creating room for anticipatory grief

enabling adult children to reflect on the impact of having a parent living with dementia

Master thesis by
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End of Life Lab

TU Delft | Industrial Design Engineering

colophon

Creating room for anticipatory grief: enabling adult children to reflect on the impact of having a parent living with dementia

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Contribution
This graduation project will contribute to the **Design for End of Life Lab** which explores how design can contribute to the quality of life in its last stage. The research and design from the lab focusses both on the person facing the end of its life and also the social context such as friends, family and formal and informal caregivers into account.

preface

Dear reader,

I am happy to share my graduation project thesis with you. This project marks the end of my time as an industrial design engineering student at TU in Delft, which started in 2015. As a first-year student, I entered the world of product design, or so I thought. Over the years, my interest, passion, and knowledge have grown in contributing to a better world by tackling social issues with creative design power. During the master's program in Design for Interaction, it became clear where my drive as a designer lay: with people. Specifically, with people's feelings, values, motives, reasons and the context where they live in. That is why I am very pleased that I was able to conclude these memorable years with these personal, impactful, and above all, socially important topics: grief and dementia.

Let me start by stating that I could not have completed this project without the many people who have directly and indirectly contributed:

During my internship period prior to this project at the social design agency Afdeling Buitengewone Zaken, I had the opportunity to participate and speak with people in several projects on the theme of grief. I was moved by the fact that grief is an experience that is common to all of us, yet we often find it difficult to handle gracefully. Where is the room for grief in our society? I want to thank each individual in the team of this agency for motivating me to find my own path in graduating and for the growth I have experienced as a designer.

From the moment I approached my coaches Marieke and Caroline, I knew I could share my motivation for the subject of grief with them. I want to thank Marieke for sharing personal stories, providing critical and careful guidance during the writing process, and offering new insights for both my project and myself as a human being. I would like to thank Caroline for her endless enthusiasm during the iteration steps, for providing perspective with a sharp eye when I could not zoom out, and for the positive motivation she gave me.

A huge thank you to the many participants on whom this project is founded. Without their time and the personal and intimate stories they shared with me, the project would not have come to where it is now. The conversations stay with me, and I find it incredibly valuable that I have been able to take a glimpse into the lives of those who have a loved one with dementia and the care surrounding it.

In addition, I want to give many hugs to my friends and family. Hugs for cooking for me, proofreading chapters, distracting me with something fun, listening to my stories, and the endless support I have experienced. In particular, it was outstanding to work so closely with Nina and Anna in each other's projects, to study together, and to continue motivating each other throughout our graduation projects. Thank you for your unconditional support, dear Pepijn, in whatever form it may have taken!

Dear Dinet, the unexpected loss of you as a unique aunt in 2018 has had effects on my life until today. But now mainly in the form of creativity, a positive perspective on life, and unconditional love.

Dear grandpa, for over eight years, you fought against the severe effects of Alzheimer's disease. How dementia changed you, how our family felt increasingly powerless against the progressive disease in your brain, and how we ultimately said goodbye long before your death in 2021.

These two experiences served as an encouragement for me to make a difference as a designer.

And for you as a reader, I hope you become inspired, get lost in the wonderful world of dementia, and are open to giving grief more space in our society.

Enjoy the read!

Maureen

M

Figure 01: *Grandpa with granddaugther Maureen (2020)*
In Memorium: Albert 1941 – 2021

Figure 02: *final design: grip*

abstract

Dementia is a part of our society. One in five people, and for women even one in three, will develop dementia. Dementia has a significant impact on the lives of those affected, as well as their loved ones. This design project focuses on the impact of dementia on the adult children of a parent with Alzheimer's disease.

Once a parent is diagnosed with dementia, a complex situation occurs that forces the adult child to adapt to - and cope with - this new situation. A situation in which three processes can be distinguished: dementia and its effects, the social connection(s) between them or others and the grieving processes. These three processes create a complex reality as each of them are unpredictable, unique to the individual, and influences and intertwines with the other processes. To understand and to design for this complex world; several research and design activities have been conducted to map this context that the child and parent with dementia are in. These activities aimed at involving the perspective and experience of both experience and dementia experts.

Due to Alzheimer's, the brain cells of the parent are damaged, affecting their behavior, thinking, and emotions. There are three stages, in which the parent first mentally and later physically deteriorates. The dementia in the parent's brain brings many changes and losses, especially of great impact on the adult child in the long term.

It is noteworthy that there are many formal caregivers involved in the care of the parent with dementia. The experience of support provided by these formal caregivers to the adult child depends on the individual characteristics and approach of the caregiver. There is a clear need from the perspective of formal care for tools and strategies to better understand and support the loved ones of the patient. Within the informal social circles of the adult child, differences in coping mechanisms can sometimes manifest themselves in not experiencing the desired support.

Because grief is often associated with loss through death, anticipatory grief that accompanies dementia does not always receive the attention it deserves. Anticipatory grief for the adult child is unique to the individual, unpredictable, and ambiguous. Providing space for this form of grief is crucial because it can lead to a healthier and less intense grieving process after the parent's death. Talking to others, sharing experiences, acquiring knowledge, and having social support are all important factors in creating this space.

The exploration of these three processes through various research activities has led to the discovery of a phenomenon: the "period of acknowledgement". This period is characterized by the realization of the adult child that dementia is a progressive disease that cannot be avoided. They also come to understand that it is the disease that is changing their parent, and not the parent themselves. Acquiring knowledge about dementia and grief, and reflecting on their personal experiences, is essential in developing this period of acknowledgement.

The design goal for this project is based on this period of acknowledgement: "**to enable the adult child whose parent is dealing with dementia to discover the impact of the dementia on themselves with the help of knowledge about dementia and grief, thereby increasing the awareness and creating more room to grieve over time.**"

Various ideas were generated in brainstorming sessions, translated into physical prototypes to be tested with adult children, and further developed in co-creation. These design activities resulted in the development of a tangible reflection tool called "grip", which aims to provide space for adult children to explore and share their personal experiences and emotions related to the impact of dementia on their lives.

The grip tool facilitates conversations between the adult child and a conversation companion with tangible words to visually represent experiences, emotions, and losses related to dementia. It allows for the exploration of coping strategies and the development of new ways of coping, and it aims to provide social support and space for the adult child to share their grief. Overall, the grip tool aims to enable the adult child to better understand the impact of dementia on their lives and increase their awareness, creating more room to grieve over time.

However, further research will be needed to test and improve the impact of grip. Design recommendations for improving the tool have been given, such as simplifying the design, improving usability, testing with people in the avoidance phase, testing the effect on the long term, and creating a more inclusive design. In addition, suggestions have been made for implementing grip in the future.

Before reading,

A brief explanation of the usage of terms and the structure of the report will be provided to facilitate its readability.

Glossary

This project is about brain diseases dementia, one affected with a type of dementia is a **person with dementia** or a **person living with dementia**: first the individual, the disease follows. Since one is not the illness, one has the disease.

A **parent** or a **parent with dementia** refers to a person with adult children.

A person above 18 years old whose parent has dementia is referred to as a **child** or **adult child**.

Grieving itself refers to all forms of grief caused with any type of loss and is not only an emotional reaction to a death-related loss.

Grieving before an object is lost, as in the case of learning of an incurable illness, is known as **anticipatory grief**.

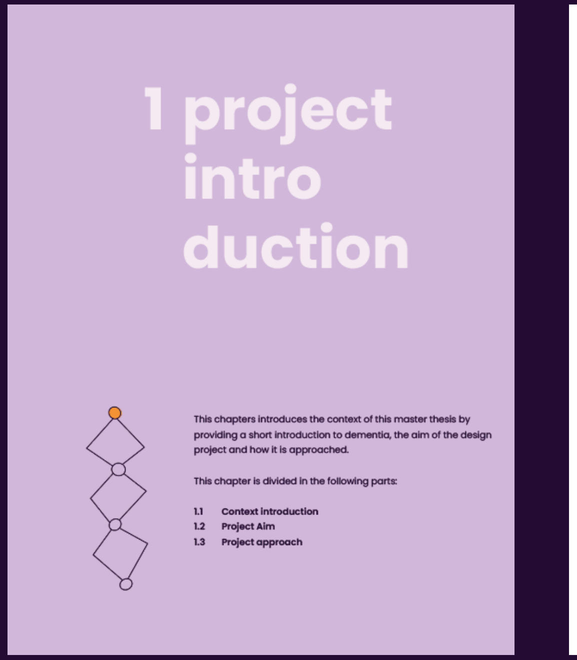
Formal care is provided by educated and paid care professionals.

Informal care is provided by informal carers, like relatives or loved ones, and volunteers, or unpaid care.

Reading guide

The report is structured according to the phases in which the project was approached (chapter 1.3). Each chapter starts and ends with the following pages:

For a quick read: the intro and outro pages give a brief summary of the project.



1 project intro duction

This chapters introduces the context of this master thesis by providing a short introduction to dementia, the aim of the design project and how it is approached.

This chapter is divided in the following parts:

- 1.1 **Context introduction**
- 1.2 **Project Aim**
- 1.3 **Project approach**

project introduction

1.1 context

Currently, more than 250.000 people live with **dementia** in the Netherlands. This amount will double the next decennia as a consequence from the increasing aging in our society and increasing life expectancy (figure FIXME). It is expected that in 2040 more than half a million Dutch people will have dementia. Therefore, everyone will experience dementia in their environment at some point; dementia affects one in every five persons. For women, it is even one in three. Dementia is part of our society.

A person and their loved ones experience **anticipatory grief** when learning of a diagnosis of dementia. Saying goodbye and grieving starts long before one loses their loved one to death, this is anticipatory grief. One's loved one becomes less and less like the person one once was due to the effects of the illness and one can have less and less contact with this person.

Actually, the development of dementia is an ongoing accumulation of **various kinds of loss**, which affects the anticipatory grief. Losses for the person with dementia and losses for the loved ones around this person. Cognitive decline, loss of personal autonomy, lack of insight and coping with complex behaviours makes it difficult for loved ones and the person with dementia to grieve together. They have both different experiences and different losses to cope with.

Many studies concentrate on the experience of dementia patients themselves. Regarding the loved ones – so also the adult children of – , the main focus in these studies is frequently how to manage the patient with dementia or how to prepare for and provide care for the disease's later stages. Less research has been done on how loved ones handle the emotional and personal process of anticipatory grief.

Figure 01: Growing number of people with Dementia (Alzheimer Nederland 2019)

14

Concluding project introduction

The lives of both the patient and their loved ones are affected by the brain disease Dementia. Anticipatory grief is experiecend since dementia includes an accumulation of changes and losses, and due o the progession of the disease one can anticipate on a future loss to death. This project focuses on the adult child whose parent lives with dementia and aims to give their anticipatory grief more room. Three phases – understand, explore and finalize – are being used to approach the project, during which various research and design activities have been conducted. To have a valuable impact on the potential end user, this project involved the perspective and experiences of multiple experts.

Key take-aways

- The lives of both the patient and their loved ones are affected by the brain disease Dementia. Anticipatory grief is experiecend since dementia includes an accumulation of changes an
- d losses, and due o the progession of the disease one can anticipate on a future loss to death. This project focuses on the adult child whose parent lives with dementia and aims to give their anticipatory grief more room.
- Three phases – understand, explore and finalize – are being used to approach the project, during which various research and design activities have been conducted. To have a valuable impact on the potential end user, this project involved the perspective and experiences of multiple experts.

Intropage

This page shows the title of the chapter, gives a brief introduction and lists the subchapters. The visual on the intro page indicates in which project phase it was executed. An explanation for this process visual, see figure 05 in chapter 1.3.

Midpage

These pages broadly elaborate on the activities, findings and insights. The left upper corner shows the current chapter, the right upper corner shows a visual cue.

Outropage

Every chapter concludes with a summary and main take aways.

Take-away references

Throughout the report, **roman numerals (I)** indicate the research key take-aways. Design key take-aways are indicated with **letters (A)**. This enables reffering to these insights in the design phase (chapter 3, 4, 5, 6 and 7).

table of content

04 Preface

06 Abstract

08 Before reading
- 08 Glossary
- 09 Reading guide

10 Table of content

12 1 Project introduction
- 14 1.1 Context introduction
- 15 1.2 Project Aim
- 16 1.3 Project approach

24 2 Understand
- 26 2.1 An introduction to the contextual analysis
- 30 2.2 Dementia
- 40 2.3 Social connections
- 50 2.4 Grief
- 70 2.5 Journey of the child

86 3 Define
- 88 3.1 A found phenomenon: period of acknowledgement
- 92 3.2 Design goal
- 94 3.3 Aspects of design goal and its desired effect

98 4 Explore
- 100 4.1 An introduction to the exploring phase
- 101 4.2 Ideation
- 104 4.3 Conceptualization

108 5 Decide
- 110 5.1 Concept choice
- 113 5.2 Concept iterations

118 6 Finalize
- 121 6.1 Introduction to grip: a tangible reflection tool
- 123 6.2 Desired journey
- 130 6.3 Key aspects of grip
- 132 6.4 Interactables: elements of grip explained

142 7 Conclusion
- 144 7.1 Evaluation of grip
- 148 7.2 Future of grip

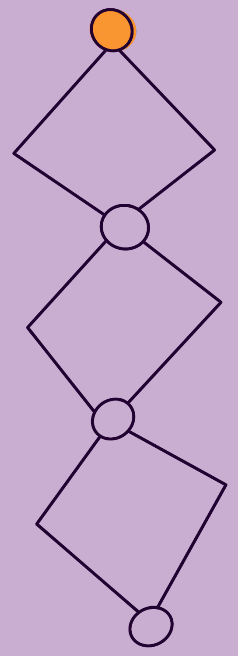
154 Epilogue

156 References

Appendices

The appendices can be downloaded as a separate document from the TU Delft repository.

1 project intro duction



This chapter introduces the context of this master thesis by providing a short introduction to dementia, the aim of the design project and how the project is approached.

This chapter is structured in the following parts:

1.1 Context introduction
1.2 Project Aim
1.3 Project approach

1.1 context

Currently, more than 250.000 people live with **dementia** in the Netherlands. This amount will double the next decennia as a consequence of the increasing average age in our society and increasing life expectancy (figure 03). It is expected that in 2040 more than half a million Dutch people will have dementia (Alzheimer Nederland, 2021). Therefore, everyone will experience dementia in their environment at some point; dementia affects one in every five persons. For women, it is even one in three. Dementia is part of our society.

A person and their loved ones experience **anticipatory grief** when learning of a diagnosis of dementia. Saying goodbye and grieving starts long before one loses their loved one to death, which is called anticipatory grief. The person with dementia starts to change and slowly lose the person it once was as an effect of the illness.

The development of dementia is an ongoing accumulation of **various kinds of loss** for both the person with dementia and their loved ones, which affects the anticipatory grief. Cognitive decline, loss of personal autonomy, lack of insight and coping with complex behaviours make it difficult for loved ones and the person with dementia to grieve together. They both have different experiences and different losses to cope with.

Many studies focus on the experience of dementia patients themselves. Regarding the loved ones - so also the adult children of the patients -, the main focus in these studies is frequently how to manage the patient with dementia or how to prepare for and provide care for the disease's later stages. Less research has been done on how **loved ones handle the emotional and personal process of anticipatory grief**

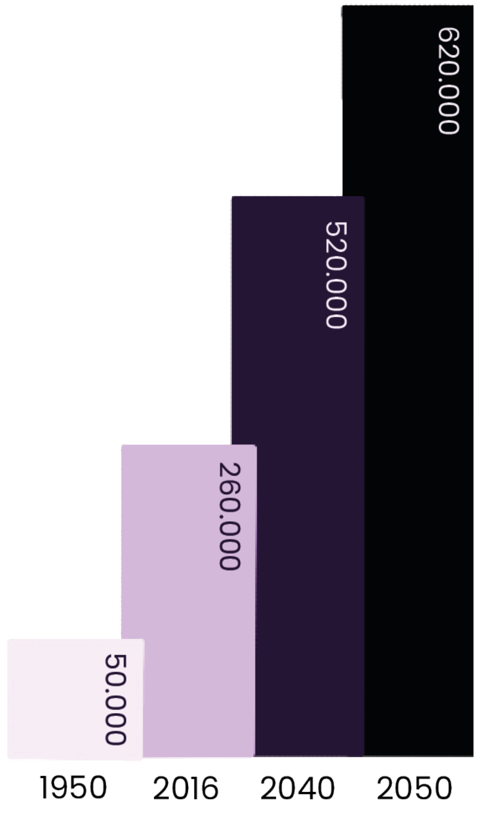


Figure 03: *Growing number of people with Dementia (Alzheimer Nederland 2019)*

project aim 1.2

When a person with (adult) children receives the diagnosis of dementia, they are frequently provided with an explanation for particular behaviours or issues. However, the diagnosis also impacts their children and raises questions and feelings with them. A complex situation occurs in which the physical and mental changes of the parent with dementia result in the need to arrange practical matters, in a changing parent-child roles and changes in personal characteristics.

An adult child must make numerous sacrifices and it has to take on responsibilities that have a significant effect on themselves and their lives. This forces the child to adapt to - and cope with - this new situation in which the child often cares for the parent with dementia in the role of informal caregiver. Even though the diagnosis is accompanied with an emotional grieving process, this new complex situation - and the adaptation to it - stands in the way of reflecting on what is happening on the deeper layers of grief. .

The process of losing a parent in small steps to dementia causes feelings that are comparable to a grieving process after death (Alzheimer's Society, 2021). However, **these feelings are often not recognized as grief**. As a result, a child may sometimes misunderstand their own reaction to the. Those around them do not understand or recognize their grief either. **The anticipatory grieving process is not socially accepted or acted up on** (Fulton, et al, 1996). While anticipatory grief and the space it is given have a significant impact on post-death bereavement (Nielsen et al., 2016).

This project aims to give this adult child's grieving more room as the disease dementia progresses. More specifically, it focuses on how design can increase the space for and improve the quality of the anticipatory grief of the child whose parent is coping with dementia (figure 04)..

Due to the aim of the research, the focus the experience of anticipatory grief of the dying person's relatives (children or grandchildren). The research was limited to adult children studies, and, as such, did not address research on the experience of the parent.

Figure 04: *Child with parent coping with Dementia*

1.3
project approach

The triple diamonds in figure 05 on the right is best used to describe the approach of this project. These three diamonds serve as a basis for describing the seven phases – and the corresponding chapters – (chapter 1.3.1), for explaining the conducted research and design activities (chapter 1.3.2) and for introducing the participants involved (chapter 1.3.3).

1.3.1 Triple diamonds

The following chapters are based on the project's seven phases, which are divided into:

1) **Introduction:** The starting point of this project, the context chosen, defined aim and approach of the project. See appendix 01 for the project brief.

2) **Understand:** The context of the potential users is studied to create a deeper understanding of the needs and opportunities.

3) **Define**: A design goal is formulated to define a direction for designing

4) **Explore:** Iteratively ideated, designed and tested possible interactions and solutions to reach the formulated design goal.

5) **Decide**: One concept direction is chosen to further develop, based on gained research insights.

6) **Finalize:** The concept is optimized by bringing it back into the end users context and integrating test conclusions into the design. A final design is visualized and prototyped.

7) **Conclusion**: The final concept is evaluated by testing it with the potential users. As a result, further recommendation for development and implementation are shared.

A more detailed planning can be found in appendix 02.

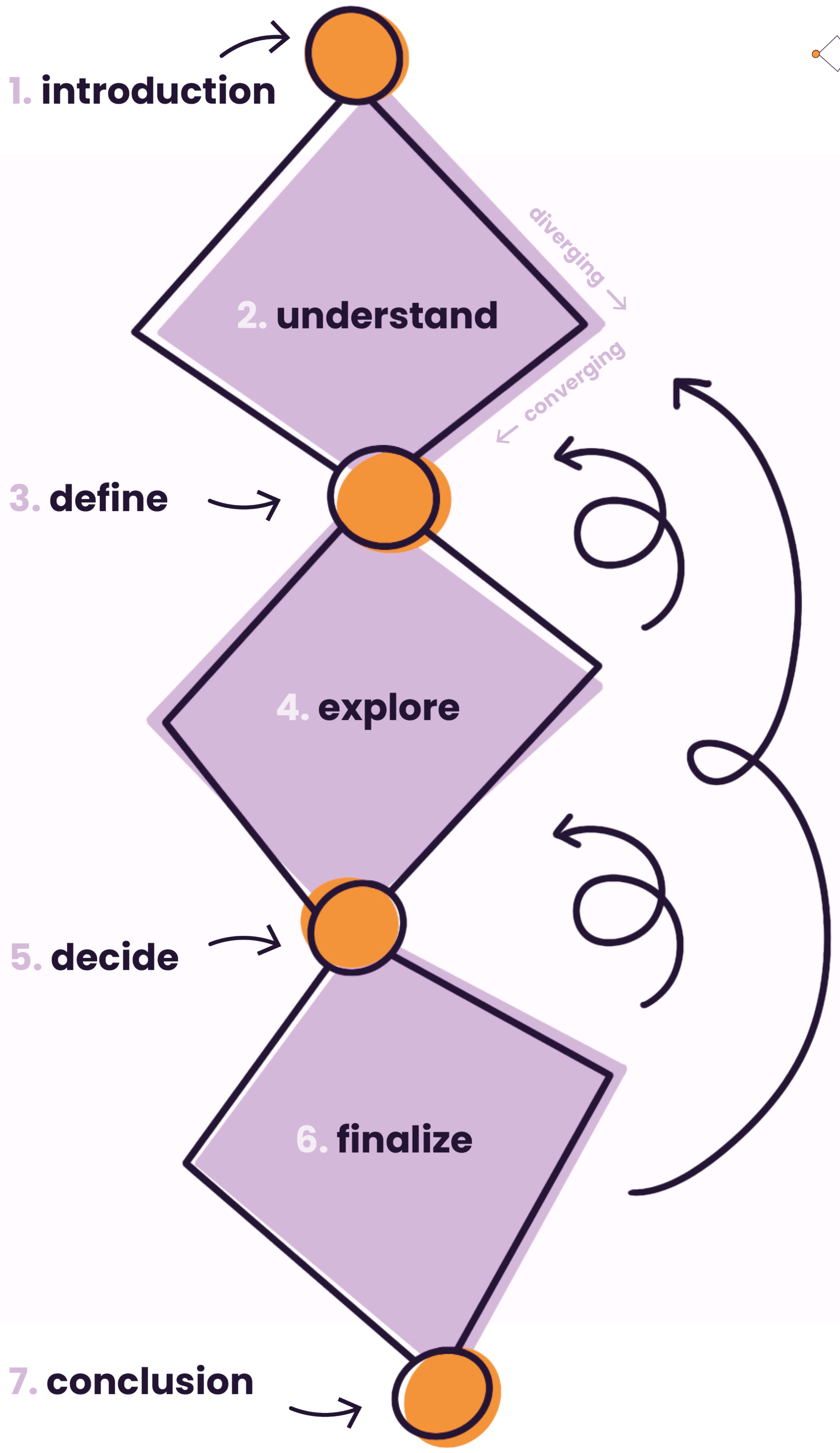


Figure 05: *Triple diamond design process*

1.3.2 Research and design activities

The three diamonds are filled with several research and design activities (figure 06). Interim insights and findings were integrated and validated in activities that followed. A brief explanation for each activity can be found on this page.

