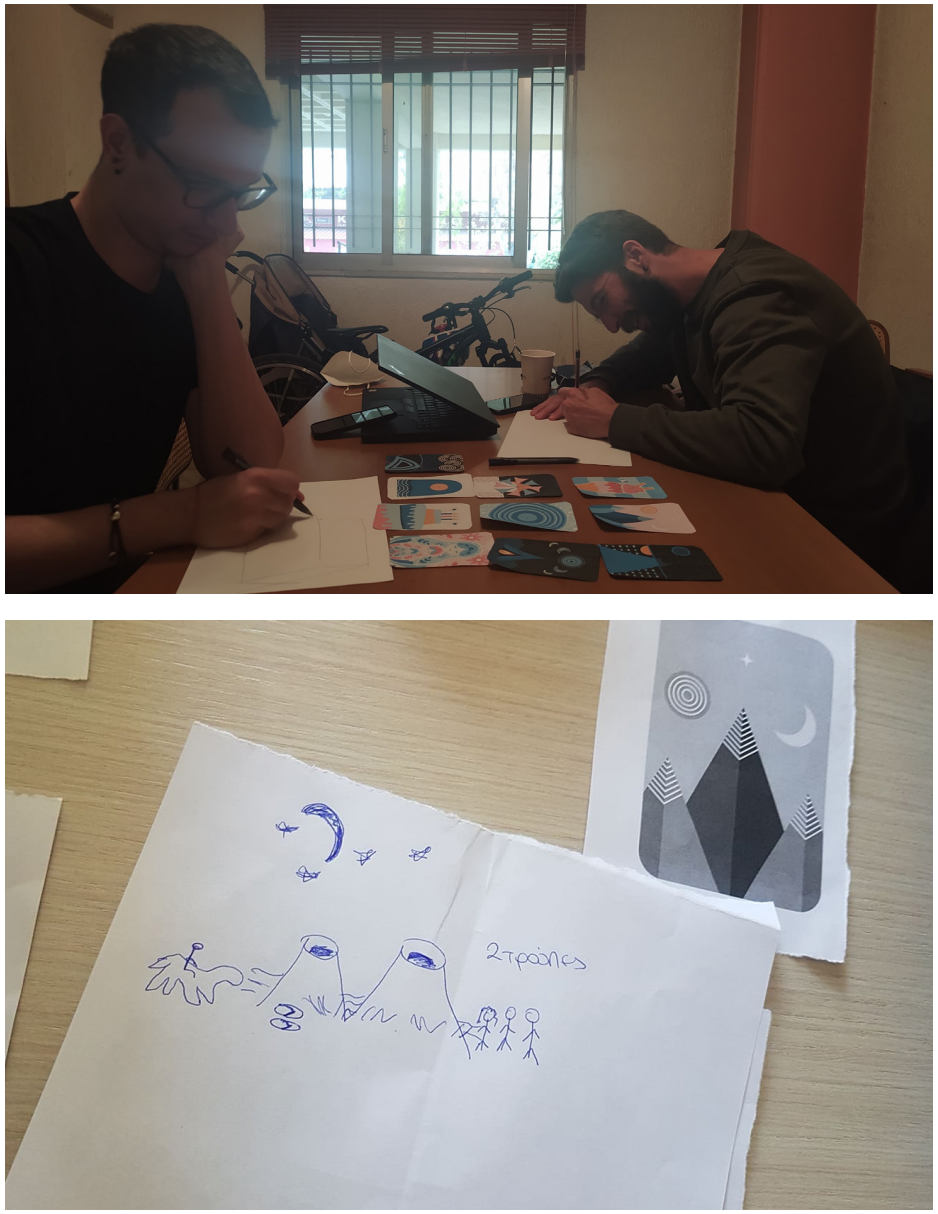


Figure 16: Testing the gameplay

# iterations

Based on the testing, three adjustments were made.

The first was to add more structure and options to the memory book, based on the feedback on the idea and the gameplay testing. A guideline was added that the stories told during the game serve as a starting point for what should be included in the memory book, and that participants can reflect on important moments and include them as well. In this way, the book can be filled with the important milestones and moments in a person's life, but also with all the "random" stories that come up during the game. Analytical instructions and suggestions of the available options, as well as the option to add short videos.

Furthermore, the tested game rules were kept as a "quick start" version to help people get started with the game and develop their communication skills if they are lacking them. And then an additional game variation was added to encourage communication between players as they have to make an association with both the cards in their hand and the story the previous player said. Game rules were also developed for solo play.