Before, during and after each activity, research questions were set up to construct the activities. Appendix 03 shows an overview of these research questions, chapter 2 elaborates on these questions.

Understand

Generative in depth sessions are conducted to explore the relationships between the progression of the dementia disease, the grieving processes of both loved ones and the patient, and the relationships between them and their social networks. These sessions are held with seven participants, people with a personal experience of a parent with dementia (Appendix 04).

In-depth interviews sessions are conducted with eight participants: people working in a day care centre for people with dementia, specialists who support informal caregivers, dementia case managers and more dementia professional disciplines (appendix 05).

Documentaries, such as Roosen & Borst and 'Gezichten met Dementie' are analysed in order to learn from every day experiences of relatives whose lives are drastically changed by dementia (appendix 07).

To empathize with the topic of grieving, different **podcasts** are listened, compared and reviewed (appendix 07).

Parallel to these research activities, **books, scientific papers and webpages** are studied to complement, confirm and enrich the collected data.

Explore

An **Alzheimer Café** is visited; a special edition where Adelheid Roosen & Hugo Borst host a discussion about saying goodbye and grieving related to dementia. Discussing and validating the found design direction with experience experts.

Individual brainstorm sessions are conducted multiple times, getting inspired by various activities and generating ideas by stimulating creativity.

Brainstorm sessions with fellow students are conducted to use the different perspectives and new energy to boost the design process in different phases

The use of different materials and techniques to build **low-fidelity prototypes** in order to test an idea, interaction or principle.

Co-reflection sessions with future users and fellow students is about ideating possible solutions that fit the design goal and presenting own idea directions in order to gain their opinions, findings and insights.

Co-creation sessions are held with future users and experts to reflect on the concept direction and further improve qualities with the use of experience and knowledge of these experts.

Small interactions, prototypes or idea directions are tested during **interaction tests** with fellow students or future users to gain insights in the usage.

Finalize

Again, small interactions are **tested in detail** in order to further improve the elements of the concept.

A **high-fidelity prototype** is built to demonstrate the actual design.

Validation tests are held with future users in order to test the design on its usage and interactions using the design goal's elements.

Recommendations explorations are defined in order to map out the possible improvements and opportunities.

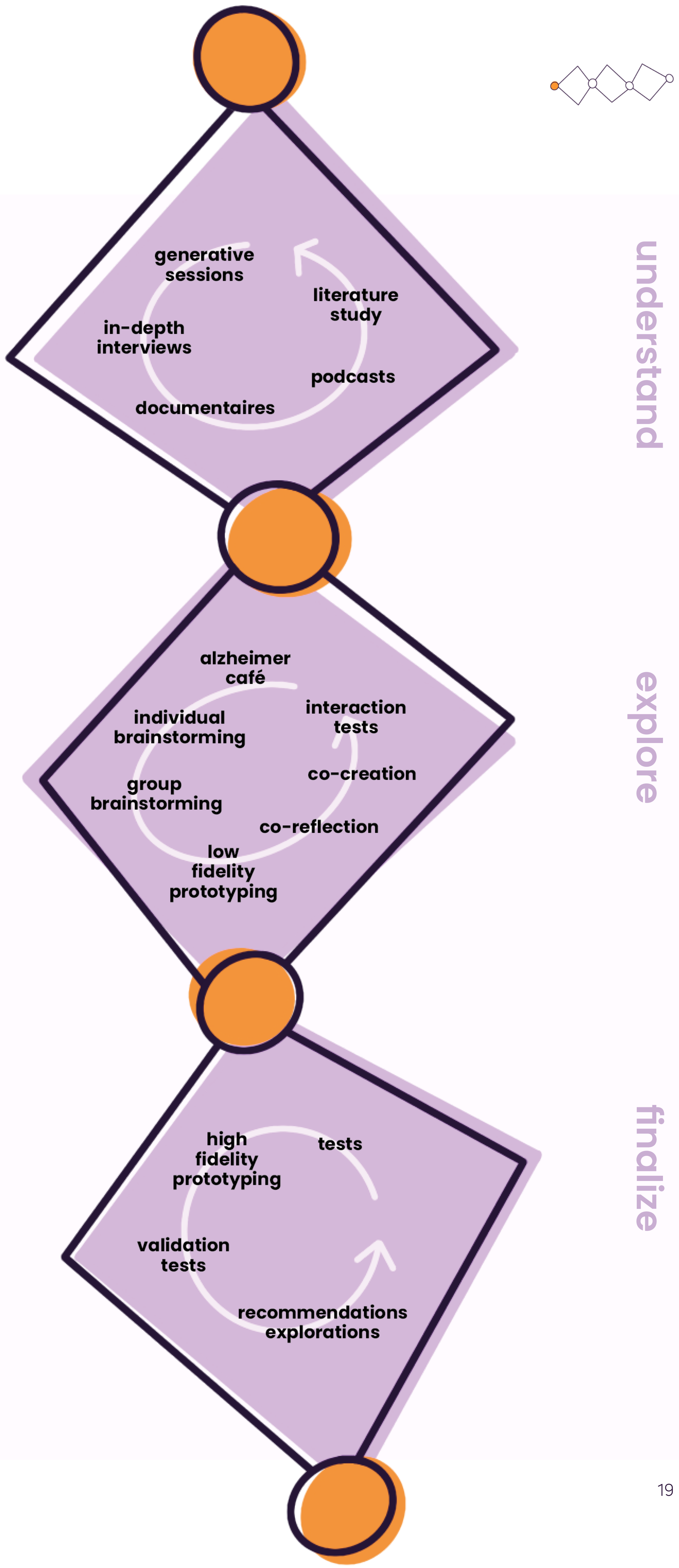


Figure 06: *Conducted research and design activities throughout each project phase*

1.3.3 Research and design participants

This project aims to involve the perspectives and experiences of experts and potential end users in each phase of the design process, as it is highly valuable for understanding and designing for the end user (Norman, 2013). These experts and users can be adult children with a parent with dementia, dementia professionals or previous researchers into this context of dementia and grief. Figure 07 provides an overview of who is involved during which phase. The corresponding code of letters and numbers refer to the participants when quoting them throughout the report, see legend on the bottom of the figure.

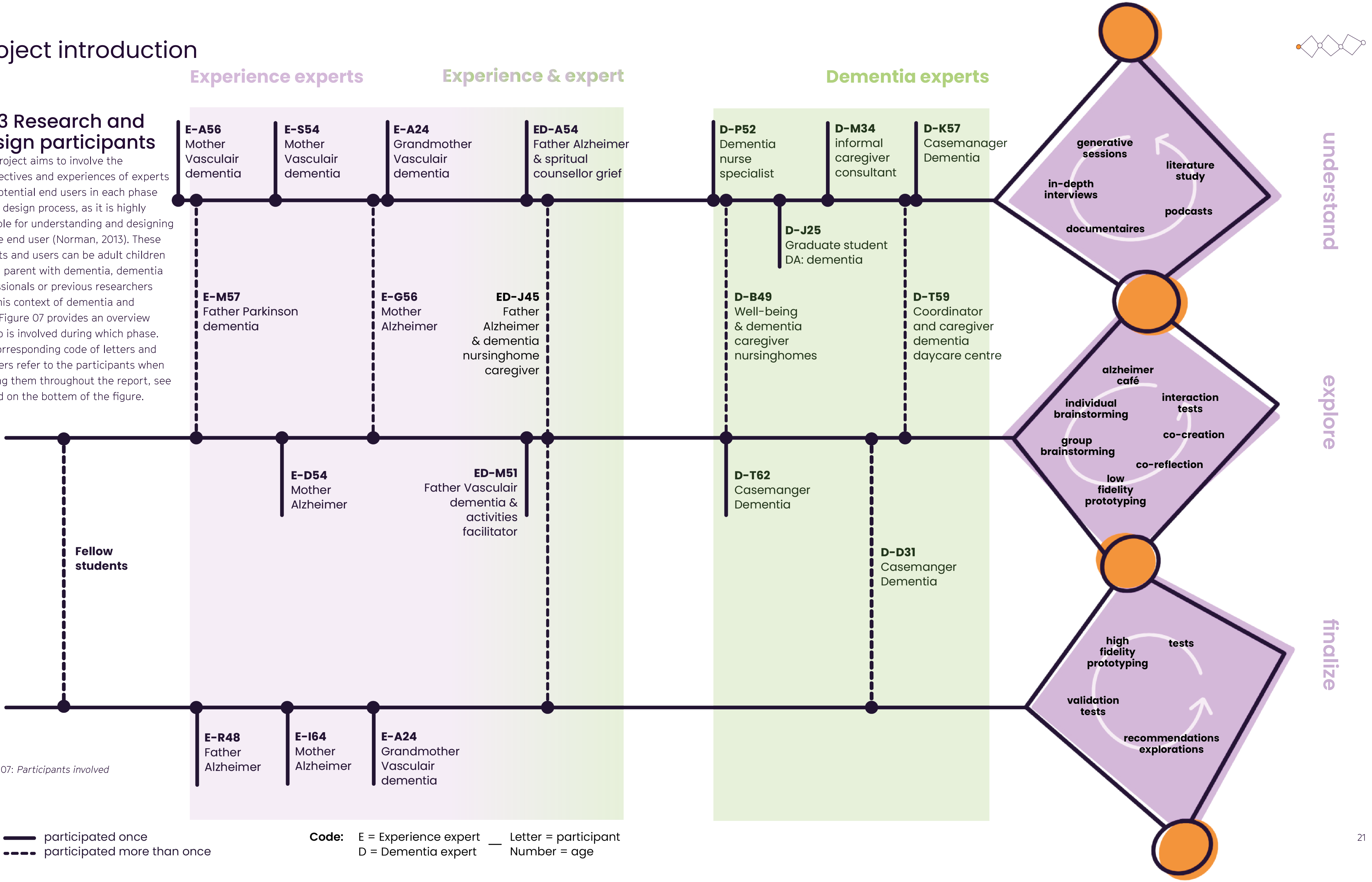
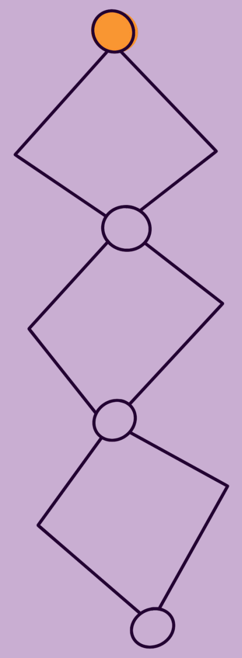


Figure 07: *Participants involved*

Concluding project introduction

The lives of both the patient and their loved ones are affected by the brain disease dementia. Anticipatory grief is experienced since dementia includes an accumulation of changes and losses, and due to the progression of the disease one has to anticipate on a future loss to death. This project focuses on the adult child whose parent lives with dementia and aims to give their anticipatory grief more room. Three phases – understand, explore and finalize – are used to approach the project, during which various research and design activities have been conducted. To have a valuable impact on the potential end user, this project involved the perspective and experiences of multiple experts.



Key take-aways

- This project focusses on **anticipatory grief**, which arises when gradually losing a loved one to the brain disease dementia.
- Project focus is on the **adult child** of a parent living with dementia.
- The research does **not address the experience of the parent**.

2 under stand

This chapter dives deeper into the context of an adult child having a parent living with dementia. Research questions and activities were set up to help guide this context analysis in three processes: the dementia, the social connections and the grief.

This chapter is structured in the following parts:

2.1 An introduction to the contextual analysis
2.2 Dementia
2.3 Social connections
2.4 Grief
2.5 Visual overview of context: journey of the child

An introduction to the contextual analysis 2.1

2.1.1 The complex reality arising when a parent is faced with dementia

As became apparent in the previous chapter, once a parent is diagnosed with dementia, a complex situation occurs that forces the adult child to adapt to - and cope with - this new situation. This chapter elaborates on three aspects of this new situation: the dementia and its effects, the social connection(s) between them or others and the grieving process (figure 08).

These three processes create a complex reality as each of them are unpredictable, unique to the individual, and influences and intertwines with the other processes. To understand – and eventually to design for - this complex world; several design research activities have been conducted to map this context that the child and parent with dementia are in (chapter 1.3.2). The contextual analysis is built upon the results of two main research activities: the **generative in-depth sessions** (appendix 04) and the **in-depth interview sessions** (appendix 05).

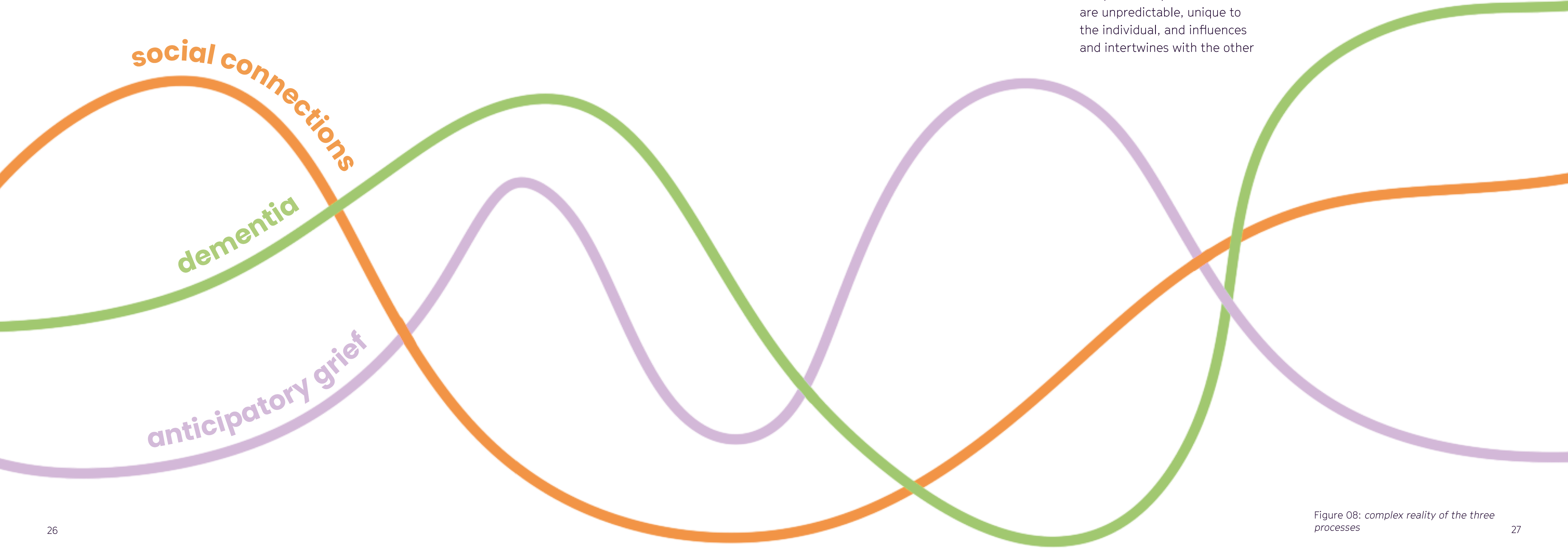


Figure 08: *complex reality of the three processes*

2.1.2 How to read this chapter

This chapter (2) is broken up into five sections; this introduction (2.1), three mid sections (2.2, 2.3, 2.4) and a conclusion section (2.5).

The three mid sections each explain one of the three aspects of the complex world (2.1.1). The mid section starts with an introduction bar in white that shows the research questions and ends with a conclusion bar that highlights the main insights and take-aways (figure 09). These five sections can be recognized by its background colour and contains the following subchapters:

2.1

This introduction

This white section introduces the complex reality and how to read on the next sections. It contains the following subchapters:

2.1.1 The complex reality
2.1.2 How to read this chapter

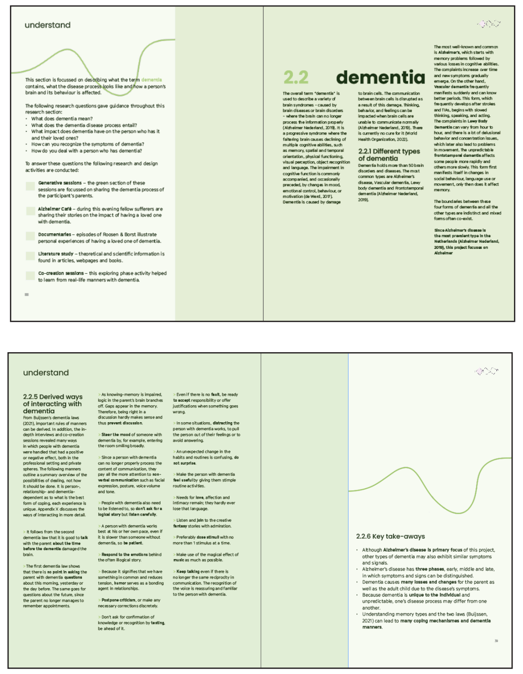


Figure 09: *Example on how to read a section: introduction bar at the start of the section and a conclusion bar at the end of a section*

2.2

Dementia section

The green section describes the brain syndrome dementia and its physical and mental effects. It contains the following subchapters:

2.2.1 Different types of dementia
2.2.2 Alzheimer signals related to loss
2.2.3 Stages of Alzheimer's disease
2.2.4 Dementia laws and types of memory
2.2.5 Derived ways of coping with dementia
2.2.6 Key take-aways

2.3

Social connection section

The orange section depicts the informal and formal social connections that surrounds the parent and the adult child. It contains the following subchapters:

2.3.1 Researching the impact of dementia on others
2.3.2 Circles of care
2.3.3 Key take-aways

2.4

Grief section

The purple section dives into the deeper layers of grief and how the parent and adult child are dealing with it. It contains the following subchapters:

2.4.1 Introducing grief
2.4.2 The room for grief in our society
2.4.3 Grieving as an integral growth model
2.4.4 When grief becomes complicated
2.4.5 The significance of emotions
2.4.6 Anticipatory grief: grieving before the loss
2.4.7 Accumulation of losses: anticipatory grief when losing a loved one to dementia
2.4.8 Importance of creating room for anticipatory grief
2.4.9 Loss of a parent
2.4.10 Losses for the adult child when having a parent with demetia
2.4.11 Key take-aways

2.5

Conclusion section

The white section summarizes the found insights and conclusions and translates this into a visual journey (figure 10). It contains the following subchapters:

2.5.1 Overview of the journey
2.5.2 A legend on how to read the journey
2.5.3 The journey of the child

Figure 10: *Visual of the conclusion section*

This section focusses on describing what the term dementia contains, what the disease process looks like and how a person's brain and its behaviour is affected.

The following research questions gave guidance throughout this research section:

- What does dementia mean?
- What does the dementia disease process entail?
- What impact does dementia have on the person who has it and their loved ones?
- How can you recognize the symptoms of dementia?
- How do you deal with a person who has dementia?

To answer these questions the following research and design activities are conducted:

Generative sessions – the green section of these sessions are focussed on sharing the dementia process of the participant's parents.

Alzheimer Café – during this evening fellow sufferers are sharing their stories on the impact of having a loved one with dementia.

Documentaries – episodes of Roosen & Borst illustrate personal experiences of having a loved one of dementia.

Literature study – theoretical and scientific information is found in articles, webpages and books.

Co-creation sessions – this exploring phase activity helped to learn from real-life manners with dementia.

2.2 dementia

The overall term "dementia" is used to describe a variety of brain syndromes caused by brain diseases or brain disorders where the brain can no longer process information properly (Alzheimer Nederland, 2019). It is a progressive syndrome where the faltering brain causes the decline of multiple cognitive abilities, such as memory, spatial and temporal orientation, physical functioning, visual perception, object recognition and language. The impairment in cognitive function is commonly accompanied - and occasionally preceded - by changes in mood, emotional control, behaviour, or motivation (de Werd, 2017).

Dementia is caused by damage to brain cells. The communication between brain cells is disrupted as a result of this damage. Thinking, behavior, and feelings can be impacted when brain cells are unable to communicate normally (Alzheimer Nederland, 2019). There is currently no cure for this disease (World Health Organization, 2022).

2.2.1 Different types of dementia

Dementia is a collective term and includes more than 50 brain disorders and diseases. The most common types are Alzheimer's disease, Vascular dementia, Lewy body dementia and Frontotemporal dementia (Alzheimer Nederland, 2019).

The most well-known and common type is **Alzheimer**'s, which starts with memory problems followed by various losses in cognitive abilities. The amount of complaints increase over time and new symptoms gradually emerge. Secondly, **Vascular dementia** often manifests suddenly and patients know 'better periods' in which the dementia is less apparent. This form, which frequently develops after strokes and TIAs, begins with slowed thinking, speaking, and acting. The complaints with **Lewy Body Dementia** can vary from hour to hour, and patients experience delusional behaviour and concentration issues, which later also lead to problems in movement. Lastly, the unpredictable **frontotemporal dementia** varies in the speed in which it affects a patient: with some more rapidly than others. This form firstly manifests itself in changes in social behaviour, language use or movement, after which it affect memory.

The boundaries between these four forms of dementia and all the other types are indistinct and mixed forms often co-exist.

Since Alzheimer's disease is the most prevalent type in the Netherlands (Alzheimer Nederland, 2019), this project focuses on Alzheimer.

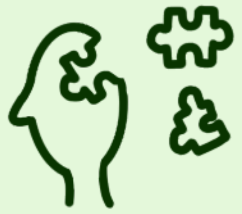
2.2.2 Alzheimer signals related to loss

Dementia is not always correctly or on time identified or diagnosed; instead, the symptoms are frequently mistaken for ailments associated with aging (Alzheimer Nederland, 2019). For this, a diagnosis is frequently given/made? when the disease has already been present for a while, despite the fact an early diagnosis of dementia has benefits such as;

- Dementia is often accompanied with other illnesses - such as depression, sleep disorders and intense fears - that can worsen the dementia. These can be treated and therefor improve general health.
- A diagnosis can tell which variant of dementia is found, resulting in the appropriate care for the patient.
- An early diagnosis gives space to the loved ones of the person with dementia to anticipate on the changes, losses and grief.
- A diagnosis can tell if the type of dementia is heritable, so family members can be spared from unneeded anxiety.
- The people around the person with dementia will (re)act with a greater compassion to the changing behaviour when they understand the cause of it.
- When dementia is diagnosed early, the affected person is often still capable of making crucial decisions for themselves, such as those involving financial matters, housing, wills or euthanasia.

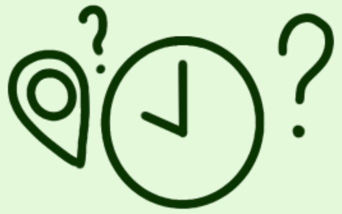
To enable early diagnosis of dementia, it is important to be aware of the dementia signals (Buijssen, 2019). Moreover, recognition of these signals is also extremely important for a dementia-friendly society (Alzheimer Nederland, 2019) and therefor to mention in this report. Furthermore, these symptoms and signals carry losses for both the parent with dementia and child and thus may affect their grieving processes.

Loss of memory:
New information, important data or events are forgotten, asking the same question again.



Loss of participating in social gatherings: Difficulty with social activities, initiate less than before.

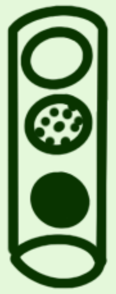
Loss of sense of place and time:
Less sense of time, frequently getting lost. Suddenly not knowing where you are anymore.



Loss of concentration and attention:
Focus issues and a decrease in interest in own surroundings.

Loss of using language right:
Difficulty with following a conversation, use of incorrect grammar, difficulty finding the right words.

Loss of judgement:
Trouble with assessing situations and making decisions



Losing things:
Losing items and being unable to locate them.

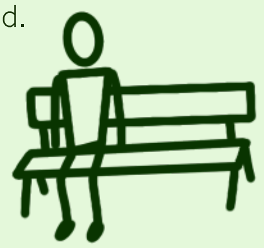
Losing track of household:
Wasting food, no longer or insufficiently cleaning or placing objects in odd places.

Loss of controlling own mood:
Agitated, depressed or suspicious mood signals for no direct reason.

Loss of rest:
A constant feeling of restlessness and the need to move around, sleeping problems is often a consequence.

Loss of sight:
Processing what or who someone sees is challenging, and depth perception is less accurate.

Loss of maintaining social contacts:
Social contacts and friendships are no longer maintained and dropped.



Loss of controlling behaviour:
Withdrawing, avoiding questions, haunting at night or becoming self-absorbed. Unpredictable behaviour like compliant one moment and a lot of resistance the next.

Loss of personal care:
Clothes backwards, shoes untied or clothes stained.

Loss of doing daily tasks:
ordinary everyday things and routines get progressively more difficult with the right order.

2.2.3 Stages of Alzheimer's disease

Dementia usually develops gradually. However, there are also cases where it develops more quickly, erratically or with a variable picture (Huijsman, 2019). Three phases of Alzheimer's disease can be distinguished according to Alzheimer Nederland (Alzheimer Nederland, 2019). Phases often overlap and some symptoms may or may not manifest themselves, so this does not imply that the disease course can also be captured in these three phases. However, the three phases are briefly explained since the symptoms and phases are used as starting point in the in-depth generative sessions (appendix 04) and during design exploration (appendix 05).

Early stage

Small changes in a person's behaviour or abilities are noticed in the early stages of Alzheimer's disease, a few signs:

- Forgetting recent conversations or events
- Repeating him or herself
- Understanding new ideas more slowly
- Become disoriented
- Speaking less fluently
- Finding it challenging to make decisions
- Losing interest in other people and activities

Middle stage

The changes intensify during the middle phase of Alzheimer's disease, and new symptoms may occur:

- Becoming upset, aggressive or suspicious more easily
- Attempting to flee or get lost
- Increasing disorientation
- Being confused about time
- Waking up in the middle of the night
- Endangering themselves or others due to forgetfulness
- Acting unusually
- Having troubles with perceptions, occasionally experience hallucinations

Late stage

At this point in the Alzheimer's' disease, the person requires even more assistance and gradually becomes totally dependent on others by:

- Having trouble with chewing and swallowing
- Losing a lot of weight despite eating sufficient
- Starting to become incontinent for both urine and feces
- Gradually losing speech, yells from time to time
- Getting restless, looking for something or someone
- Being sad or aggressive, particularly when feeling threatened

Figure 11: *Mapping the dementia stages in time in order to discuss moments of changes and grief with participants of the generative sessions*

2.2.4 Dementia laws and types of memory

Dementia laws

Several books about dementia have been written by Huub Buijssen, a psychogerontologist, former healthcare psychologist, and foremost expert on experience with a number of dementia cases in his close surroundings. As author of the book “Als een dierbare Alzheimer heeft” (Buijssen, 2021), he created two laws to explain the hidden logic behind the behaviour of a person with dementia. These laws offer a fundamental framework for understanding and dealing with dementia, as many of the advice on managing loved ones with dementia can be derived from them.

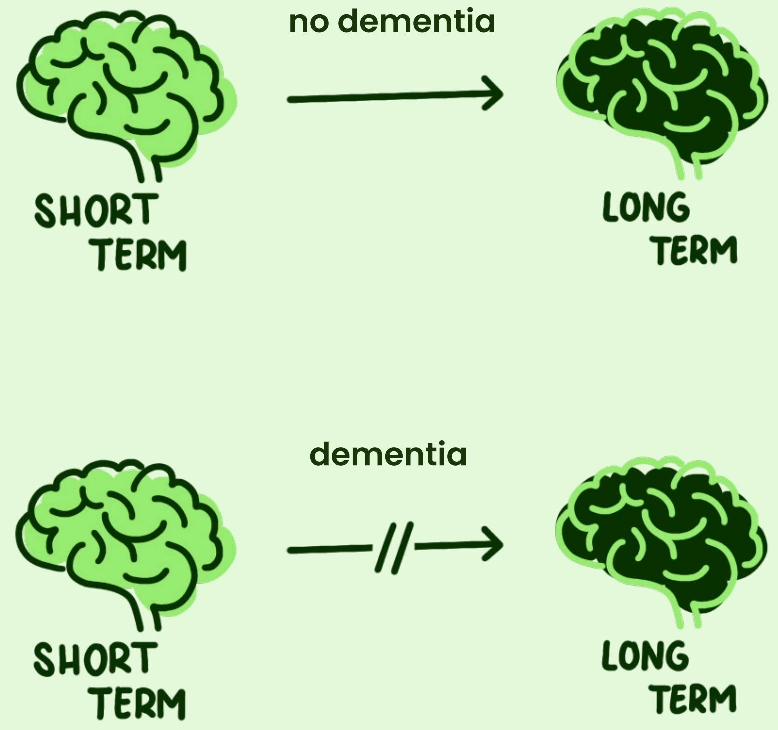


Figure 12: *law one*

Law one

A dementia patient is **unable to retain information for longer than 30 seconds**. The imprint of the information is disturbed. Information that enters the short-term memory can no longer be transferred to the long-term memory (figure 12).

Exceptions:

- In some cases it is possible for a person with dementia to still retain information if it is received with a lot of emotion.
- Repeating information often increases the likelihood that it will be remembered.

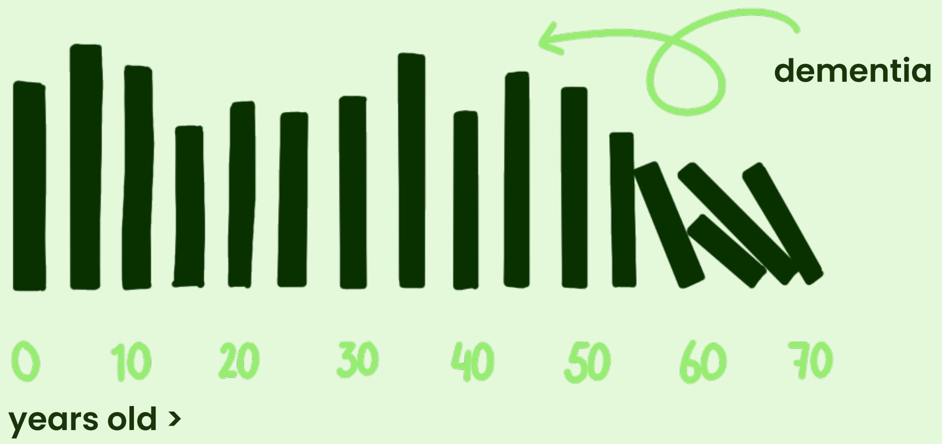


Figure 13: *law two*

Law two

As the dementia progresses, the previously stored information in memory disappears. The most recent years are wiped out first, followed by the earlier years. This causes **the memory to be rolled up from front to back**, they go further and further back to their childhood (figure 13).

Types of memory

When someone is diagnosed with dementia this affects the short and long term memory in a human brain. In addition to a classification based on time, you can also categorize the brain based on the type of content it is made of (Buijssen, 2019). Three types or forms of memory can be distinguished;

The knowing-memory: is made up of all the facts and memories we can recall regarding different events. From an evolutionary point of view this memory was the last to emerge which makes it the most vulnerable. Dementia therefore affects this type of memory first and the most.

The doing-memory: stores skills that we acquire throughout our lives. This type of memory is the strongest and most resilient. If a person with dementia does not eat its sandwich, it is because they cannot identify it as food – thus the knowing-memory is affected even though the motoric system still functions.

The rhythmic memory: contains everything that has a rhythm, such as music and children’s rhymes. This type of memory is between the two types of memory above. It is still a mystery how the body and mind exactly process music, but it is certain that there is a strong connection between the part of the brain where sounds are processed and the part where feelings are located. That is why music can arouse intense emotions.

2.2.5 Derived ways of coping with dementia

Important rules of ways of coping can be derived from Buijssen's dementia laws (2021). In addition, the in-depth interviews and co-creation sessions revealed many ways in which people with dementia are handled that had a positive or negative effect, both in the professional setting and private spheres. The following ways of coping summarize the possibilities of dealing with dementia, and does not intend to formulate a guideline. The best form of coping depends on the person-, relationship- and type of dementia. Each experience is unique. Appendix X discusses the ways coping in more detail.

- Following from the second dementia law, it is good to **talk** with the parent **about the time before the dementia** damaged the brain.

- The first dementia law shows that there is **no point in asking** the parent with dementia **questions** about this morning, yesterday or the day before. The same goes for questions about the future, since the parent no longer manages to remember appointments.

- As knowing-memory is impaired, logic in the parent's brain branches off. Gaps appear in the memory. Therefore, being right in a discussion hardly makes sense and thus **prevent discussion**.

- **Steer the mood** of someone with dementia by, for example, entering the room smiling broadly.

- Since a person with dementia can no longer properly process the content of communication, they pay all the more attention to **non-verbal communication** such as facial expression, posture, voice volume and tone.

- People with dementia also need to be listened to, so **do not ask for a logical story** but **listen carefully**.

- A person with dementia works best at his or her own pace so **be patient**.

- **Respond to the emotions** behind the often illogical story.

- **Humor** serves as a bonding agent in relationships as it signifies that we have something in common and reduces tension.

- **Postpone criticism**, or make any necessary corrections discretely.

- Do not ask for confirmation of knowledge or recognition by **testing**, be ahead of it.

- Even if there is no **fault**, be ready **to accept** responsibility or offer justifications when something goes wrong.

- In some situations, **distracting** the person with dementia works, to pull the person out of their feelings or to avoid answering painful questions.

- **Avoid surprises**, an unexpected change in the habits and routines is confusing.

- Make the person with dementia **feel useful** by giving them simple routine activities.

- Needs for **love**, affection and intimacy remain; they hardly ever lose that language.

- Listen to and **join** creative **fantasies** with admiration

- Preferably **dose stimuli** with no more than 1 stimulus at a time.

- Make use of the magical effect of **music** as much as possible.

- **Keep talking** to the person with dementia - even if there is no longer the same reciprocity in communication. The recognition of familiar voices is reassuring to the person with dementia.

2.2.6 Key take-aways

I Although **Alzheimer's disease is primary focus** of this project, other types of dementia may also exhibit similar symptoms and signals.
II Alzheimer's disease has **three phases**, early, middle and late, in which symptoms and signs may vary.
III Dementia causes **many losses and changes** for the parent as well as the adult child due to the disease's symptoms.
IV As dementia is **unpredictable** and **unique** to each individual, disease processes differ from person to person.
V Many **coping mechanisms** can be derived from the understanding of memory types and the two laws (Buijssen, 2021).

This section focusses on the insights in the social connections of the adult child whose parent has dementia.

The following research questions guided the research section:

- Who provides care for the parent with dementia?
- Who cares about the adult child of a parent with dementia?
- What are the differences and similarities between these social circles?
- What role does formal care play in both social circles?

The following research and design activities are conducted to answer these questions:

Generative in-depth sessions – the orange section of these sessions focus on illustrating and learning about the informal care environments surrounding both the parent who has dementia and the adult child.

In-depth interview sessions – the orange section of the interviews focusses on the formal care surrounding both the parent with dementia and the adult child.

Documentaries – episodes of Roosen & Borst depict the support received and personal experiences of having a loved one of dementia.

Literature study – scientific research and data have been added to the information discovered during the aforementioned research activities.

2.3 social connections

2.3.1 Researching the impact of dementia on others

As has become clear by now, dementia has a profound impact on the life of the affected person, but also impacts those who are close to them. Relationships change, roles shift, and a growing amount of care is required.

Care and support constellations are made with the participants in the orange section of the in-depth interviews and generative in-depth sessions to explore what this social and care context looks like (Figure 15, 16 and appendix 06). This was done for both the person with dementia and for the loved ones around them. Who provides them with support and care in their current circumstance was discussed. Next, the participants were questioned about how their network could be improved. An impression of the actual set-up is shown in figure 15,16.

Figure 14: *Woman with Alzheimer with formal caregiver (Furlow, 2021)*

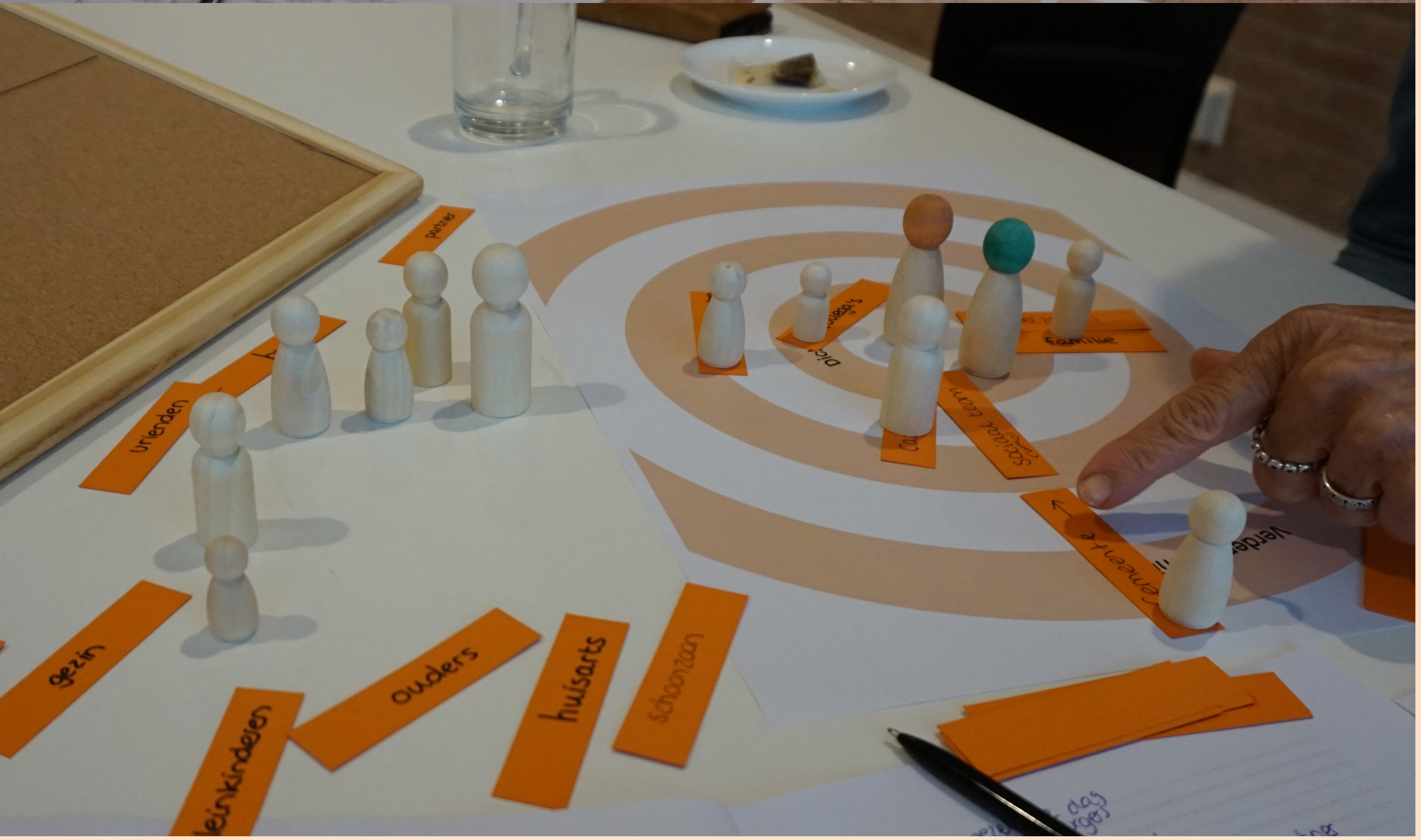


Figure 16: *Care and support constellation around the participants (grand)mother with dementia*

Figure 15: *Care and support constellation around a child of a person with dementia, according to a dementia daycare worker*

2.3.2 Circles of care

In addition to professional care, loved ones frequently also provide care. There are several formal and informal caregivers around a person who has dementia while there is less support and care for the adult children of the dementia patient.

The next pages show how the circles of care look like around both the adult child and parent after an analysis and clustering of the data of the interviews and sessions. The upper side of the visual shows the social circles around the adult child with all mentioned and existing stakeholders, the lower side shows the social circles around the parent with dementia.

Analysing and discussing the care constellations with the participants led to several distinct insights, these and the circles are discribed on the following pages. First the formal care environments are shown, and secondly the informal care.

Formal care

The person with dementia has clear symptoms and therefore directly requests for help. The loved ones who are close to the dementia patient, who also struggle with the effects of the illness, have **less visible care needs**. As a result, the person with dementia usually receives a lot of attention and care as opposed to the parent's child.

Analyzing the wellbeing of the loved ones who are close to the person with dementia, **formal care can play a signaling role**.

> **I notice with caregivers - who bring their loved ones to our day care - that they mainly want to do well. They keep help at bay, because it feels like failure.**
> – Thea

The extend to which the adult child is involved in the support and care **depends** enormously on the attitude of the **formal care** around the parent with dementia. The wellbeing and health of the adult child are more likely to be better understood by a caregiver who is co**mpassionate and empathetic**.

There **are hardly any established protocols** for how to handle the loved ones who are around a person with dementia in formal care.

> **We work ad hoc, it's actually good not to stick to a protocol. So with the loved ones, we often have a spontaneous chat, depending on the accessibility to this loved one.**
> – Thea

The person with dementia is surrounded by significantly more formal care stakeholders than the child is. When a person's environment detects signs of dementia, formal care stakeholders can be involved in a variety of ways. This frequently results in a diagnosis and a patient centered care plan. Other care disciplines are added as necessary, depending on the disease process. Perspectives and experiences vary on dementia care because it is customized to each patient. Furthermore, having a large number of healthcare stakeholders does not always equal a better experience in this context; it is frequently perceived as **overwhelming or as an endless search** for the adult child.

The above-mentioned take away is a big difference with the adult child of the person with dementia, which is surrounded by **less formal care stakeholders**. These care stakeholders advocate for the informal carers and relatives, but unfortunately do not always find each other.

It is **essential to support and empower formal caregivers to identify adult children at risk**, and providing timely and suitable interventions to prevent complications, such as complicated post-death grief (chapter 2.4.4) (Cheung et al., 2018).