Finally, the introductory cards explaining the context and purpose of the game were reworded to address concerns that the game might take away hope. Originally, the cards containted phrases like "end of life" and "closure" which were removed in the rewording, and overall the new text had a less straightforward approach. It now mentions that the activity is for people with a serious illness and their loved ones, but specifies that it is created to provide peace and support regardless of life expectancy. With the new wording, the activity is not focused on terminal illness and closure, which allows people to maintain hope or even do the activity in early stages of the illness before it is terminal.

CHAPTER 10

# final solution/ design component

# what

The solution is an activity designed to encourage people with a serious illness , regardless of life expectancy, and their loved ones to explore and discuss their time spent together. It was named “Mneme”, which is the greek word for memory, so people can make the connection with the concept.

It includes a set of illustrated cards to help reflect on life and memories through associations, and a memory book to create a physical representation of them. People can use the stories that come up during the card game as a starting point for creating the memory book.

# why

During a serious illness, conversations can revolve heavily around treatment and practical matters. Mneme creates the time and space for people to express their love, gratitude, or anything else they need by talking about their life together and recreating it in a tangible way.

This time is an opportunity to have open, honest conversations that can deepen the relationship and bring a sense of peace and support. The association cards provide a starting point, as it is sometimes difficult to find the time, start these conversations or even be aware that these conversations should be held. The memory book acts as an “aftercare” [50] by helping participants frame their experience and organise their thoughts while creating something tangible that can be kept as a keepsafe.

# how it differs from existing solutions

From the analysis of the available products, resources or activities that already exist in the end of life industry (Chapter 7), it was found that they focus heavily on the practical aspects of dying, how to plan final affairs and wishes, and how to talk about illness and death. The solution I propose focuses on talking about life.

The solution is a legacy making activity, but it differs from existing ones because it addresses problems that current legacy making activities have and that were also analysed in Chapter 7. The association card game provides a way to start conversations and gives structure to what (not) to talk about, who is leading the conversations, and removes some uncertainty so that families do not feel overwhelmed and intimidated. Another issue is that the activities should be offered earlier in the course of the illness [38], which is addressed in the proposed solution through the use of phrases that are not associated with end of life and can therefore be introduced earlier. In addition, the activity was designed to require little to no effort from medical staff and therefore they do not need to be trained or spend additional time to promote the activity. Finally, there is a need to vary the activities to make them more individualised [38]. The association card game offers individualization as the illustrations evoke memories based on how people interpret the illustrations depending on their experiences and life. The memory book offers many mediums for people to express themselves in different ways, depending on what suits them best.

# association card game

## Introductory cards

There are four introductory cards. (Figures 17A & 17B) The first two explain what the game is and what its purpose is. By explaining the purpose, people might realise that they should talk to their loved ones about their time spent together, or if they already know that, it may help them convince their loved ones to talk about it. The other two introductory cards give a brief overview of how to use the association cards and the memory book.

INTRODUCTORY CARD

01

## What is Mneme?

Mneme is an activity designed to encourage people with a serious illness , regardless of life expectancy, and their loved ones to explore and discuss their time spent together.

It includes a set of illustrated cards to help reflect on life and memories through associations, and a memory book to create a physical representation of them. You can use the stories that come up during the card game as a starting point for creating the memory book.

You are offered several options that you can mix and match to create a custom experience that best suits your needs.

INTRODUCTORY CARD

02

## Why Mneme?

During a serious illness, conversations can revolve heavily around treatment and practical matters. Mneme creates the time and space for people to express their love, gratitude, or anything else they need by talking about their life together and recreating it in a tangible way.

This time is an opportunity to have open, honest conversations that can deepen the relationship and bring a sense of peace and support. Mneme provides a starting point, as it is sometimes difficult to find the time or start these conversations.

Figure 17A: Introductory Cards

INTRODUCTORY CARD

03

## How to play the game

There are three games you can play depending on your needs and situation:

1. **Quickstart (2+ players):**
   This is the easiest game and does not require much effort (read more on card 05).
2. **Advanced (2+ players):**
   This game requires a little more effort to make associations, but encourages communication and dialogue (read more on card 06).
3. **Solo (1 player):**
   This game is played by one person to reflect on their memories (read more on card 07).

The rules for each game are contained in the following cards. However, if you find other ways to use the cards, you are welcome to break the rules!

INTRODUCTORY CARD

04

## How to create the memory book

You can use the memories shared during the card game as a starting point for creating the memory book. Start by writing down the memory and try to bring it to life by adding different elements (see the memory book for concrete examples and suggestions).

Try not to limit yourself to just the memories that were shared during the game, but also use them to reflect on moments or memories that are important to you and include those in the memory book as well. The main point is to create a tangible representation of your memories and time spent with your loved ones.