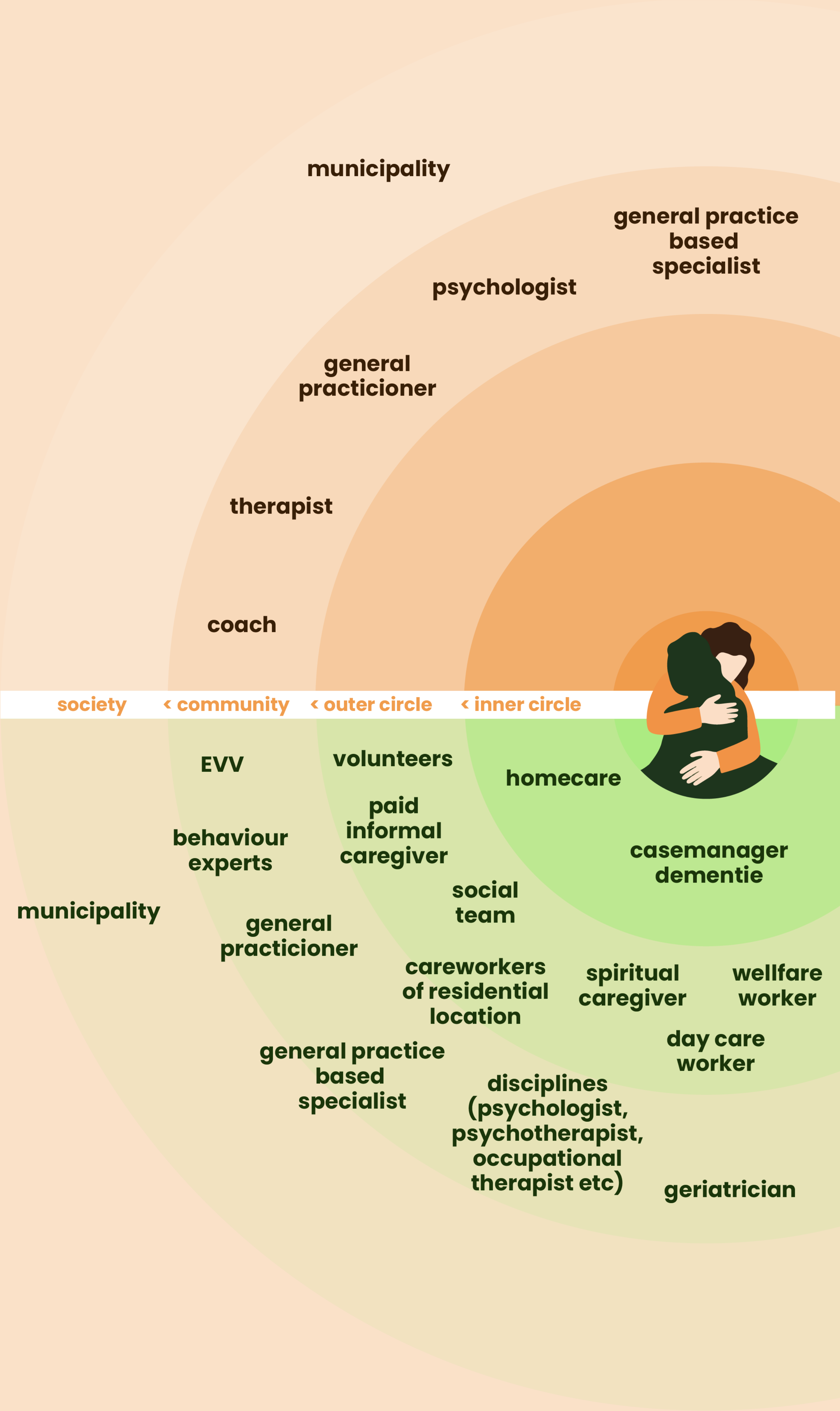


Figure 17: *Circles of formal care >*

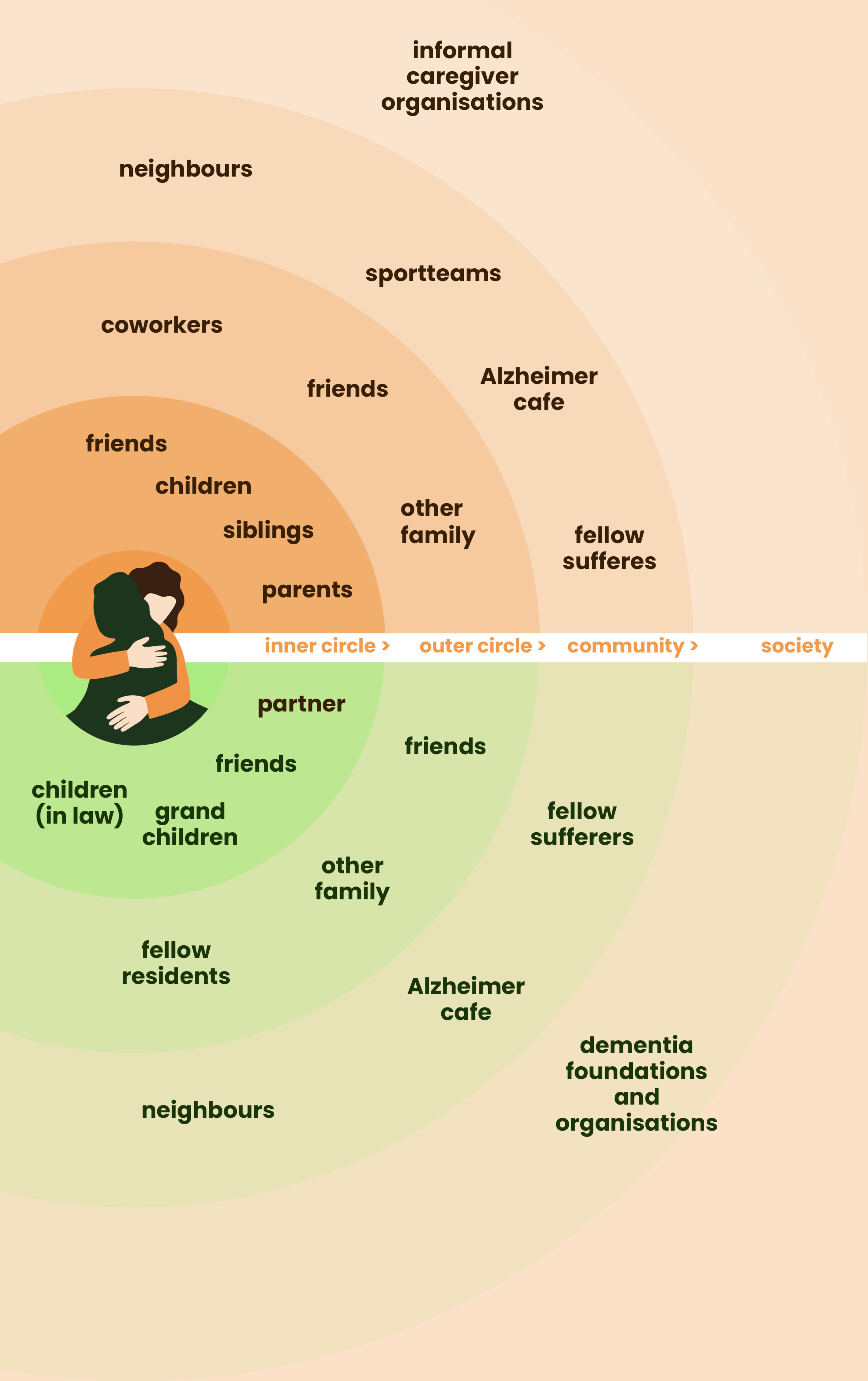


Figure 18: *Circles of informal care*

Informal care

For a variety of reasons, the burdens and grief of the loved ones who are close to the parent with dementia are frequently **barely visible**;

- **Loved ones are not aware of the impact of dementia** on their own lives and health
- Therefore, **refrain from asking for help in their informal network.**
- When children ***do*** decide to ask for help, they **are often left to look** for this help by themselves in contrary to the more convenient ways of finding help for a person with dementia
- **Guilt** or the perception that they are failing their loved one with dementia when they seek help for themselves also discourages the adult children to look for help for themselves.

Usually, grief is associated with death. As a parent with dementia is still alive, people around the child are **less aware** of the effects of the disease and the care requirements that this brings along and thus do not reach out to the child for help.

The way in which other siblings and possibly the second parent handle their parent's dementia has a significant impact on the parent with dementia.

- If each of them have a **different coping mechanism** (chapter 2.4.7), this has negative effects on both the parent and the children. When children interact with their parent differently, it can be confusing for the parent who has dementia – while dementia benefits from structure and stability. It can also cause frustration for the child if there are unattainable expectations of each other and mutual friction arises.
- – The adult children will have more space to love and accept the dementia when they surround the parent with dementia in a more **unified manner**. This leads to a peaceful environment that is advantageous to both the parent and the children.
- When a **second parent** is still alive, they often have a great influence on the adults child's relationship with the parent with dementia. **Spousal caregivers cope** with the situation **in a different way** compared to adult children caregivers (Cheung et al., 2018)

> **My brother doesn't come often, he's not very interested. If I give him an assignment, he does it, but he doesn't visit very often. He keeps to himself a lot. My sister and I come every week and take care of all the care, contacts, and administration, so they are closer to my mother.**
> – E-A56

> **Everyone helps, but in their own way. The most important thing is to be honest with each other about what you're struggling with. Because we approach our mother in the same way, especially with love, we have seen a stable pattern for several years now.**
> – E-G56

> **Because my mother is at home there every day, I don't have time alone with my father. Both of my parents need very different types of attention and my mother interacts with my father in a very different way than I do. This clashes**
> – ED-M51

Figure 19: *Impression of generative in-depth sessions - the orange section*

2.3.3 Key take-aways

VI The person with dementia receives a lot of attention and (in)formal care. The **care for their loved one's is often overlooked or forgotten**, despite the fact it also significantly impacts them.

VII The experienced support and care for the adult child **depends on who they meet in the social and care environments**. There are both unfavorable and favorable example experiences.

VIII The effects of dementia and the many types of caregivers around the person with dementia are frequently perceived as **overwhelming** by their child and, most importantly, **unknown**.

IX There is a **need from formal caregivers for more tools to see and support loved ones** around someone with dementia. At the same time there is the wish to not formalize the whole process into a protocol.

X Everyone who is close to someone who has dementia uses a **different coping mechanism**. If this is not acknowledged or accepted, it complicates cooperation, mutual support and room for grief.

This section focuses on what grief is, the role it currently and ideally plays in our society and its effects on grieving for someone with dementia.

The following research questions guided the research section:

- What is grief?
- What place does grief have in our society?
- How do people cope with loss?
- What is anticipatory grief?
- How is anticipatory grief related to dementia?
- What is the impact of losing a parent?

To answer these questions the following research and design activities are conducted:

🟪 **Generative in-depth sessions** – the purple section of these sessions are focussed on exploring the experiences of the adult child and their feelings of grief when a parent is living with dementia.

🟪 **In-depth interview sessions** – the purple section of these sessions focussed on how formal caregivers currently support loved ones around a person with dementia.

🟪 **Podcasts** – Several podcasts gave insights on different perspectives on the term grief.

🟪 **Literature study** – scientific research and data have been added to the information discovered during the aforementioned research activities.

grief 2.4

2.4.1 Introducing grief

Grief is often associated with death. However, grief is more complicated than just the loss of life. Other profound loss experiences can initiate grief in the form of a search for meaning, the process of adjusting and changing our lives, redefining our self-image, recalibrating our relationships, regaining emotional balance, bearing the pain of the loss and how this pain can transform a person, until we 'are what we have lost' (Maes & Modderman, 2021). Griefing for a loss experience is often referred to as 'processing the loss', but this evokes wrong associations. It implies that it will pass. The sorrow does not go away, instead, you must learn how to deal with it, you work on it and you try to live with it (Keirse, 2017).

Major loss experiences can take many different forms, such as a divorce from a partner, a stillbirth or miscarriage, the death of a loved one, a decline in one's own or others' health, retiring from a job, or seeing dreams fade away.

Grief and loss are existential phenomena that affect everyone at some point in their lives. Grief is a healthy process of adaptation and change, a process that is shaped by our experiences and the environment in which we grow up (Maes & Modderman, 2021). It is part of our identity, each individual grieves in his or her own way. There is no fixed path for a grieving process.

> **Grief is so deeply human in all its dimensions, layers and forms, so universal and unique. –** Johan Maes and Hariëtte Modderman (Maes & Modderman, 2021)

2.4.2 Room for grief in our society

However, is not always seen as a unique adjustment process in which the loss is integrated into life. The 'standard grief model' starts with the idea that loss is something negative and grief is a malfunctioning of the individual (Maes & Modderman, 2021). Grief is seen as a shortcoming, something that entails problems and complaints and must be resolved and processed in someone's life. But without grief there is no love, without sorrow there is no joy. Grieving is human, but it is not always given the space in our society.

> **Lost dreams, hurt loves, relational breaks, illness, aging, decay and death will all be a part of our lives. The obviousness of incorporating this sadness into who we are and the consoling power of our social fabric seems to fade. -** Dr. Dirk De Wachter, professor (Maes & Modderman, 2021).

The dominant cultural perspective in the Netherlands is a medical model that makes a simple distinction between healthy and sick, normal and pathological. In this clinical setting, the individual is seen, as it were separated from social, historical, cultural embedding. The grieving individual adapts well (normally) or not well (abnormally) to the loss. It is sort of isolated from how it interacts with the environment and sociocultural norms and values (Maes & Modderman, 2021).

Lindemann (1944) suggested that grief work, the psychological process of coping with a significant loss, required the bereaved person to become emotionally detached from the deceased person and adapt to a new environment in which the deceased was not included. This theory initiates that grief is resolvable, a unified process that each individual must go through. Grief is reduced to only painful emotions that one feels around a loss, which are expected to diminish. If the painful emotions are not experienced or if positive emotions are experienced shortly after the loss, this is labeled as delayed or denied grief. If the emotions are too intense, the grieving is called prolonged, chronic or complicated. In essence, grief is treated as a pathological condition (Maes & Modderman, 2021).

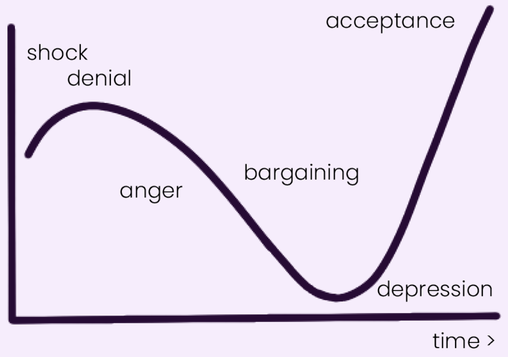


Figure 20: *Kubler-Rosse five phases model*

In the 1970s, Elizabeth Kübler-Ross (Maes & Dillen, 2015) described the grieving process as five stages that you have to go through. These stages are denial, anger, negotiation, depression, and acceptance (figure 20). Despite Kübler-Ross's intentions, the model is now frequently perceived as coercive or normative and is therefore referred to as outdated (Network Palliative Care, 2019). In the case that all of the described phases occur, they rarely do so in the order described (figure 21).

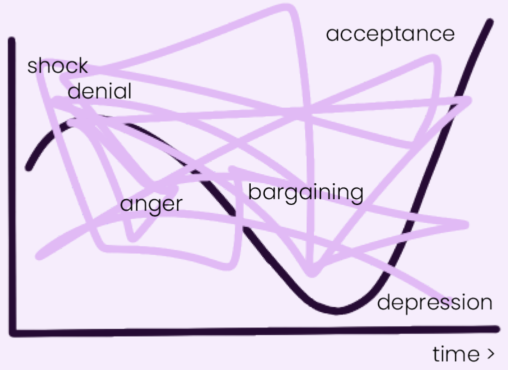


Figure 21: *Kubler-Rosse five phases model in reality*

A number of characteristics and assumptions follow from these aforementioned grief theories and standard grief vision:

The purpose of grief work is to **let go** of the emotional bond with the lost object or person and to be able to live without it.

Grieving happens **intrapsychically** in a private sphere, grieving is something an individual goes through and expresses independently of the context.

There is an immediate **need for (formal) help**. This can be done by taking medication, attending therapy sessions, or actively seeking out other sufferers in conversations.

Grieving has a **restorative** function: a grieving person is expected to recover and become its 'old self' again.

Grieving is viewed as a **static** process with a beginning and an end.

According to this theory, the grieving process develops **linearly** and gradually over time. It begins with a high-intensity phase and progresses to awareness and recovery over time, frequently with an end in sight.

Grieving is a standard model; universal and **homogeneous**. Grief processing goes through certain tasks or phases for everyone.

The goal of these grief models is often the same: **to recognize and (emotionally) process the loss so that one can let go and give it a place.**

You can see grief as snow. From a distance the snow is universal, but up close each snowflake has its own crystal structure and you will find endless unique patterns.

Figure 22: *Snowflake Macro (Burden, 2016)*

2.4.3 Grieving as an integral growth model

Despite the fact that no scientific study has been able to demonstrate the validity of the standard grief model discussed on pages 52 and 53, it is widely accepted in society. They are called the mourning myths (Silver & Wortman, 2002) or mourning veils in our culture (van den Bout, 1996). However, these myths dominate the view of grief. Grieving as a healthy coping process involves more than just 'grief work'. A new vision on the grieving process is therefore needed and Johan Maes proposes the 'integrative development model' in his new handbook (Maes & Modderman, 2021). In this model loss is seen as an inherently existential and essential human experience, these loss experiences are stressful and traumatic but part of life and therefore of our growth as human beings. They are integrated into our identity and course of life. Maes (2021): grief therefore includes an adjustment process throughout our life course, which changes us and continues to change and transforms our world in different ways. Grief is inherent in our existence. We are born of loss, accumulate losses over the course of our lives, and when we die, we lose again.

> **Surviving grief has more to do with remembering than forgetting. Grief is seen too much as something you have to get over it and process, while the emphasis should be on the relationship that lasts. A person you have loved will always be part of your life.**
> – Manu Keirse (2017)

> **Grief is essentially the response we give (that we are!) to the loss of a meaningful relationship (with someone or something) and the way we adapt and reshape our lives or live on, with the loss, in continuous interaction and dialogue with our environment (the interpersonal, social, cultural, historical context).**
> - Johan Maes (2021)

A new perspective on the characteristics of grieving results from this new vision:

The purpose of grieving is to **integrate** the loss into the emotional bond with the lost object or person and to be able to live with it.

We do **not** grieve **alone**: our environment shapes and influences both our experience and our expression of it.

The **meeting with compassionate and empathically attuned caregivers**, who create a healing experience for grieving people of being understood and supported in their grieving process or journey through the loss, forms the basis of every grief counseling and therapy.

Grieving serves a **developmental purpose** because it forces one to constantly adapt and rediscover themselves.

This grieving process is **dynamic**, a continuous process of growth that never comes to an end. Forgetting and cherishing, rearranging and always being connected, pain and healing, vulnerability and growth. It all occurs.

A loved one who dies is never forgotten, the pain of the loss does not pass: sometimes it increases because the environment forgets the loss, sometimes it decreases. The process is **not linear**.

Mourning is a universal human experience, but each response to grief is unique: grief processes are **heterogeneous** and vary in experience and expression, intensity, colour, meaning.

With this, Johan Maes brings a new goal of grieving: **integrating the loss so that it furthers our personal growth in our relational and sociocultural contexts in life.**

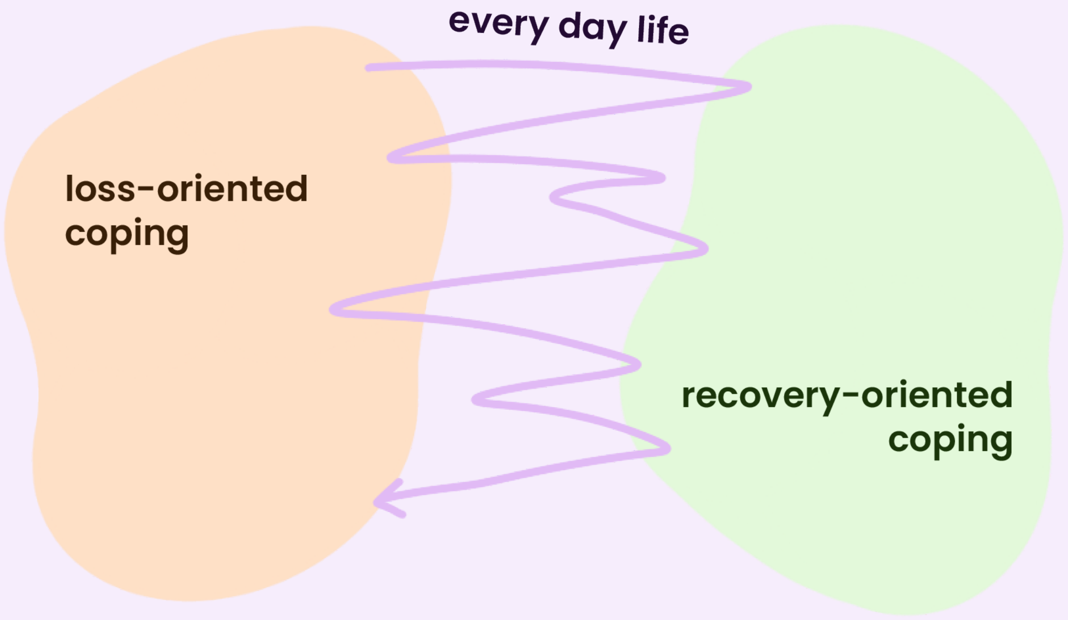


Figure 23: *dual process model of grief (Stroebe and Schut, 1999,2002)*

The dual process model of grief of Stroebe and Schut (1999, 2002) fits into this new integral vision. This model is based on two coping mechanisms that arise in a grieving process:

Loss-oriented coping: the bereaved person has lost an object or person and must learn to deal with the emotions, feelings and thoughts that this loss entails. The situation before the loss is maintained.
Recovery-oriented coping: One's own life must continue at the same time. They look ahead and look for distractions in order to (temporarily) avoid dwelling on the loss.

One must give themselves time and space to grieve, but daily responsibilities also require attention. According to this model, mourning requires continuous balancing or switching between these two realities. Healthy grieving is moving back and forth between the loss orientation and the recovery orientation (Figure 23).

2.4.4
When grief becomes complicated

Complicated grief may develop in situations where bereaved persons are unable to move on or they become stuck in the grief. This is recognizable in a lack of new goals, daily dysfunction, isolation and a lasting desire for the lost object.

If the grieving process develops into an unhealthy impact on life, well-being and health, we speak of complicated grief. This grief can result in depression, PTSD, anxiety and many other physical and psychological complaints.
In this vision, this type of mourning is acknowledged and not underestimated (Maes & Modderman, 2017).

2.4.5
The significance of emotions

Emotions are essential; they are experiences, feelings, perceptions, actions, expressions and communication. Emotions are like a compass for ones needs and serves a signal. Therefore, it is crucial to support grieving persons in discovering their emotions, experiencing them, accepting them, exploring them, managing them and changing them as needed. Our emotions guide us toward deeper meanings and the potential development of new goals, directions and life changes (Greenberg, 2012).

A loss experience is accompanied by a wide range of emotions, both positive and negative emotions. All of these emotions are allowed, but one shouldn't dwell there. Emotion regulation keeps painful emotions, without being overwhelmed by them. It creates a dynamic between being open and closed, being able to move towards and away from pain or zoom in and zoom out from the pain. A grieving person who has the ability to regulate emotions is emotionally flexible, is more resilient and can adapt more easily after a loss (Maes & Modderman, 2017).

In addition, experiencing and expressing positive emotions also serve a crucial adaptive purpose in the healing process of grief. Positive emotions like appreciation, love, gratitude, and kindness improve wellbeing and reduce emotional suffering (Joseph & Linley, 2012).

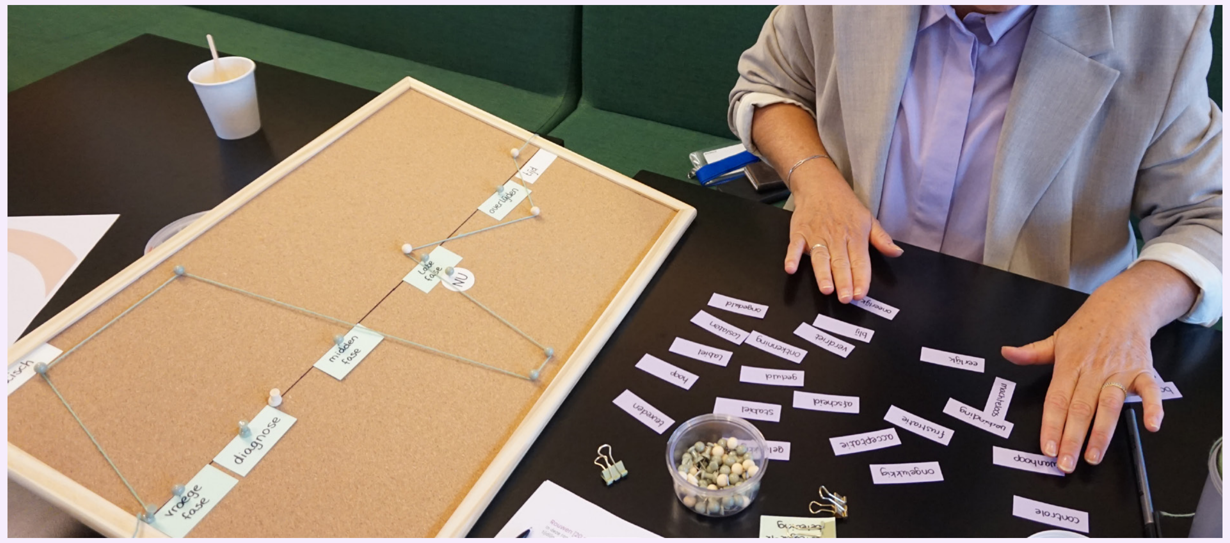


Figure 24: *Connecting emotions to experienced losses in generative in-depth session*

2.4.6 Anticipatory grief: grieving before the loss

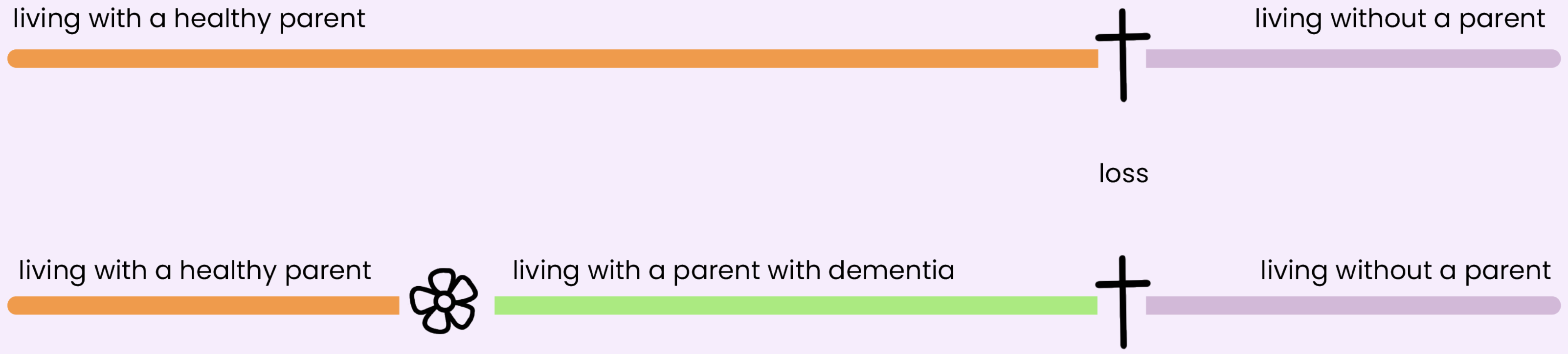
Going through the grieving process before you actually lose something or someone, such as through an illness, a divorce, or retirement is known as anticipatory grief. Because what you risk losing is still present, it is a very ambivalent process (Verlieskunst, 2022).

There is not a strict distinction between the life before the loss and the life after the loss, but someone is in a phase where he or she knows that the loss is coming while the object or person is still there. It is often unclear when the loss will be definite. Therefore, every day represents an unfinished loss. Tension and fear arise in this phase, uncertainties accumulate and sadness and hope are experienced at the same time (McGovern, 2022).

Because the loss itself has not yet occurred, hope is a unique aspect of anticipatory grief. For instance, one can always hope for a cure for an incurable disease, the reappearance of a missing person, or the healing of a relationship after a divorce.

Anticipatory grief is influenced by many factors and, like grief after death, is unique to each individual. Previous experiences of loss, the social support from your environment, demographic background, cultural background, your personality, history of attachment and coping, the significance of the relationship with the lost object, the nature and circumstances of the loss, and the pressures or expectations of the environment, prevailing mourning culture are examples of factors that influence the anticipatory mourning process (Maes & Modderman, 2017).

Figure 25: *A period of anticipating on the loss*

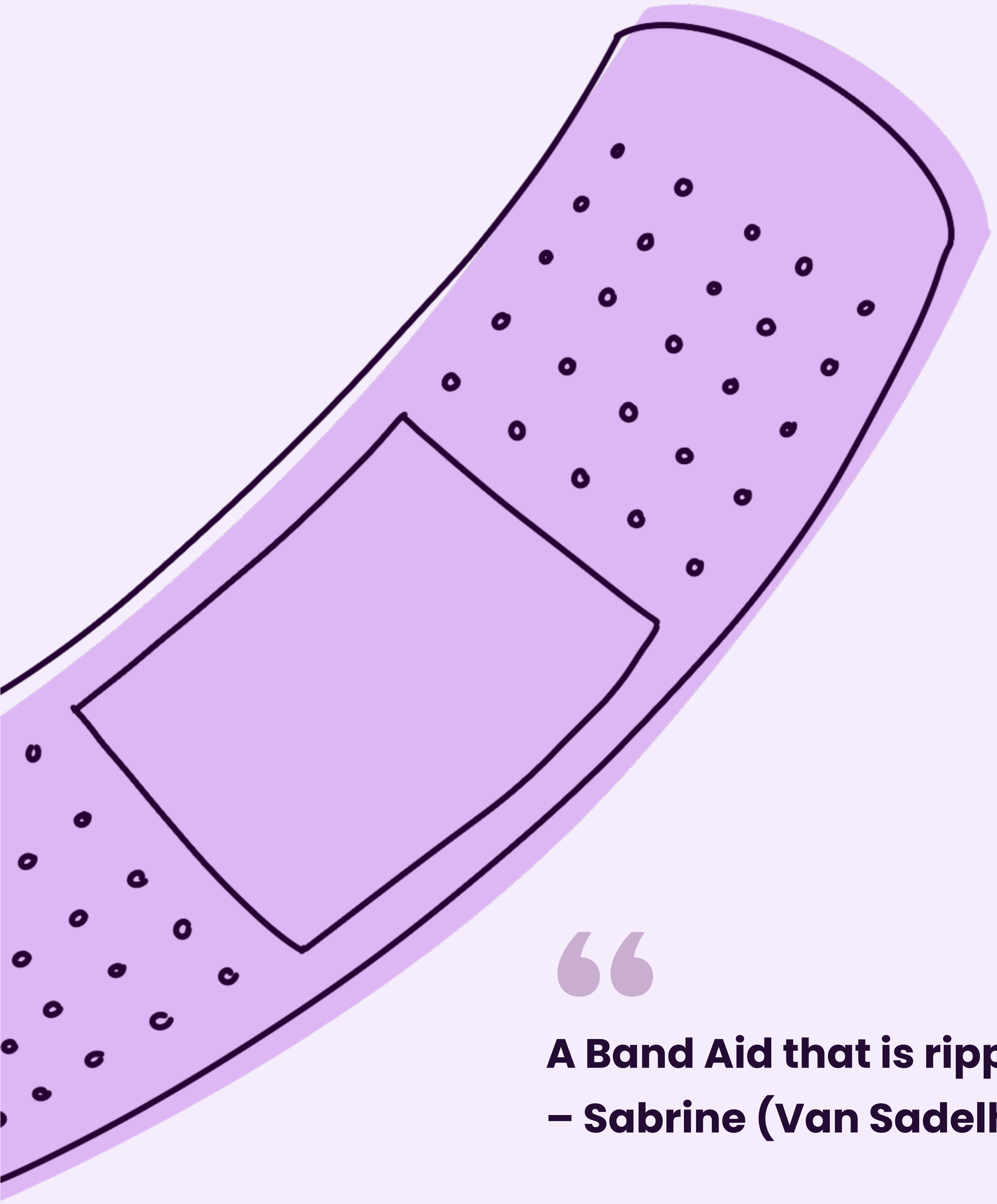


Ambiguous loss

Pauline Boss developed the idea of ambiguous loss in the mid 1970s. It refers to a loss situation that is still uncomplete, confusing, or uncertain for loved ones, which is often the case with anticipating grieving. Boss (1999) separated ambiguous loss into two categories:

In the first type it is not clear whether the person is dead or alive, so loved ones perceive the person as **physically absent but psychologically present**. Families of men missing in war and families of missing children may experience this kind of ambiguous loss.

-In the second type, loved ones perceive the person as **physically present but psychologically absent**. Loved ones with a relative who has a form of dementia disease, a brain injury, a stroke, or other chronic illness are often associated with this type.



> **A Band Aid that is ripped off very slowly.**
> **– Sabrine (Van Sadelhoff, 2021)**

2.4.7 Accumulation of losses: anticipatory grief when losing a loved one to dementia

Anticipatory grief for a loved one with dementia is often experienced as a plaster that is being pulled off very slowly. As the degree of cognitive impairment rises, a loved one with dementia appears to be physically alive but gradually disappears psychologically from their loved ones' lives (Boss, Caron, & Horbal, 1988). In small unpredictable steps, the adult child says goodbye to the parent.

Dementia causes memory loss, loss of life control, and loss of personal autonomy for the parent. The adult child on the other hand loses a functioning parent, some stability, a part of their identity, and their freedom on their own agenda (Chapter loss of a parent). Both grieving processes develop differently, making it challenging to comprehend one another and grieve together (Chan et al., 2013). Once a disease intensifies, the personality of the parent can slip away and affect their ability to fulfil parental roles (Waldrop et. Al., 2005).

Additionally, grief can occur in response to loss of personal freedom, worries about the future, changes in roles and role conflict, and disruptions in functioning. As the disease progresses, loved ones are forced to deal with losses of a wide range of different aspects of the person they know, including the loss of deep connection, emotional intimacy, and personal characteristics. All of these emotions may be factors in the adult child's grief (Holley & Mast, 2009).

In addition, each individual lives in their own reality, with two healthy persons these two realities have a lot in common. However, dementia increasingly drives these realities apart (Figure 26), making it sometimes difficult to find each other in the overlapping reality. Misunderstanding grows.

As a result, compared to the grieving process of the child, different losses caused by dementia may have different effects on the parent.

> **My father could no longer live at home, he had to move to a permanent residential care location. I was relieved when my father moved because I could now delegate care, worry less about his safety, and have more personal space. But my father started acting more abrasively, became very confused about it, and began blaming me."**
> –Anke

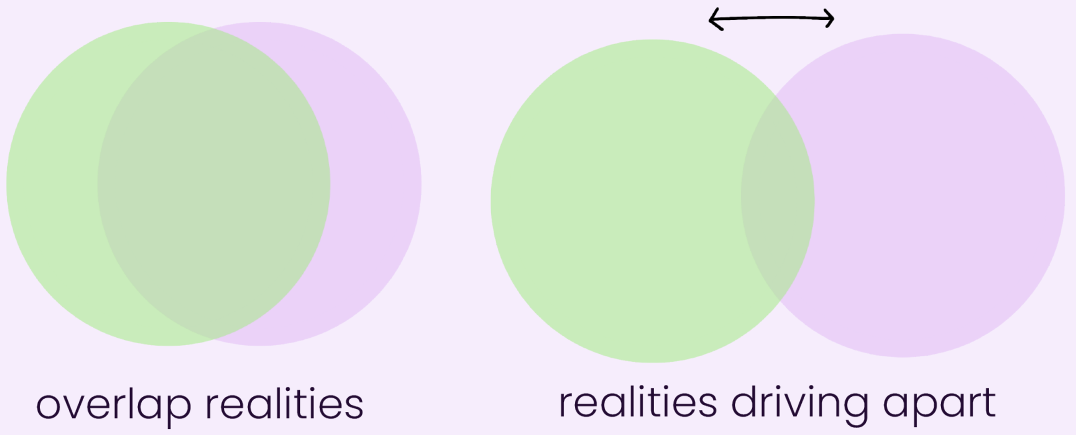


Figure 26: *Realities driving apart due to dementia*

Ambiguous loss within anticipatory grief

Research indicates that of all caregiving roles, providing care for a person with dementia may be among the most challenging, frustrating, and upsetting (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Watching a loved one gradually decline and psychological loss as they suffer from dementia is one of the most painful experiences for those who are close to that person (Dupuis, 1997). It requires significant sacrifices from loved ones because the parent who has dementia is becoming less and less aware of the losses and in this situation the child must adjust to the changing parent. In a sense, the child must not only adapt to the losses that dementia brings, but also to its own behavior and interactions with the parent. “In later stages of dementia, adult children also experience confusion regarding whether their loved ones still exist for them as well as great emotional distress and turmoil related to that confusion” (Boss, 1999). This phenomenon is known as ambiguous loss.

> **My mother and I got along very well and I don’t have anything to make up for and I don’t have any unresolved concerns. We didn’t have any, we worked it all through. If I viewed myself as a very intense caregiver now, I am not sure how healthy that would be for me. I don’t know that either of us would gain from that. I know that my mother can no longer help me . . . she can’t do that. I need to acknowledge that and move on. We all feel that we were great when it was time to be great and we really can’t help her any more than this. (Dupuis, 2001)**

Coping strategies

According to Sherry L. Dupuis’ PhD study from 2001, adult children go through at least three stages when coping with ambiguous loss, including **anticipating the loss**, going through the **progressive psychological loss**, and **acknowledging the loss**. The adult children use two coping strategies for dealing with the acknowledged loss of their parent: acceptance or avoidance of the situation.

Accepting the loss is one way some adult children manage grief. They come to terms with the fact that their parent is no longer present in their lives, at least not in the same way they once were, and they choose to view the situation more positively. By using this strategy, the adult children shift their attention to taking control of their own lives and enhancing their own wellbeing. When one of the study’s participants (Dupuis, 2001) said her mother was ‘no longer here”, she explained how she had been able to arrive at this state of acceptance.

Other participants in Dupuis’ study (2001) focus on protecting themselves from the loss by avoiding the situation altogether in order to cope with the loss. Rarely did these adult children visit their parent, and even less frequently did they visit them alone. If both parents were still alive, some of these adult children turned their attention to the other parent. They valued having a connection to that healthy parent. Others shifted the attention to themselves and their efforts to cope with the loss. They found it extremely difficult, if not impossible, to change their perspective and see the situation more positively.

Unsurprisingly, those who were able to reach a point of acceptance of the situation expressed much less pain and emotional distress than those who chose to avoid the situation. Thus, compared to those who were able to accept their parents’ passing, these avoidant adult children found it much more difficult to move on. Once adult children have gone through the acknowledged loss phase, many of them are ready for their parents to die physically or think that it would be less painful if their parents would die (Depuis, 2001).

> **I see death as a good thing, as a relief.**
> – E-M57

2.4.8 Importance of creating room for anticipatory grief

It is believed that sudden and unexpected death is more likely to cause severe bereavement reactions, whereas anticipatory mourning and having some advance knowledge of impending death help to lessen the bereavement reactions of the loved ones once the death actually occurs (Margolis, Kutscher, Marcus, Raether, Pine, Seeland & Cherico, 1988; Zilberfein, 1999). Within this paradigm, the bereaved can complete any unfinished business, say their goodbyes, clear up any misunderstandings, and get ready for upcoming social adjustments, leading to a less upsetting and disabling period of bereavement when the death actually occurs (Zisook, 2000). Therefore, it is assumed that relatives of a chronic illness death will do better than relatives of a sudden death. But with dementia, time is running out, since the child is already gradually saying goodbye psychologically, which makes communication difficult.

Apart from a relative's passing, it is said that witnessing a close relative have a terminal progressive illness is one of the most upsetting life events for people (Grimby & Svanborg, 2013). Grieving starts early in the process of ambiguous loss and lasts the entire journey because the loss of the parent happens over a very long period of time. The majority of the grieving takes place while the parent is still alive.

When a parent passes away, adult children's grieving behaviors can be characterized as responses to a series of losses that occurred prior to the parent's death. In two studies, Chan et al. (2013) found evidence that grieving in an open and flexible way prior to death may be advantageous for loved ones after death, making it less intense and distressing. In the study by Johansson, Wijk, and Grimby (2013) more than half of the participants reported feeling lonely, having trouble accepting the diagnosis, **needing to talk to others** about their relative's illness, and having trouble focusing. According to a Chan et al. study (2013), loved ones of persons with dementia also appeared to be **seeking for information and social support**.

Overall, **it is crucial to allow adult children to anticipatory grief** in the early stages of dementia.

2.4.9 Loss of a parent

The first question that is frequently asked when someone mentions that their mother or father is dying is how old they were, followed by the phrase "Great age!" (Keirse, 2017). This implies as if an old age minimizes grief. You only experience the loss of a mother or father once, and only then do you understand the significance of those roles. It is a radical and intense event, although it is not generally seen as such (Rubin, 2012).

A living parent offers a child a form of safety, protection, and continuity (Keirse, 2017). When a parent passes away, the barrier between the child and death dissolves, the bond is irreplaceable, and all of a sudden you are the older generation rather than the child. Which brings your death closer. Along with your parents, you bury your own 'being-a-child'. You become an orphan.

Many different emotions, including helplessness, frustration, love, anger, guilt, and shame start to emerge the moment your parents become dependent, as is the case with dementia. The journey of the child (page 70) provides more insight on these.

The relationship with a parent is unique and not identical to that between the siblings and the parent. Everyone experiences their own father or mother in their own unique/specific way. Different responses may occur when the parent becomes ill. This can affect the adult child's grieving process.

> **We have an exceptional special situation, where we all support our mother with a total of 9 brothers and sisters. If everyone helps in his or her way that fits into his or her life, and respects each other, then there is harmony.** – E-G56

The death of a parents is a final sealing of the parent-child relationship. The balance of life is drawn up (Van den Eerenbeemt, 2012) and questions arise for the child. What did we mean to each other? Did I visit often enough? Who cared the most? Did they understand what I did? Missed opportunities, satisfaction, powerlessness, feelings of guilt, anger, dissatisfaction, and satisfaction mix and form a melting pot of emotions (Keirse, 2017). Due to dementia, these emotions already occur before the loss to death, but the progressive brain disease makes it difficult to receive satisfying answers to these questions, which cafes and frustrates.

> **I think her character has not been affected, but she can no longer express herself. A mutual conversation is no longer possible. –** E-G56

2.4.10 Loses for the adult when having a parent with dementia

A parent with dementia brings many changes and losses (chapter 2.2.3) and has a significant impact on the adult child's life and the relationship between them. This impact is explored using a bulletin board in the generative in-depth sessions (appendix 04) and in-depth interview sessions (appendix 05). On this, individual key touch points are mapped, allowing visualizing grief lines and connecting emotions to them. This resulted into seven grief journeys of adult child participants.

These journeys are analyzed and clustered, along with prior literature research and documentary analysis, which led to an overview of possible changes and losses brought up by dementia.

Each dementia process, relationship and coping mechanism is unique, just as the changes, losses and adjustments caused by dementia. This page's overview present **general abstract terms**, each of which has a unique meaning and value for each individual.