You can create the book with your loved ones or alone, immediately after the game or at a later date. It is up to you to create it the way you think and feel is best.

Figure 17B: Introductory Cards

## Game rules cards

There are four game rules cards. (Figures 18A & 18B) The first three contain the rules for the three different game versions (quick start, advanced, solo) and the third contains instructions on how to use the safety cards.

## Safety cards

There are two additional cards that help indicate whether a topic is sensitive and whether or not it should be discussed. (Figure 19) The cards are placed on the table and when a player needs to use one they can point or tap on the card.

GAME RULES

05

## Quickstart (2+)

1. To begin the game, shuffle the deck and deal 2 cards to each player. Players should not show their cards to each other. A draw pile is formed with the remaining cards.
2. Players look at the cards and try to associate a memory with a card.
3. Whoever associates a memory places the card face up on the table for the other players to see and shares the memory with as much detail as possible.
4. The other players can add their recollection to the memory or ask follow-up questions to turn it into a discussion.
5. When there is nothing left to add, the player who put the card down picks up a card from the draw pile, and the next player puts a card on the table and repeats the process.
6. The game lasts as long as the players wish.

GAME RULES

06

## Advanced (2+)

1. To begin the game, shuffle the deck and deal all cards to each player equally. Players should not show their cards to each other.
2. Players look at the cards and try to associate a memory with a card.
3. Whoever associates a memory places the card face up on the table for the other players to see and shares the memory with as much detail as possible.
4. Once the memory has been shared, the next player must place down a card that they somehow associate with the shared memory, sharing it with as much detail as possible and explaining how it is connected it the previous memory.
5. Continue the rounds in the same manner.
6. The game lasts as long as the players wish.

Figure 18A: Game Rules Cards

GAME RULES

07

## Solo (1)

1. To begin the game, shuffle the deck and place the cards face down to create a draw pile.
2. Pick up a card and try to associate it with a memory.
3. Think of as many details as possible (e.g. what happened, who was there, what could you see/hear/smell/taste/touch, how did you feel, what did you learn etc.)
4. Repeat the process with other cards.
5. The game lasts as long as you wish.

GAME RULES

08

## Safe Cards

There are two additional cards that help indicate whether a topic is sensitive and whether or not it should be discussed. The cards are placed on the table and when a player needs to use one they can point or tap on the card.

**Orange Card:** A player may use this card at any moment to indicate that a topic is sensitive, but that they are willing to discuss it in a cautious manner. The player describing the memory should be careful to phrase their words respectfully and not cross boundaries or cause tension.

**Red Card:** A player may use this card at any moment if they don't want to talk about a topic and wish to move on to another. The player sharing the memory should stop immediately and the next round can begin. Before the next round begins, check in on the players' emotions and discuss whether they need to take a break or end the game altogether.

Figure 18B: Game Rules Cards

Figure 19: Safety Cards

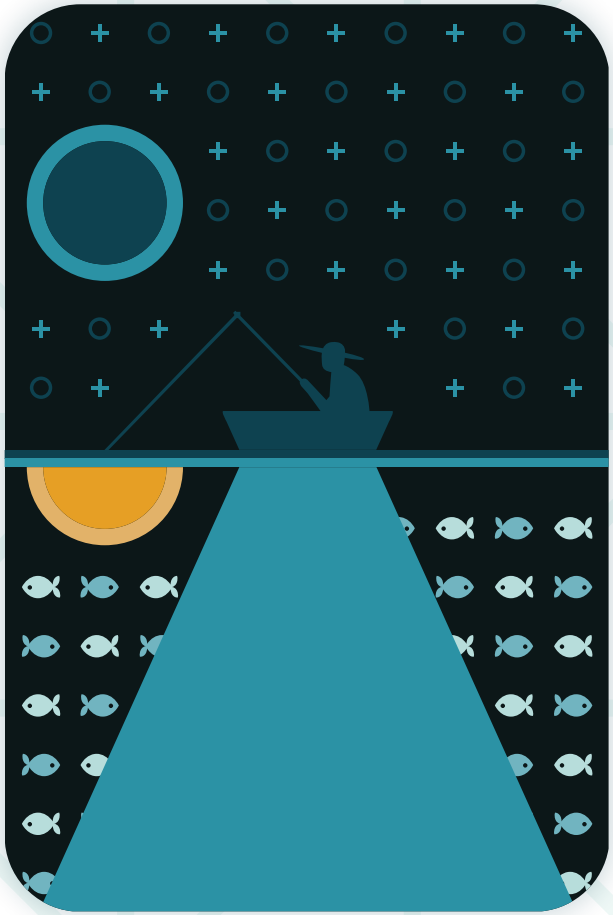
## Illustrated cards

The illustrated cards are the cards used to play the association game and share memories. A sample of 15 illustrated cards have been designed, to give an overview of the look and feel of the game. (Figures 20A-E)

## Back of the cards

On the back of the cards it is indicated what type of card it is (introductory, game rules, safety). The cards without indication are illustrated cards. The pattern used on the back of the cards represents in a minimal way the aim of the game, to draw connections between moments in their lives. (Figures 21A & 21B)

Figure 20A: Illustrated Cards



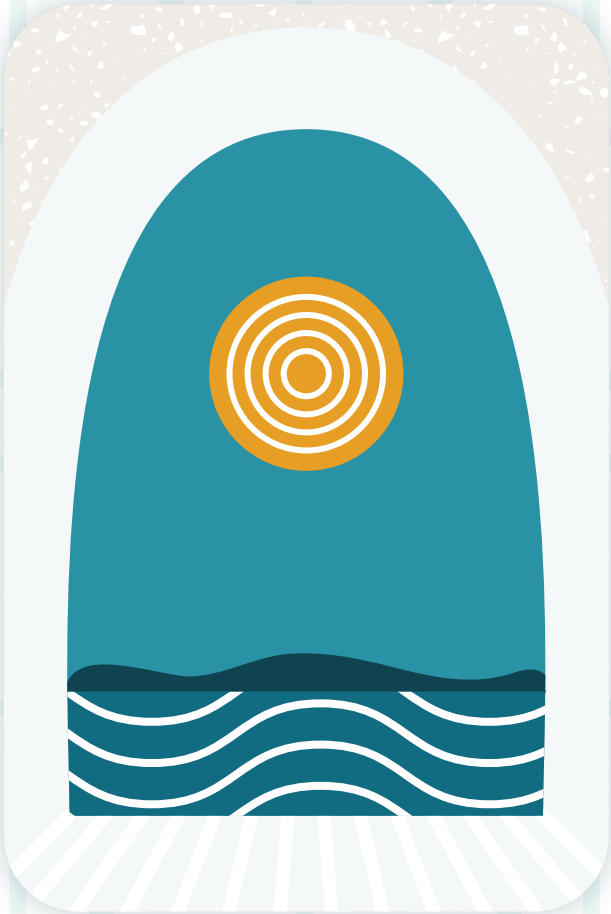


Figure 20B: Illustrated Cards

Figure 20C: Illustrated Cards

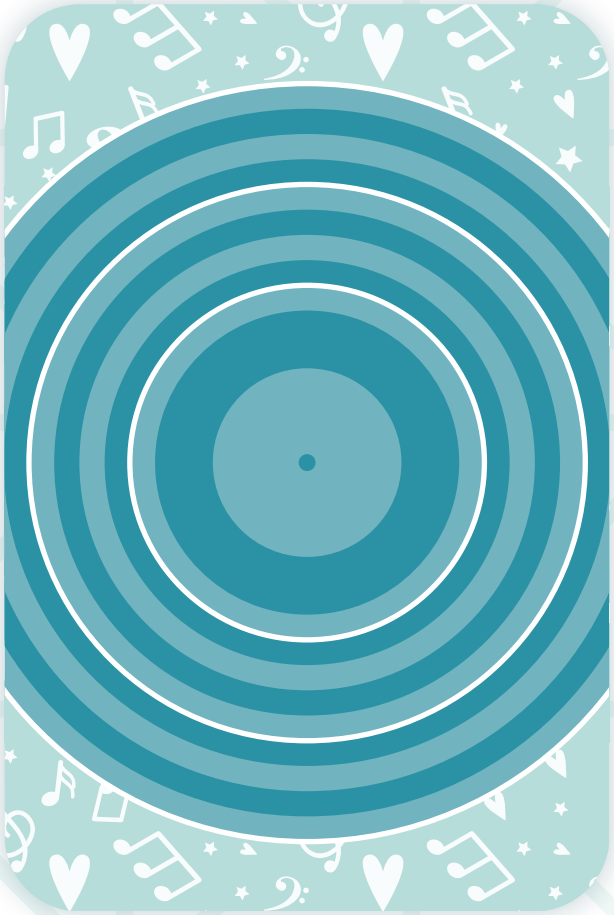


Figure 20D: Illustrated Cards

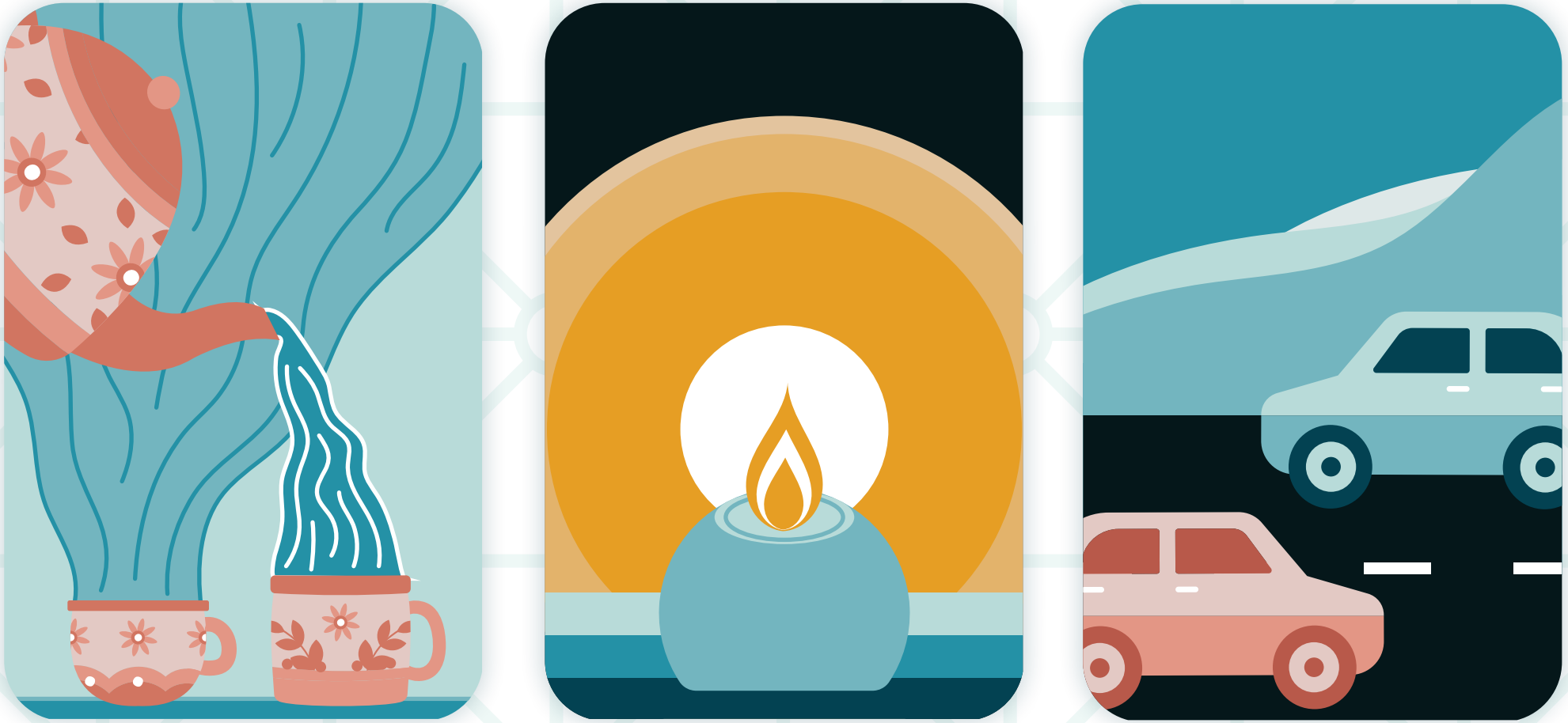


Figure 20E: Illustrated Cards

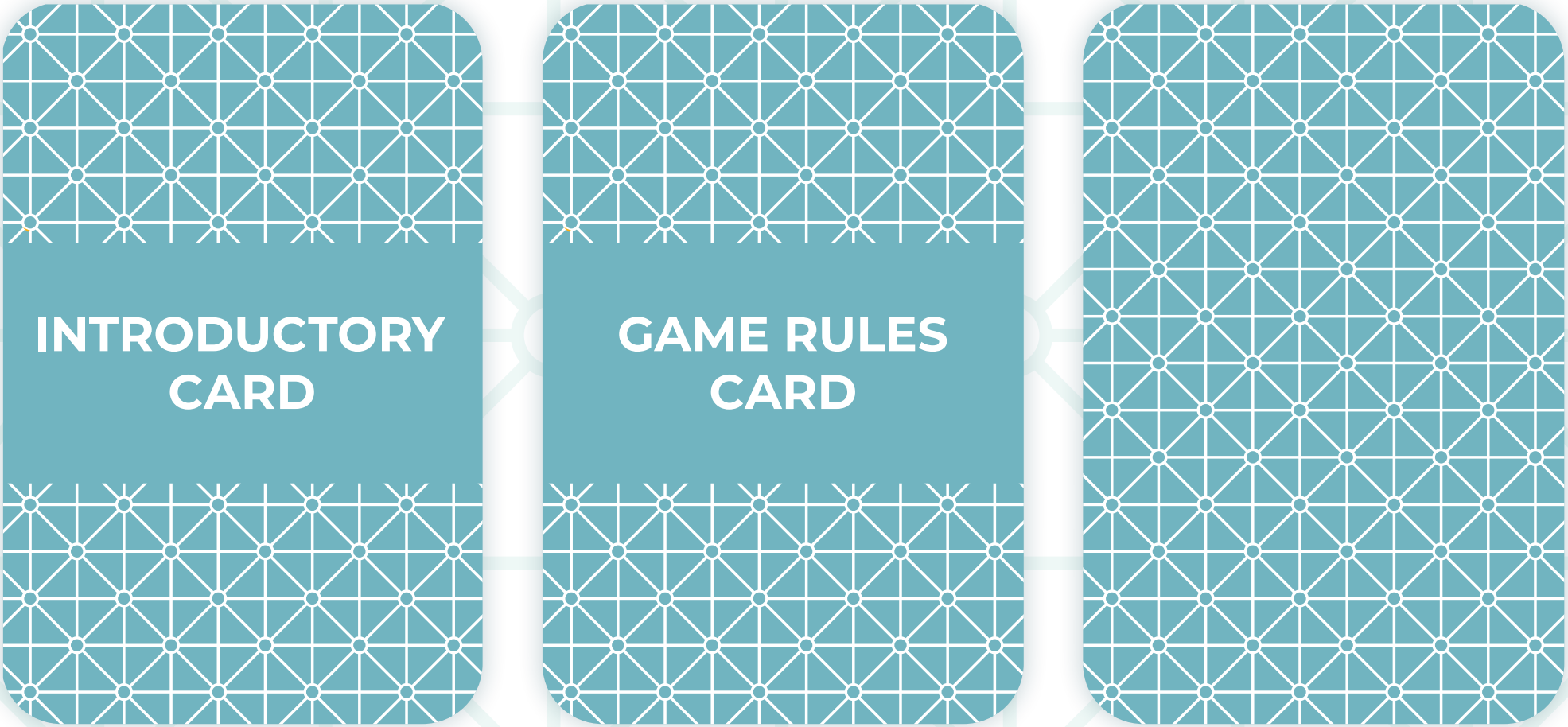



Figure 21A: Back of the Cards

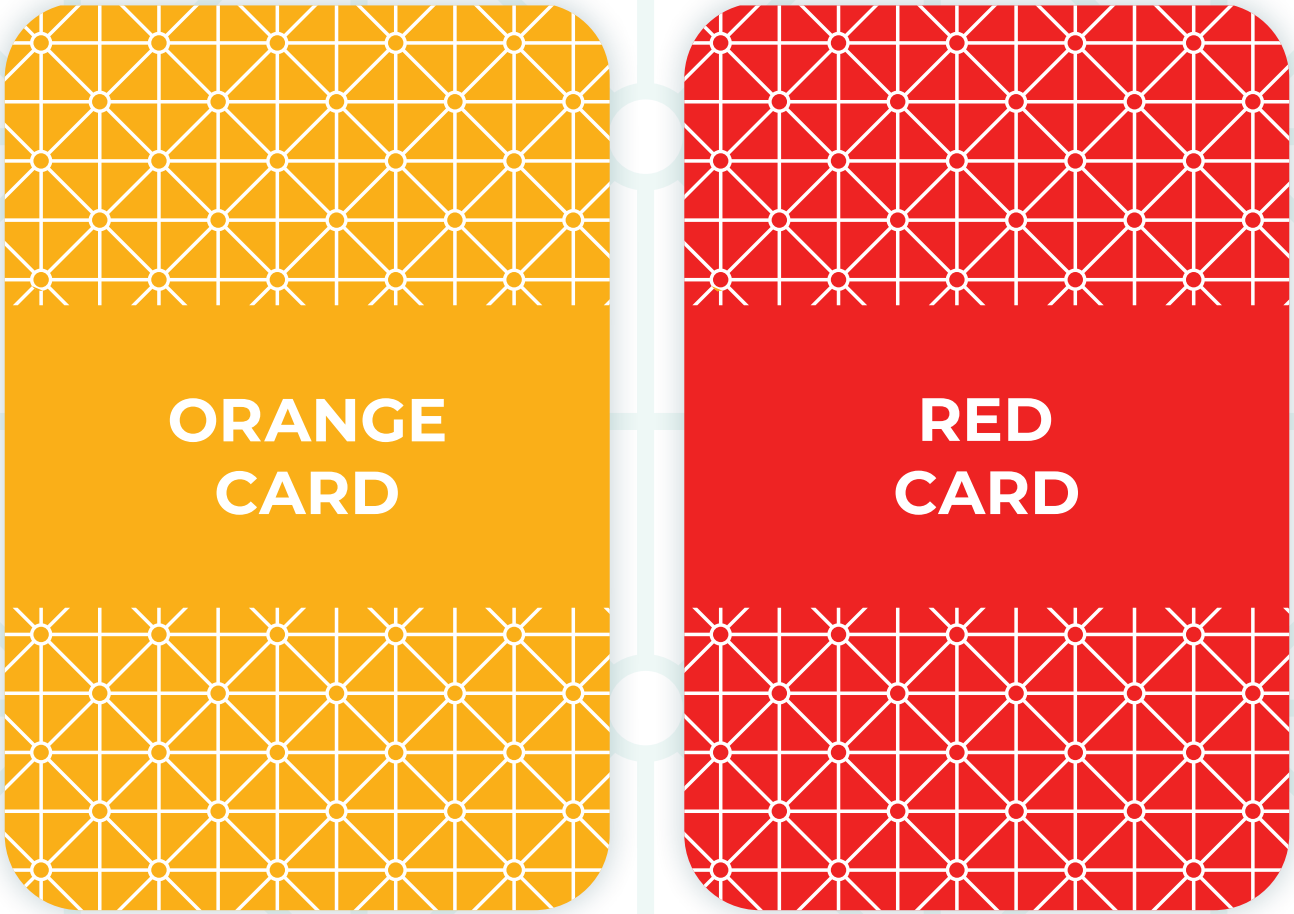



Figure 21B: Back of the Cards

# memory book

The memory book is a hardcover book (Figure 22) with blank pages so that people can create visual representations of their memories in it, and it also includes options for people to add audio and video toexpress themselves as they see best. Apart from the overview included in the introductory card of the association game, the first page of the book includes guidelines in how someone can fill in the memory book. There is a list of ways they can fill in their memories, as well as prompts to help them reflect on important moments and milestones of their life. (Figure 23)