> Reciprotory
> Support
> Advice
> Equality
> Trust
> Pleasure
> Social contacts
> Personal freedom
> Meaningful talks
> Connection
> Empathy
> Understanding
> Carefree
> Safety
> Control
> Time
> Warmth
> Future plans
> Character
> Saying goodbye

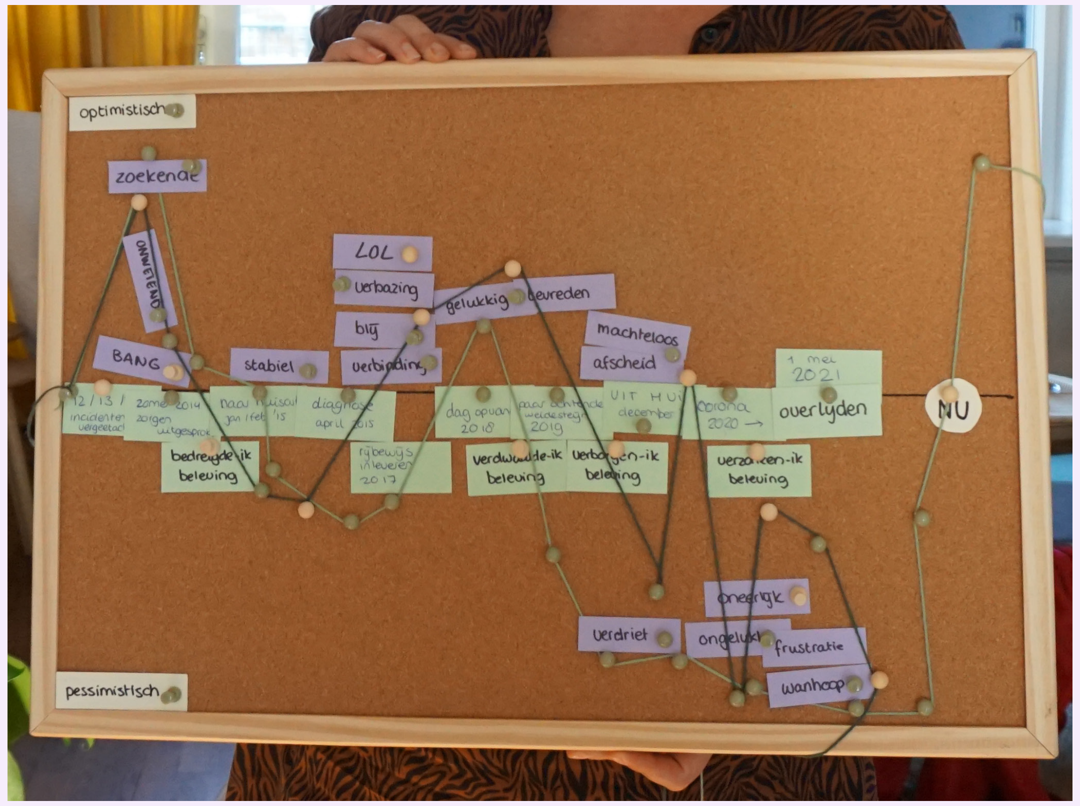


Figure 27: *Participant with personal grief and dementia lines on bulletin board.*

2.4.11 Key take-aways

XI Grief can take **many different forms** due to the variety of loss experiences; it is not only associated with a loss to death.

XII Several outdated grief theories are based on the idea that grief is something that passes and is a misfunctioning of the individual. The goal of these grief models is often the same: to recognize and (emotionally) **process the loss so that one can let go and give it a place**.

XIII An integrative development model by Johan Maes (2017) initiates a new vision on grief. A model where loss is **inherently existential and an essential human experience**. These events are stressful and traumatic, but a part of life and therefore of our growth as human beings. With this, Johan Maes brings a new goal of grieving: integrating the loss so that it furthers our **personal growth** in our relational and sociocultural contexts in life.

XIV Both **positive and negative emotions** play a significant part in the grieving process.

XV Grieving for a parent who has dementia is an **ambiguous** loss because one is grieving for someone who is still alive but is deteriorating gradually in small steps.

XVI These steps translate into an **accumulation of multiple losses**. The child must not only adapt to these losses that dementia brings, but also in its own behavior and interactions with the parent.

XVII The child can use two different types of coping mechanisms (Dupuis, 2001); **acceptance or avoidanc**e of the situation.

XVIII It is crucial to allow adult children to anticipatorily grief in the early stages of dementia. Among other things, this can be done by **talking with others, seeking information and receiving social support**.

journey of the child

2.5

2.5.1

Overview of the journey

A journey is created to understand what a child is going through when a parent develops dementia. The experiences, emotions, and effects of dementia are involved into this journey to provide a glimpse of what the child is dealing with. The journey acts as a summary of this research's insights and found opportunities.

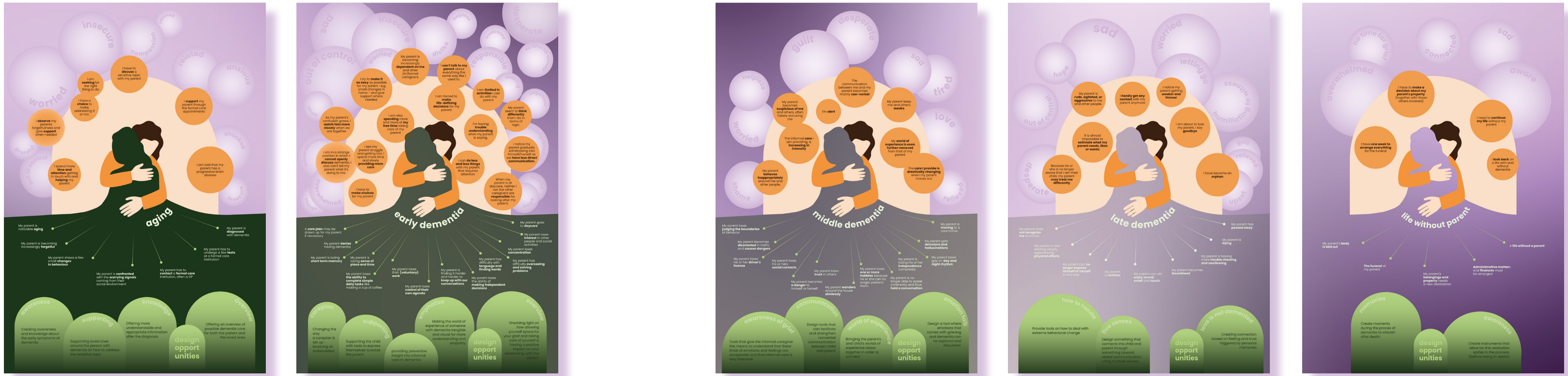


Figure 28: *Overview of Journey of the Child*

2.5.2 A legend on how to read the journey

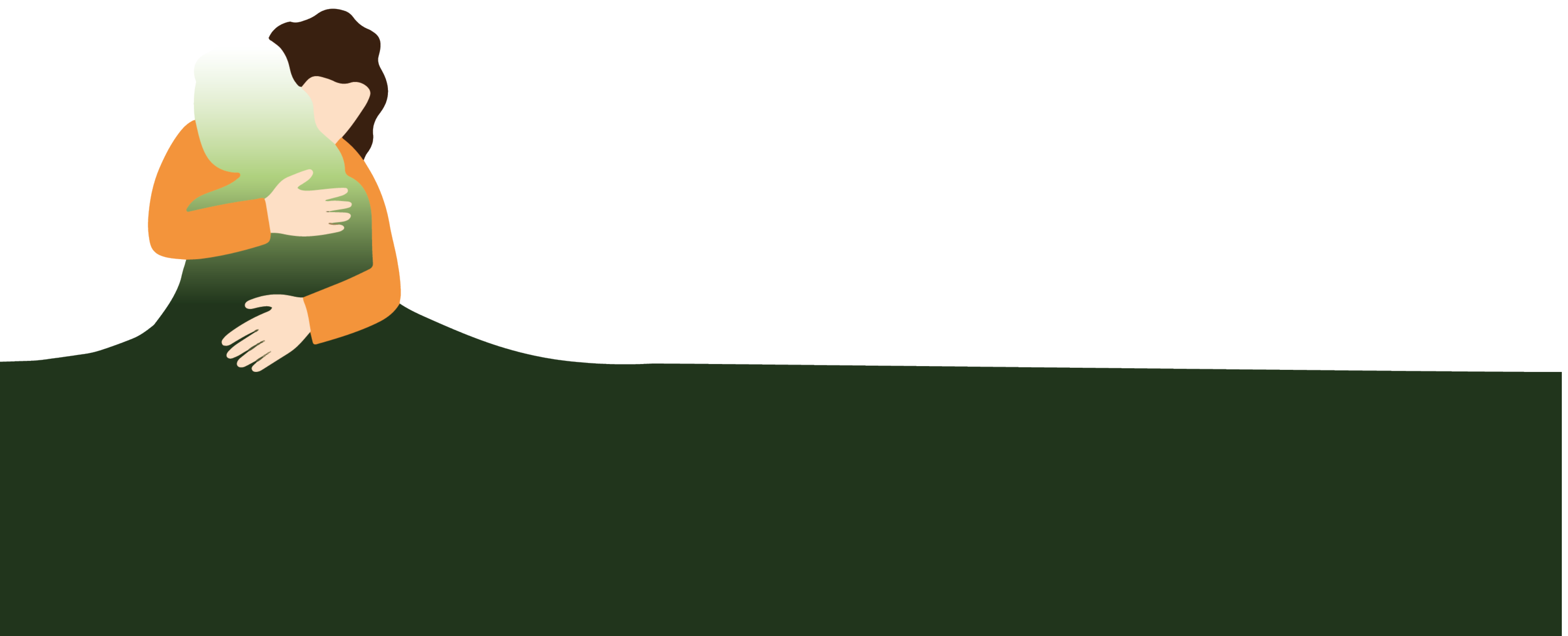
In this five-part journey, each part represents a stage. The first stage depicts a parent's aging phase in which – often afterwards – early symptoms of dementia can be recognised. The second stage shows the early dementia phase in which the dementia slightly becomes more noticeable. The third stage is the middle dementia phase, when the effects start to become more pronounced and severe. The fourth stage shows findings on how dementia causes a parent to become totally dependent on others. Lastly, the final stage provides insights into a parent-less life after death.

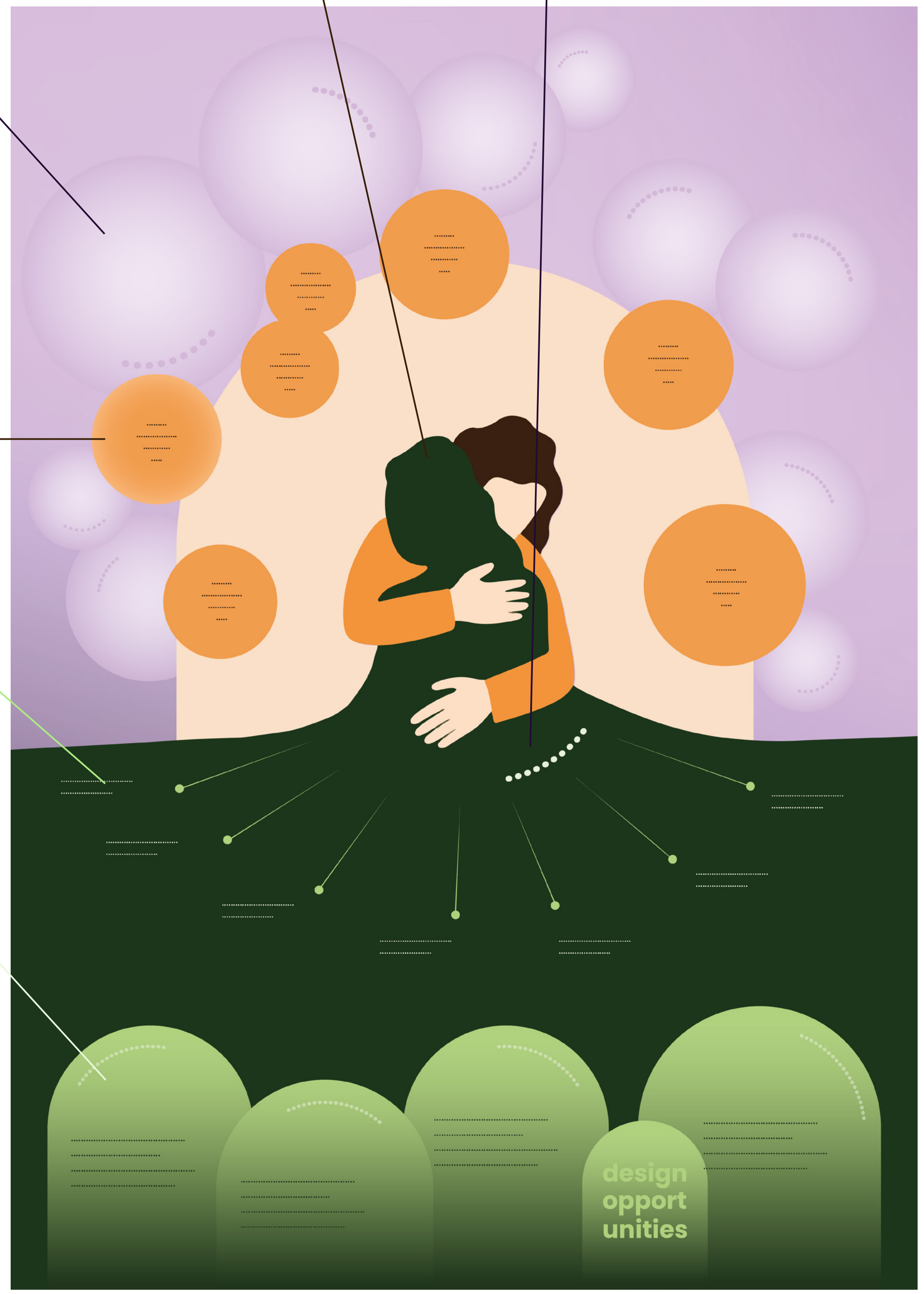
Since dementia, grief, and the social relationship with a parent are unique and unpredictable for each individual and illness case, this journey is not a chronological representative of a dementia experience. Every alteration in the dementia patient's behaviour, impact on the child, and emotional state can differ for each person and occur at a different time. Late dementia symptoms can pop up very early in de progress or the loss of a parent to death can happen any time. Additionally, not every case of dementia necessitates a brief stay in a daycare centre or a longer stay in a nursing home.

A legend explaining how to read the setup of this journey can be found in figure 29. The numbers indicate a reading direction. Each stage is further described on the pages that follow.

2.5.3 The journey

The journey is visualized on the following pages.





1 The child in orange. The parent with dementia in green.

Title of stage ⓪

4 The child's **feelings and emotions** as a result of these changes and effects. Frequently not visible or in the background due to caring for a parent and unawareness of grief.

3 The mainly practical and noticeable **effects** of these changes on the child.

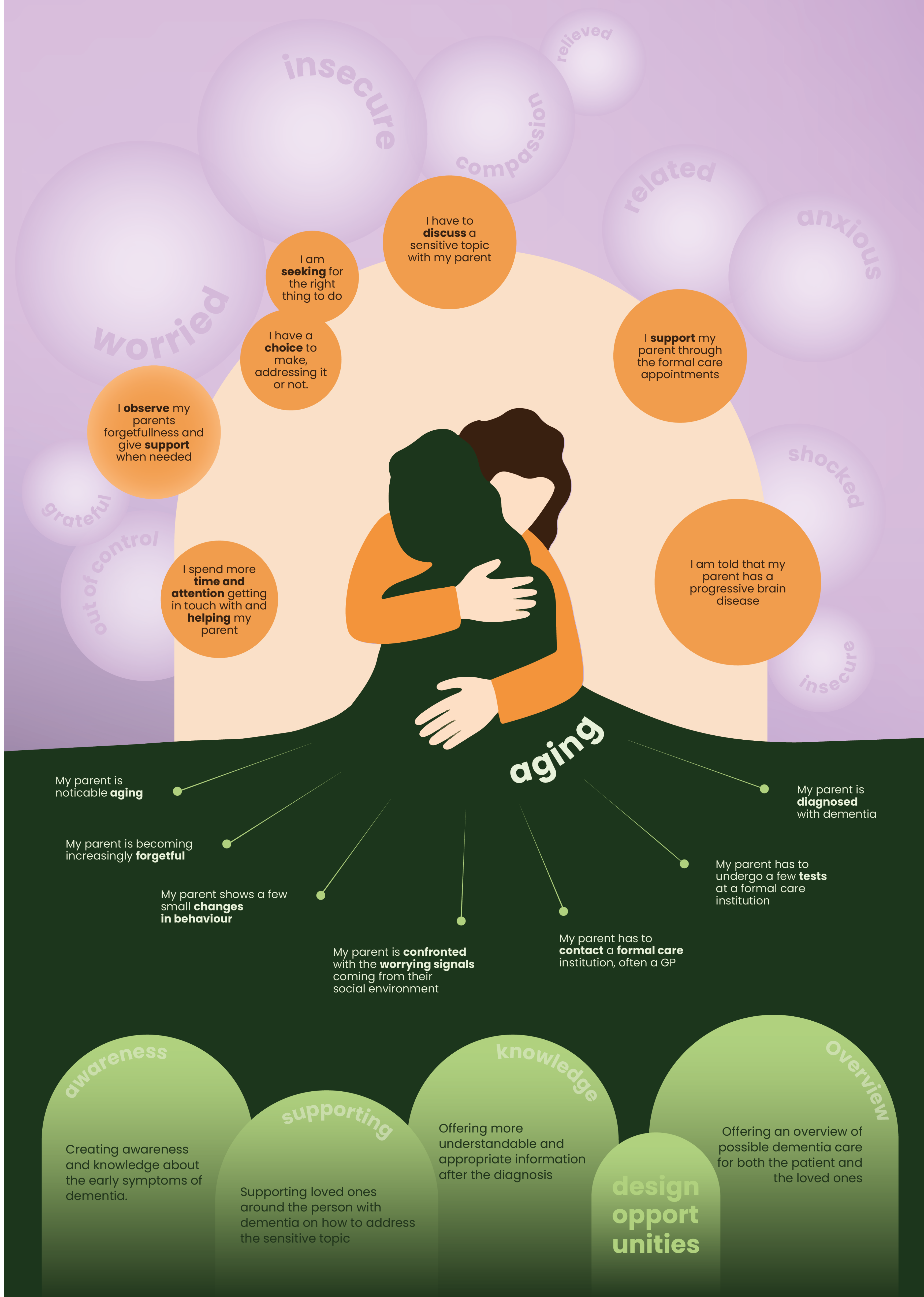
2 The parent's potential mental and physical **changes** brought on by dementia.

5 Possible found **directions to design** for.

Figure 29: *Legend of the journey of the child*

understand

The parent is getting older by the day. **Signs of aging** are noticed and the child starts to occasionally assist the parent. Specific forgetfulness and behavioral changes cause the child to become **worried**. Should it be acted upon and how should it be addressed? It is a **sensitive** topic that brings a lot of emotions when it is discussed. The child helps the parent through the diagnosis process, which is a very **overwhelming** period for everyone involved.



I have to **discuss** a sensitive topic with my parent

I am **seeking** for the right thing to do

I have a **choice** to make, addressing it or not.

I **support** my parent through the formal care appointments

I **observe** my parents forgetfullness and give **support** when needed

I am told that my parent has a progressive brain disease

I spend more **time and attention** getting in touch with and **helping** my parent

My parent is noticable **aging**

My parent is becoming increasingly **forgetful**

My parent shows a few small **changes in behaviour**

My parent is **confronted** with the **worrying signals** coming from their social environment

My parent has to **contact** a **formal care** institution, often a GP

My parent has to undergo a few **tests** at a formal care institution

My parent is **diagnosed** with dementia

awareness

Creating awareness and knowledge about the early symptoms of dementia.

supporting

Supporting loved ones around the person with dementia on how to address the sensitive topic

knowledge

Offering more understandable and appropriate information after the diagnosis

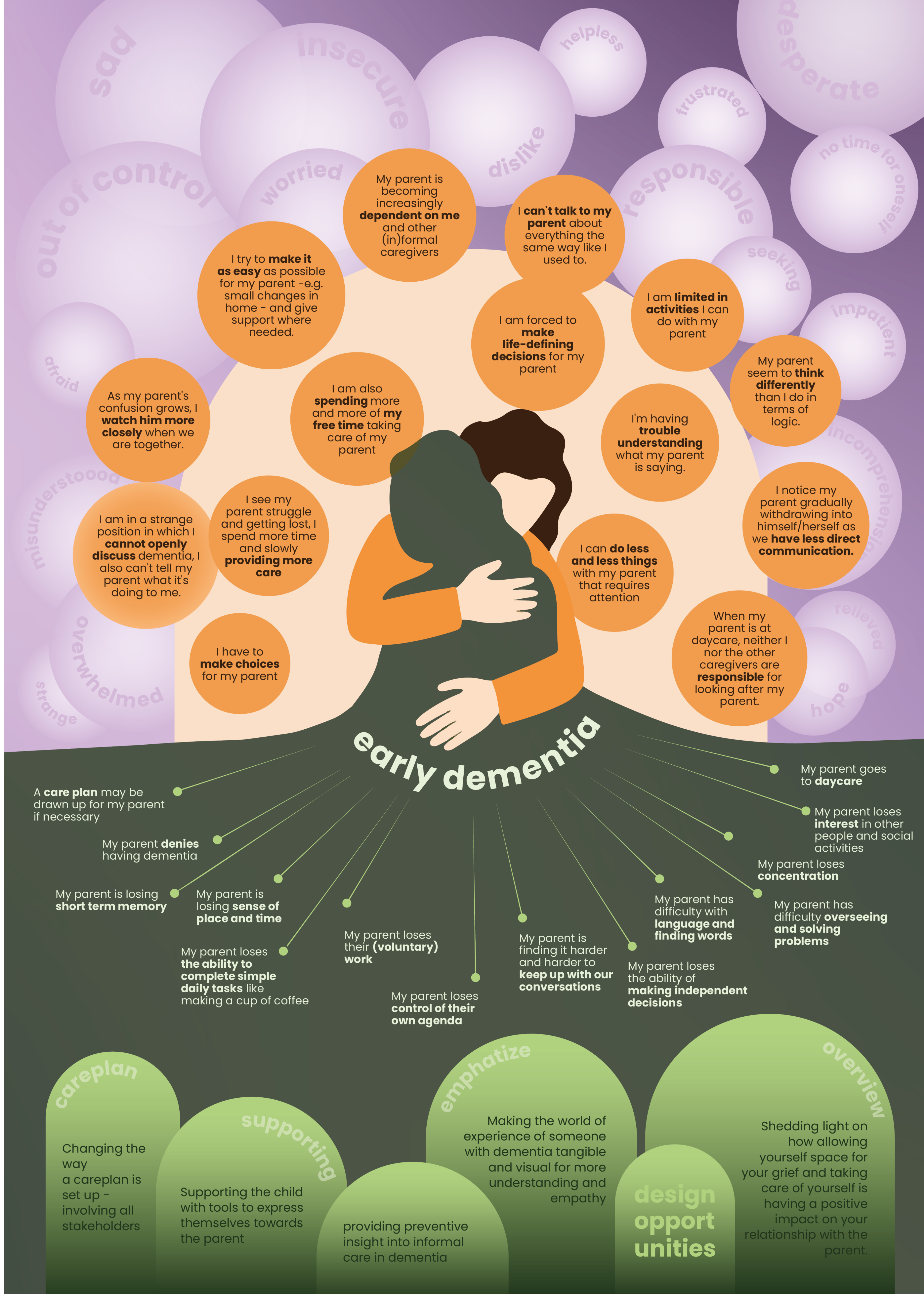
overview

Offering an overview of possible dementia care for both the patient and the loved ones

Figure 30: *Journey of the child stage 1 'aging'*

understand

The diagnosis of a parent's dementia affects both the child and the parent. Many **uncertainties** are brought on by this diagnosis, which prompts a search for the best course of action. The child takes on **more caregiving duties** as the initial symptoms become more obvious. In addition to providing care for their physical needs, children are also **forced to make decisions** about their parents' lives. **Roles are shifting**. A lot is happening, but little attention is paid to the impact on the child. The **practical aspects** of what dementia entails **stifle the feelings and emotions**.



My parent is becoming increasingly **dependent on me** and other (in)formal caregivers

I **can't talk to my parent** about everything the same way like I used to.

I try to **make it as easy** as possible for my parent -e.g. small changes in home - and give support where needed.

I am forced to **make life-defining decisions** for my parent

I am **limited in activities** I can do with my parent

As my parent's confusion grows, I **watch him more closely** when we are together.

I am also **spending** more and more of **my free time** taking care of my parent

My parent seem to **think differently** than I do in terms of logic.

I'm having **trouble understanding** what my parent is saying.

I see my parent struggle and getting lost, I spend more time and slowly **providing more care**

I am in a strange position in which I **cannot openly discuss** dementia, I also can't tell my parent what it's doing to me.

I notice my parent gradually withdrawing into himself/herself as we **have less direct communication.**

I can **do less and less things** with my parent that requires attention

I have to **make choices** for my parent

When my parent is at daycare, neither I nor the other caregivers are **responsible** for looking after my parent.

A **care plan** may be drawn up for my parent if necessary

My parent **denies** having dementia

My parent is losing **short term memory**

My parent is losing **sense of place and time**

My parent loses **the ability to complete simple daily tasks** like making a cup of coffee

My parent loses their **(voluntary) work**

My parent loses **control of their own agenda**

My parent is finding it harder and harder to **keep up with our conversations**

My parent loses the ability of **making independent decisions**

My parent has difficulty with **language and finding words**

My parent has difficulty **overseeing and solving problems**

My parent loses **concentration**

My parent loses **interest** in other people and social activities

My parent goes to **daycare**

Changing the way a careplan is set up - involving all stakeholders

Supporting the child with tools to express themselves towards the parent

providing preventive insight into informal care in dementia

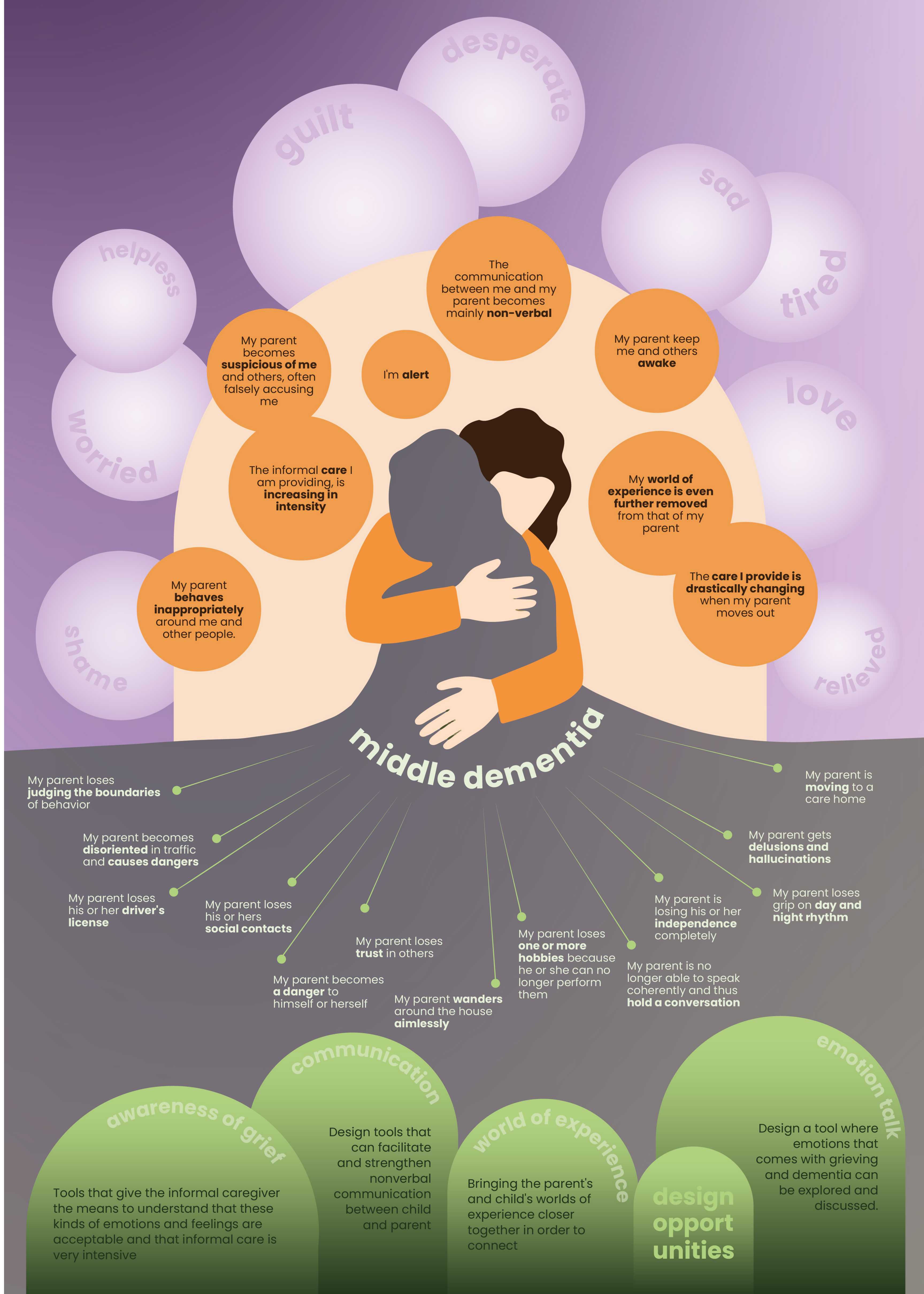
Making the world of someone with dementia tangible and visual for more understanding and empathy

Shedding light on how allowing yourself space for your grief and taking care of yourself is having a positive impact on your relationship with the parent.

Figure 31: *Journey of the child stage 2 'early dementia'*

understand

The child becomes **increasingly aware of losing** the parent in small steps. The child has to take on **more responsibility** while also feeling more **helpless**. The extent of the **impact on the child gets more apparent** when the care is (partly) taken out of their hands, whether by arranging homecare, going to a day care centre or moving into a permanent care facility. The child is less and **less able to communicate** with the parent and their worlds of experience are **growing apart**. In a sense, the child has already said **goodbye** to the parent.



The communication between me and my parent becomes mainly **non-verbal**

My parent becomes **suspicious of me** and others, often falsely accusing me

I'm **alert**

My parent keep me and others **awake**

The informal **care** I am providing, is **increasing in intensity**

My **world of experience is even further removed** from that of my parent

My parent **behaves inappropriately** around me and other people.

The **care I provide is drastically changing** when my parent moves out

My parent loses **judging the boundaries** of behavior

My parent is **moving** to a care home

My parent becomes **disoriented** in traffic and **causes dangers**

My parent gets **delusions and hallucinations**

My parent loses his or her **driver's license**

My parent loses his or hers **social contacts**

My parent loses **trust** in others

My parent becomes **a danger** to himself or herself

My parent **wanders** around the house **aimlessly**

My parent loses **one or more hobbies** because he or she can no longer perform them

My parent is no longer able to speak coherently and thus **hold a conversation**

My parent is losing his or her **independence** completely

My parent loses grip on **day and night rhythm**

Tools that give the informal caregiver the means to understand that these kinds of emotions and feelings are acceptable and that informal care is very intensive

Design tools that can facilitate and strengthen nonverbal communication between child and parent

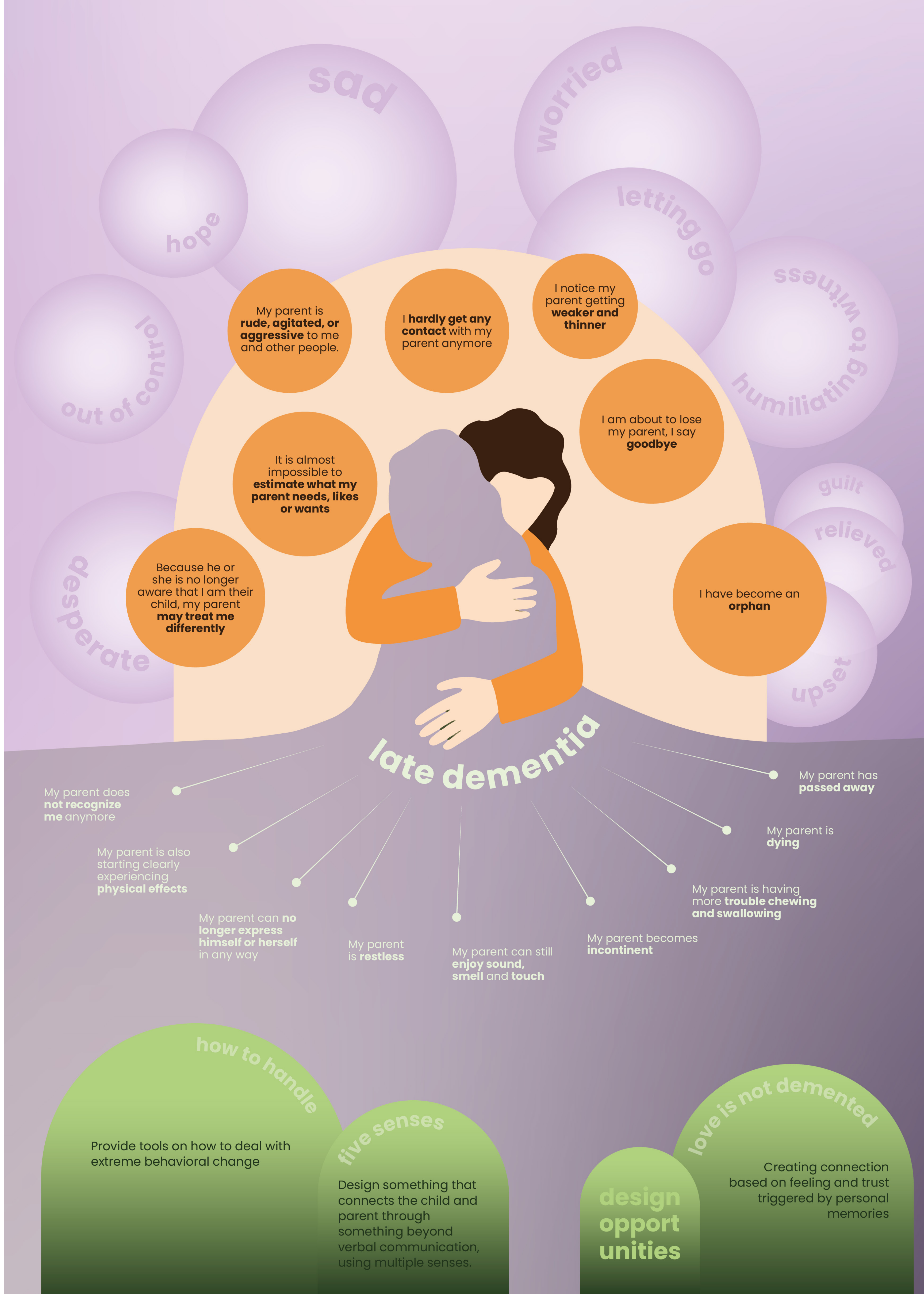
Bringing the parent's and child's worlds of experience closer together in order to connect

Design a tool where emotions that comes with grieving and dementia can be explored and discussed.

Figure 32: *Journey of the child stage 3 'middle dementia'*

understand

The parent is **totally dependent** on others and the **physical symptoms** of dementia increase. Contact is extremely limited, making it **difficult** for the child **to understand** the needs and preferences of the parent. The child sees **death as a good thing**, which is the **end** to the severe dementia **suffering**. In the end, the child loses the parent to death, which is often experienced as a certain **relief**. The child had **already lost the parent** to the dementia.



My parent is **rude, agitated, or aggressive** to me and other people.

I **hardly get any contact** with my parent anymore

I notice my parent getting **weaker and thinner**

I am about to lose my parent, I say **goodbye**

It is almost impossible to **estimate what my parent needs, likes or wants**

Because he or she is no longer aware that I am their child, my parent **may treat me differently**

I have become an **orphan**

My parent does **not recognize me** anymore

My parent is also starting clearly experiencing **physical effects**

My parent can **no longer express himself or herself** in any way

My parent is **restless**

My parent can still **enjoy sound, smell** and **touch**

My parent becomes **incontinent**

My parent is having more **trouble chewing and swallowing**

My parent is **dying**

My parent has **passed away**

Provide tools on how to deal with extreme behavioral change

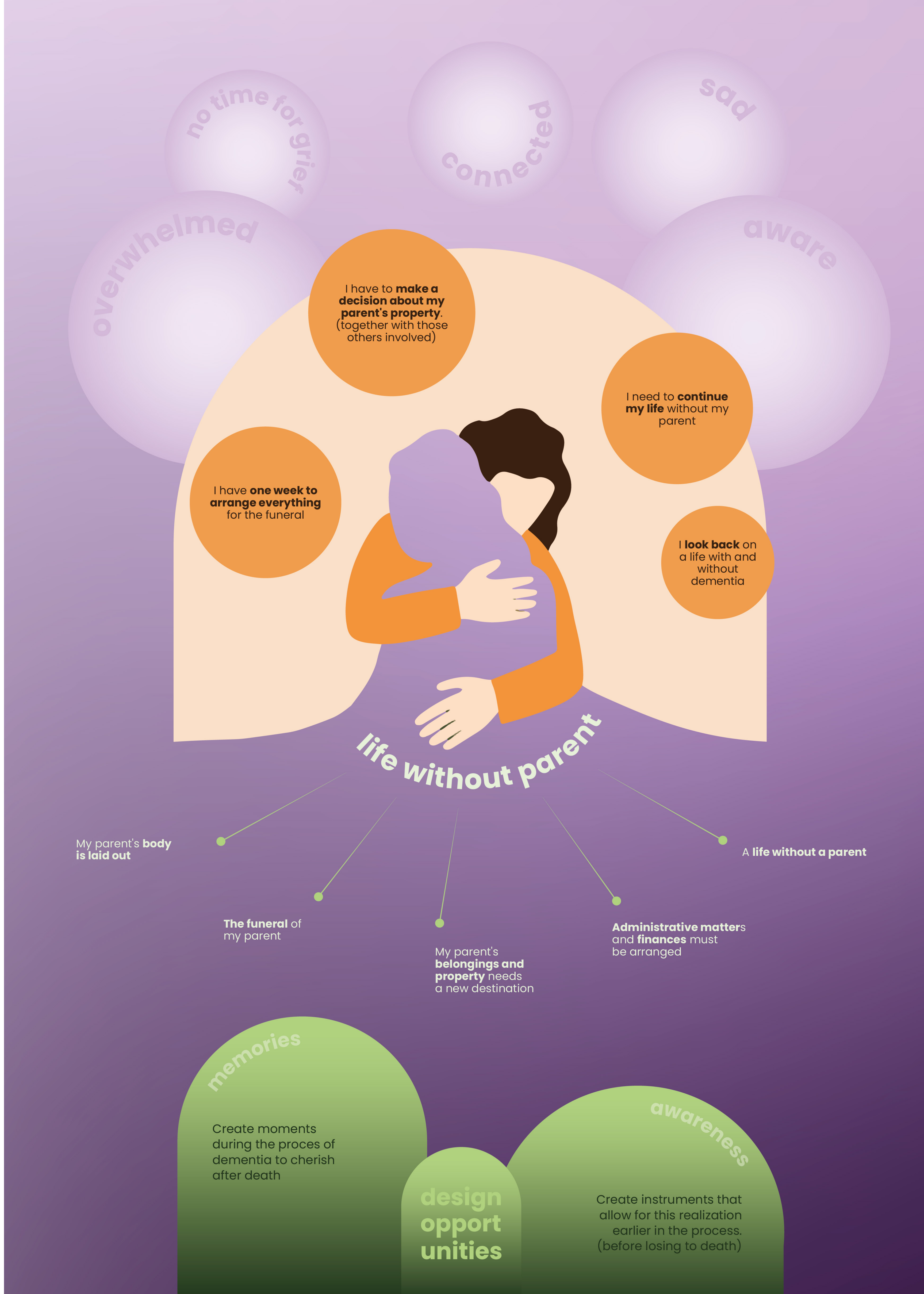
Design something that connects the child and parent through something beyond verbal communication, using multiple senses.

Creating connection based on feeling and trust triggered by personal memories

Figure 33: *Journey of the child stage 4 'late dementia'*

understand

After a **physical farewell**, a period full of **practical matters** follows. **Awareness** is growing and people are **looking back** at a period before and after dementia. Anticipatory grief flows into **grieving** after death, which is intertwined in a life without a parent.



I have to **make a decision about my parent's property**. (together with those others involved)

I need to **continue my life** without my parent

I have **one week to arrange everything** for the funeral

I **look back** on a life with and without dementia

My parent's **body is laid out**

The funeral of my parent

My parent's **belongings and property** needs a new destination

Administrative matters and **finances** must be arranged

A **life without a parent**

Create moments during the proces of dementia to cherish after death

Create instruments that allow for this realization earlier in the process. (before losing to death)

Figure 34: *Journey of the child stage 5 'life without parent'*

Concluding: understand

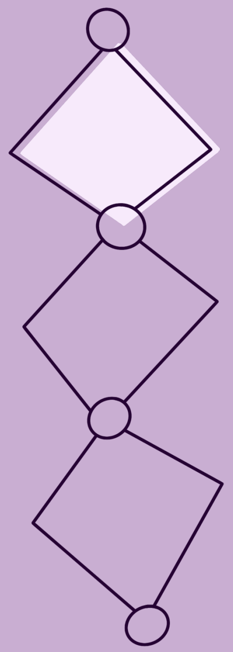
The understanding chapter introduces the complex world in which a child with a parent with dementia finds themselves. Three important processes in this world are explored and described in three sections: dementia, social connections, and grief.

Dementia occurs due to damage to brain cells. Because these cells can no longer communicate effectively, the behavior, thinking, and emotions of the person are affected. There are more than 50 types of brain diseases that fall under the umbrella term dementia, this project focuses on Alzheimer's disease. Because dementia is a progressive and unpredictable disease, signals and losses accumulate. Alzheimer's has three stages, an early, middle, and late stage, each with characteristic symptoms. Dementia requires different ways of interacting with the person with dementia for the adult child and other loved ones.

When a parent is living with dementia, there are formal and informal caregivers and organizations for both the parent and the child. These have been explored in the generative in-depth sessions and in the in-depth interview sessions by creating social set-ups. It depends on who is encountered in both environments, how the support is experienced by both the parent and the child. There is more care around the parent with dementia than around the child, even though the dementia also has a huge impact on their life. Formal caregivers do not have the right resources to include and empathize on the grief of the loved ones around the patient in their work.

Grief does not only occur with a loss due to death but has many forms. Whereas grief used to be seen as something temporary and surmountable, grief is now seen more as something that is part of life and contributes to personal growth. Grieving before actually losing the object or person is called anticipatory grief and is part of the process of having a parent with dementia. Because dementia brings multiple losses, the grief is ambiguous. Space for this form of grief is crucial because it ensures a healthier and less intense grieving process after death, among other things. Talking to others, sharing experiences, acquiring knowledge, and having social support are important aspects in creating this space. A list of different losses that a child of a parent with dementia may experience has been drawn up.

A journey of the child is used to visually close and summarize the research chapter and to discuss changes brought on by dementia, its effects on the child, and feelings of grief



Key take-aways: understand

I **Alzheimer's disease is primary focus** of this project.
II Alzheimer's disease has **three phases**, early, middle and late.
III Dementia causes **many losses and changes** for the adult child.
IV Dementia is **unique to the individual** and unpredictable.
V There are **many coping mechanismes** and dementia manners.

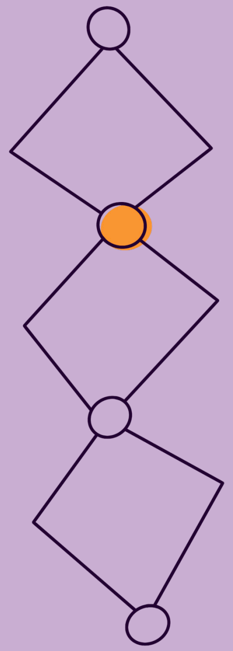
VI Dementia also has a significant **impact on the person's loved ones**.
VII The experienced social support is **depending on who you meet**.
VIII The variety of care providers is perceived as **overwhelming** and **unknown**.
IX Formal caregivers are **seeking for more tools to pay attention to and support loved ones**.
X Loved ones around someone who has dementia each uses a **different coping mechanism**. If this difference in way of coping is not acknowledged and accepted, it complicates collaboration, mutual support and **room for grief**.