The memory book also comes with sound modules for the ability to add short voice notes to the book, and small envelopes to add letters to be read in the future (such as special occasions) or small tangible items associated with the memory. (Figure 24) The back of the book has a built-in touch screen where people can add videos or pictures from their digital devices. (Figure 25)

In this way, a variety of options are given as to how the memories are expressed in the book, and through the different media, they are brought to life in many ways.

These ways of adding audio and video to printed matter already exist in another context. Sound modules are used in birthday cards, and some offer the ability to record your own audio/messages to personalise them. [51] Screens have been used with print products for promotional purposes (video brochures) or for special occasions (e.g. weddings). [52]

Figure 22: The memory book

# memory book

The purpose of the memory book is to co-create a visual representation of life and time spent toge-ther with your loved ones. Through this activity, you create new memories together while reminiscing about existing ones, and create a tangible artifact of your life.

The association game can be used as a starting point to decide what to include in the book. After the game, you can choose your favourite memories that you have shared and add them to the book. Use the stories as a starting point to reflect on your life and the moments that are most precious and important to you and add them to the memory book.

**Some moments you may want to reflect on are:**

- Childhood
- Accomplishments you are proud of
- Trips/Holidays
- Hobbies and interests
- Work
- Relationships/marriage
- Parenthood
- Family traditions
- Favourite family activities

Make sure to take your time, there is no need to hurry. Take the time to consider what you can add to bring your stories to life in a variety of ways.

**Below are some options and suggestions on what can be included, but the limit is your imagination!**

- A description of the story. Go into as much detail as possible - who was there, what happened, what did you do, how did you feel, what did you sense and so on
- Anything in written form: notes, quotes, poems, recipes, advice, etc.
- Sketches, drawings, paintings
- Photos
- A collage from magazine and paper clippings
- You can use the envelopes to add small items/memorabilia
- You can use the envelopes to add letters/notes to be read in the future, such as a special occasion like a birthday, anniversary, graduation, etc. (be sure to write next to it when it is to be read and by whom).
- You can add audio notes, up to 2 minutes, with the sound modules provided. Read more about how to use them in the following pages.
- You can transfer videos or images from your digital devices to the video album at the end of the book. Read more about how to transfer and view your videos in the following pages.

You can either fill this book in with important moments/milestones or keep adding memories based on the stories you reminisce about while playing the association card game. You decide when the memory book is complete!

Figure 23: First page with guidelines

Figure 24: Memory book example with text, sketches, photos, objects and audio

Figure 25: Back of book with built-in screen for videos

# helping people through the grieving process

Circling back to the starting point of this project, the solution provided could help people through the grieving process as analysed below.

First, it can help family members go into the grieving process without regret because nothing has been left unsaid, and that can help them move on after the death. In the aftermath of death, people tend to remember and reflect on their final interactions with their loved ones, and so communication during this time can have the greatest and most lasting effect on family members. [3]

Open, honest end of life communication helps people express their feelings and wishes, and feel understood and supported. This communication is crucial to a “good death” that can bring comfort and peace to family members. “True regret comes from what is not communicated at the end of life.” [3] The association cards create a starting point for these conversations and encourage communication between family members at the end of life.

The creation of the memory book, also encourages communication and helps people interact and spend quality time together at the end of life. The memory book provides a tangible way to remember the deceased and the family members can connect over it and continue creating it together even after their loved one has passed. It can also help future generations “connect” with their ancestors.

The memory book can be related to the Continuing Bonds Theory which states that “healthy grievers do not resolve grief by detaching from the deceased, but establish a new relationship with the them. The deceased do not disappear from our lives. They are still beloved members of our families, still beloved friends. We learn new ways to relate, and the relationships continue as we continue, grow and evolve.” [53]

CHAPTER 11

# reflection

# reflection on the process

At the end of a project it is always a great learning experience to see where one started and where they ended up. As mentioned at the beginning of this paper, I decided to research this topic to see how we can use design thinking to change the mindset around death and encourage people to be more open about discussing this topic and be prepared for this natural part of life. Although this is an extremely important topic and there is still a lot of work to be done in the field of death education to change this mentality, through research I discovered an opportunity that led to a solution that encouraged talking about life rather than death.

In the case of terminal illness people know that death is near. Even if one is in denial, much of daily life revolves around this fact, even if the word “death” is not uttered. This is a time that offers the opportunity to say all that needs to be said, to go into the grieving process with a sense of closure and the assurance that the loved one knew they were loved, appreciated, forgiven, given the opportunity to forgive, and so on. People regret the things they didn’t get a chance to say. So in this case, it is as important to talk about life as it is in life to talk about death.

I believe I have achieved my project and personal goals, learning important lessons that I can apply to my future work. First, I better understand the importance of having a structure and planning next steps, but also being flexible and able to adapt. Throughout the project, this combination of structure and flexibility helped me achieve my overall goals for the project. At the same time, my flexibility allowed me to react to anything unexpected and find the best strategies to achieve the desired goals and results in a realistic time frame.

I also now appreciate even more the value of communicating and talking about the results and process with others. Although this was a personal project, I had a number of people to turn to when needed. I had scheduled weekly meetings with fellow designers and classmates to discuss our progress and challenges, which helped me reflect on my weekly progress and also broaden my perspective. Meetings with my mentor helped plan actionable steps to achieve goals, even when obstacles arose, and find clarity through all the insights and information I gained during the process. Additional meetings with the supervisors and checkpoints with the rest of the class brought new ideas and perspectives to my process. Seeking advice from experts on topics I was not very familiar with helped me refine my concept. Overall, seeking help when needed or simply talking about  progress, plans, and challenges is a valuable source of inspiration.

Finally, when I first started working on the project, I was concerned that I would be biased because of my personal experience. Through research and interviews, my perspective was broadened and my focus shifted to the people I was designing for. This project has taught me how to use my experiences to empathise with others and understand the problem in a deeper way, while at the same time not taking them into account when making decisions and avoiding letting them influence my judgement.

# future developments & considerations

Besides the fact that I have achieved my goals for this project, I want to develop it further. My plan is to test it in real life scenarios to see how easily it can be implemented in people's daily lives and how they feel about it overall. Although I have tested the functionality of the activity and received feedback on the idea from people who are or have been part of my target group, I think that further testing in a real environment and over a longer period of time will help me refine and further develop the solution. Unfortunately, due to the limitations of covid-19, it was not possible to test in this way. However, I am in contact with experts who have expressed interest in testing and developing this idea further.

Another aspect I would like to explore, and based on the research it is a pain point that all legacy making activities have, is how the solution fits into the daily lives of people working in end of life facilities. Although it requires little to no effort on their part, it is important that staff advocate and support these types of activities and raise awareness of their existence and importance.

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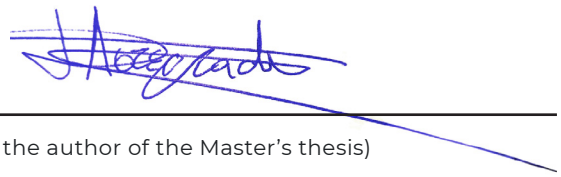

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