XI Grief can take **many different forms**.
XIII **Loss** is an **inherently existential and essential human experience and loss experiences** contributes to the personal growth as human beings.
XIV Both **positive and negative emotions** play a significant role in grief.
XV Grieving for a parent who has dementia is an **ambigous loss**, one is grieving for someone who is still alive but is deteriorating gradually in small steps.
XVI The child must not only adapt to these **accumulation of multiple losses** that dementia brings, but also in its own behavior and interactions with the parent.
XVII The child can use two types of coping mechanisms: **acceptance or avoidance** of the situation.
XVIII It is crucial to **allow** adult children for **anticipatory grief** in the early stages of dementia. T**alking with others, seeking for information** and receiving **social support** are aspects of allowing to this anticipatory grief.

3 define

This chapter acts as a bridge between the understanding phase and the design phase (explore and finalize) by explaining the phenomenon that was discovered during the contextual research and formulating a design goal.

Making a design goal is a crucial first step in the design process because it establishes the project's focus and direction. A design goal is a short, concise, and specific statement of what the design should achieve and the problem it solves.



This chapter is structured in the following parts:

3.1 A found phenomenon: period of acknowledgement
3.2 Design goal
3.3 Aspects of design goal

3.1 a found phenomenon: period of acknowledgement

3.1.1 Shift in coping mechanism

The development of dementia in a parent leads to a period of anticipatory grief that lasts until the parent's eventual death. This is a gradual process of losing the parent before the actual physical loss, which can lead to feelings and emotions similar to mourning after death but with the added uncertainty of what lies ahead. It is a difficult period marked by a multitude of losses, intense emotions, and uncertainties.

Through in-depth interviews and generative sessions (appendix 04 and 05), it has been shown that there is a period of acknowledgement that can occur during a difficult time like this (figure 35). It is a phase where the adult child comes to terms with the fact that dementia is a progressive disease that cannot be avoided. A shift in coping mechanism takes place, from avoiding the situation to accepting it (chapter 2.4.7). Additionally, the child understands that their parent's mental and physical changes are a result of the disease and not because of their parent themselves. This realization can be difficult as it means that the child is already losing their parent due to this serious and pervasive illness.

If a period of anticipatory grief has developed, it can create an opportunity for a **new form of connection** between the parent and the child. This can open up new possibilities to shape the relationship in a different way, experiment with different forms of contact, and approach the parent from a new perspective. These efforts can bring the parent and child closer together, but they require primarily adjustments from the child, which can be heavy and challenging.

Acknowledging the dementia also allows **room for grieving** the loss of the parent before their actual physical passing. The child goes through a lot during this period and experiences a range of emotions. It is normal for the child to go through ups and downs, feel uncertain, and require assistance. All of these experiences belong to anticipatory grief, and giving these grief space is crucial.

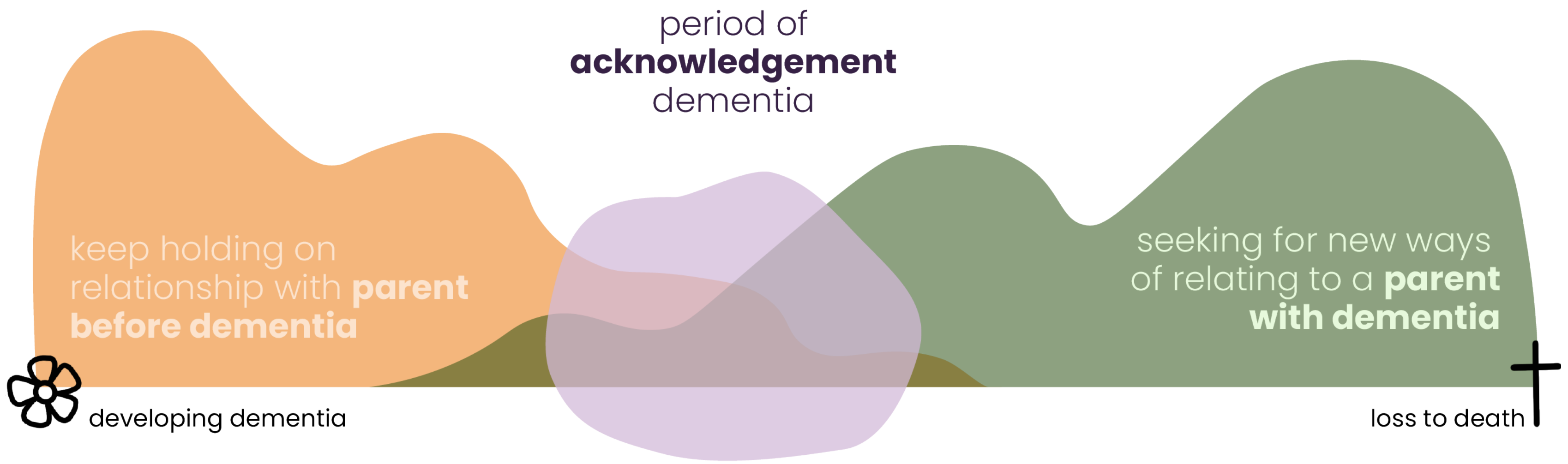


Figure 35: *Period of acknowledgement*

3.1.2 Framework acknowledgement

How does such a period of acknowledgement arise? Certain elements are crucial to achieving a period of acknowledgement, but it is important to note that it does not occur instantly or for everyone. An overview based on insights from generative sessions and in-depth interviews is presented in figure 36. To be receptive to this period, one needs a **trigger**. This can be anything from a stimulating conversation to a compelling documentary or book. The trigger opens people up to gain **knowledge**, which they reflect on their own experiences, creating **awareness**. This loop can continue indefinitely until the realization dawns that it is the dementia that changes the parent and not the parent themselves, thereby **acknowledging** the dementia. Even after this insight, the loop keeps going. This period of acknowledgement allows **space for grief** and fosters the emergence of a **new connection** between the child and the parent.

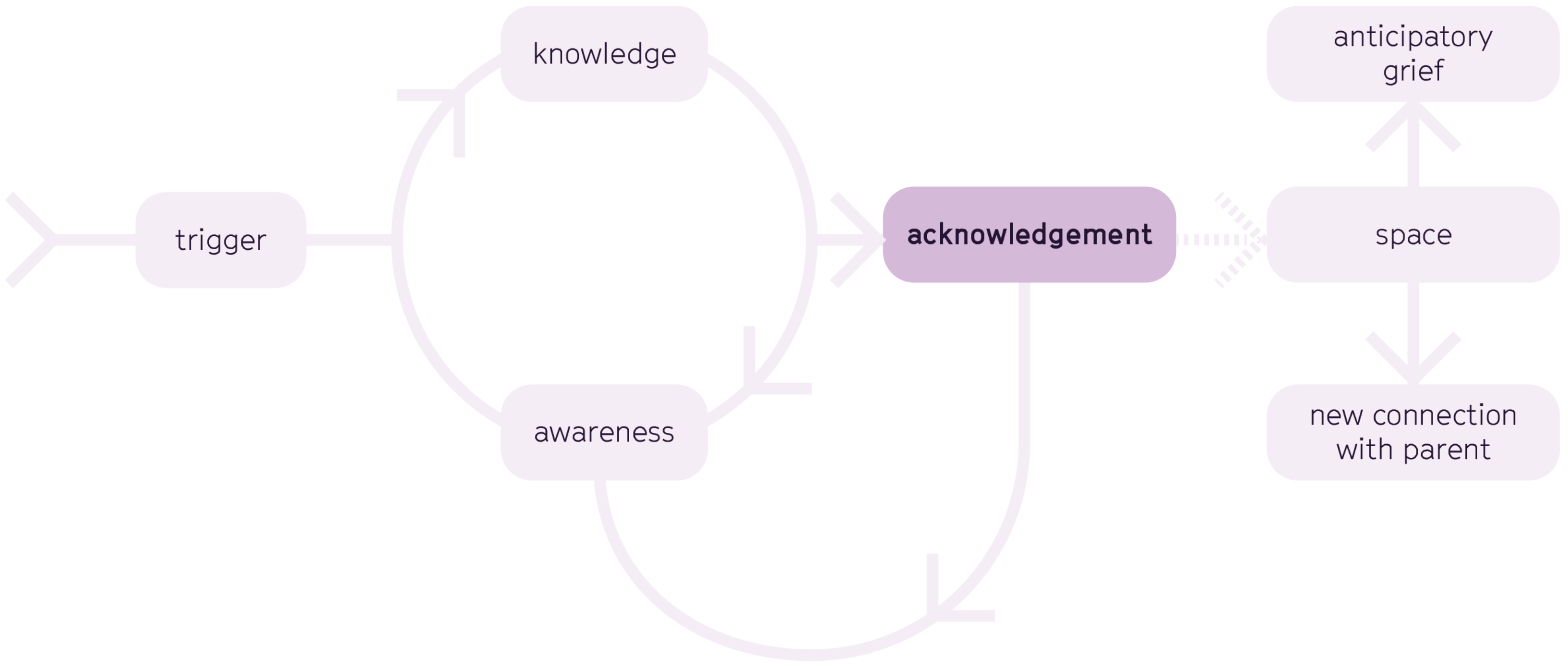


Figure 36: *Overview elements within period of acknowledgement*

3.1.3 Validation of phenomenon

This found phenomenon was repeatedly brought back to participants whose parent has dementia. An online survey form (appendix 10) was sent to the participants who had already participated. For the participants who still needed to be spoken to, the found phenomenon is part of the project introduction to them, both in the generative sessions, in-depth interviews (chapter 2), and design activities such as co-reflections and co-creations (chapter 4). Additionally, a conversation piece (figure 10) is created with statements about the aspects of the path to a period of acknowledgement. The tool is used to engage visitors of the Alzheimer Café Roosen & Borst (appendix 09) in conversation.

These activities allowed validation of whether adult children of a parent with dementia recognized themselves in one of the two found periods and, more important, in experiencing a period of acknowledgement. Responses and insights from these activities show that there are actually two periods of acceptance and avoidance that can occur in life with dementia until death. The ways in which individuals experience this period of acknowledging dementia are diverse but each contains acquired knowledge and reflection.

Participant E-M57 shared her experience of recognition as follows:

> “
>
> **How special, when we spoke in September I was still emotionally in that first denying period. I did not want to see the dementia. But now, for the past few weeks, I am really in that second period and I know better how to deal with my father. So that it can still be a pleasant period for both of us. I completely understand what you are saying.**

This understanding of the acknowledgement led to the creation of the design direction and goal stated in the next subchapter.

Figure 37: *Conversation piece for Alzheimer Café*

design goal

3.2

To enable the child in discovering the impact of the dementia on themselves with the help of provided knowledge about dementia and grief, thereby increasing the awareness and creating more room to grieve over time.

3.3

aspects of design goal and its desired effect

To enable the adult child whose parent is dealing with dementia in discovering the impact of the dementia on themselves with the help of provided knowledge about dementia and grief, thereby increasing the awareness and creating more room to grieve over time.

When someone is diagnosed with dementia, it affects not only them but also those they love. This design focusses on the **adult children** of someone with dementia, without an age limitation.

The **parent** of the child is dealing with early **Alzheimer** symptoms, which can be similar to other types of dementia.

Understanding as a child how dementia affects them is not only specific to that person and their circumstances, but it also cannot be enforced. The right tools can help the child **develop insight on their own**.

The design should include **knowledge** about both dementia and grieving since knowledge is an essential aspect of acknowledging the disease.

With providing knowledge, the child is encouraged to reflect this knowledge on their own experience and circumstances which will increase the **awareness** about the impact it has on them.

The child **allowing** themselves to experience **grief** is a long-term intended effect of this goal.

Because the acknowledgment period is crucial for creating space for grief, the design goal is formulated as stated on the previous page. Focusing on the autonomous discovering of the child in order to create awareness about the impact of dementia on themselves and their lives. Aspects of this goal are explained in figure 38.

Figure 38: *Aspects of the design goal*

This design goal is focused on the knowledge and awareness part of the overview in figure 39. It is not possible to force grieving, so creating room for grief acts as the intended effect of this goal.

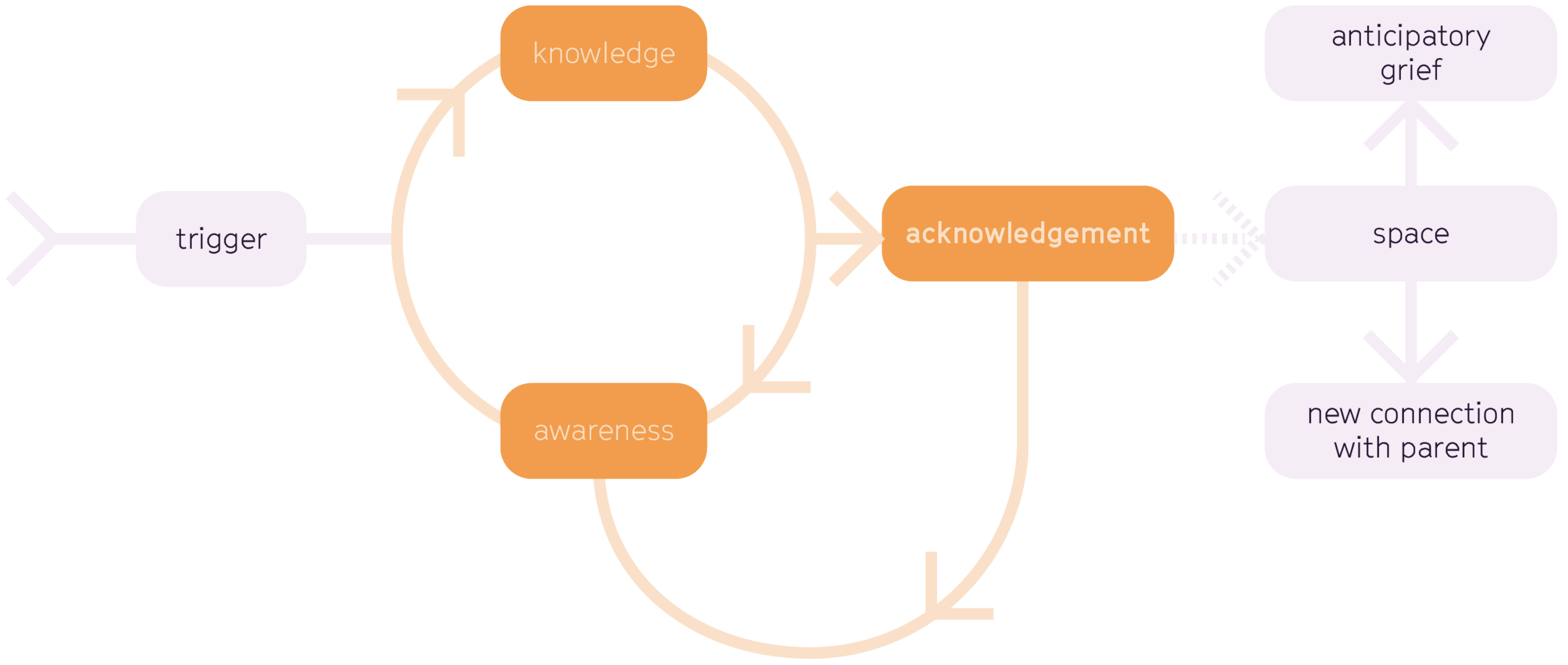
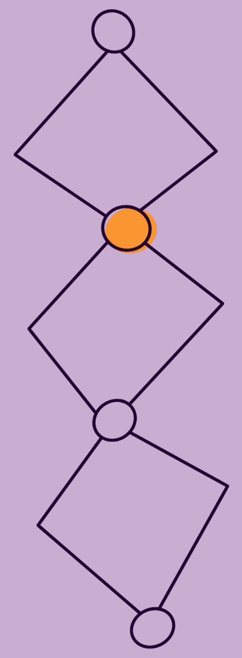


Figure 39: *Design focus within framework acknowledgement*

Concluding: define

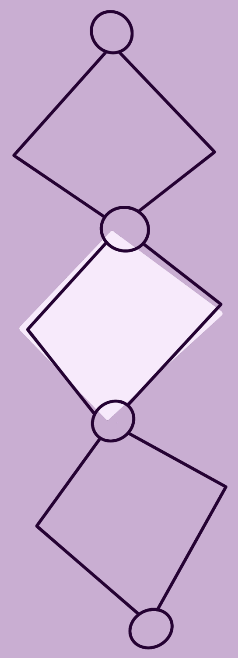
During contextual research, a phenomenon known as the “period of acknowledgement” was identified. This is a period in which the adult child come to the realization that dementia is a progressive disease that cannot be avoided. They also understand that it is the disease that is changing their parent, and not the parent themselves. Gaining knowledge about dementia and grief and reflecting on their own experiences is crucial to develop this period of acknowledgement. The design goal is based on this period: “to enable the adult child whose parent is dealing with dementia to discover the impact of the dementia on themselves with the help of knowledge about dementia and grief, thereby increasing the awareness and creating more room to grieve over time.”



Key take-aways

- To acknowledge the dementia: **knowledge and awareness** about one own situation is crucial.
- More **room for anticipatory grief is an effect** of acknowledging the dementia.
- If the adult child acknowledges the dementia, it creates an opportunity to discover a **new form of connection** between the child and the parent.
- **Design goal** is formulated and explained.

4 explore



This chapter describes the generated idea directions and shows the prototypes that are used to test and co-create interactions in order to arrive at the final design concept.

Throughout this chapter “explore” and the next chapter “decide,” important **insights** are indicated with **capital letters** and a purple background. In the chapter “finalize”, design choices refer to these insights.

This chapter is structured in the following parts:

4.1 An introduction to the exploring phase
4.2 Ideation
4.3 Conceptualization

4.1 an introduction to the explore phase

4.1.1 Research questions and design activities

The found acknowledgement period and its aspects serve as a basis to explore possible design opportunities and directions within the formulated design goal. Several design activities are conducted and are listed both below and in chapter 1.3.2. The following research questions are used to guide these activities.

- How do you encourage adult children to learn?
- How can you become aware of your losses?
- How can you gain knowledge about dementia?
- How can you gain knowledge about grief?
- How can knowledge about dementia help understanding?
- How can you raise awareness about the impact of dementia?

- **Individual brainstorming**
- **Brainstorm with fellw students**
- **Co-reflection sessions with future users and fellow students**
- **Low-fidelity prototyping**
- **Co-creation session with future users**

ideation 4.2

4.2.1 Brainstorm sessions: 2 idea directions

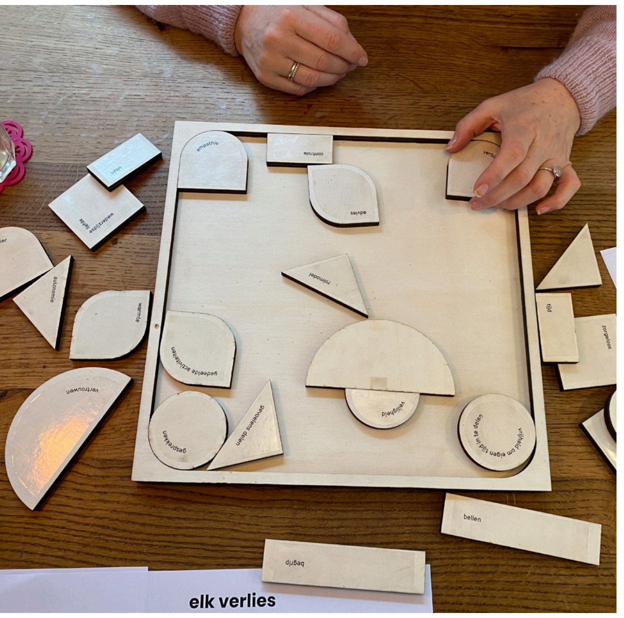
Ideas for providing adult children with knowledge - to understand the effects of dementia on themselves - are emerging, both through individual brainstorm sessions and in collaboration with peers (figure 40). These led to three potential design directions, which are compared and discussed in order to assess the feasibility of achieving the design goal (appendix 12). After this, two ideas are translated in two low-fidelity prototypes presented on the following pages.

Figure 40: *Brainstorm sessions with fellow students*

Figure 41: *Interaction during co-reflection with idea direction 1*

Idea direction 1: Future Path

Future Path (figure 41) is an interactive experience in a space where an adult child of a parent with dementia can walk through alone or with another. Step by step, a “situation” is presented, a situation that can arise from dementia and explains an experience. The situation prompts the child to reflect on their own comparable experience and suggests multiple ways of acting. Based on the choice between these actions, the path continues until the child reaches a part of the space. This presents a persona with a coping mechanism, in which the visitor may or may not recognize themselves. With this persona, the adult child can reflect retrospectively on the choices they have made. Through these interactive situations and choices, visitors are stimulated to reflect on their own experiences and ways of dealing with



Idea direction 2: A Grief Ritual for every loss

This second idea is called ‘a Grief Ritual for every loss’ (figure 42) and involves a tangible object with different forms containing terms related to a relationship. These blocks with terms represent emotions and losses. The adult child can create a visual overview of their relationship with their parent by positioning these blocks on the board. When the child notices a change in this relationship, they can pick a corresponding block. Using a reflective guide, the child can then discuss this block with someone else, delving into deeper layers. The block is then flipped over and replaced with a positive term that still describes the relationship. This way, the child can develop a grieving ritual for each change that comes with dementia, taking small steps to recognize the losses that come with it.

Figure 42: *Interaction during co-reflection with idea direction 2*

4.2.2 Co-reflections

These two prototypes of the idea directions were used to test the interactions and qualities with six participants, of which one participant also participated in the generative in-depth session and five fellow students (appendix 13). A co-reflection method is used consisting of three phases: explore, brainstorm and confront, in which the user’s experience with dementia was explored, ideas were generated within my design goal, and the two prototypes were presented. The main insights of each idea are discussed below, an understanding of the method, an overview of the test materials and participants can be found in appendix 13.

Main insights

Idea direction 1

A / **Sharing this experience** with others in your immediate environment was seen as something very valuable, It lowered the threshold to a follow-up conversation.

B / The experiences **prompt the user to reflect** on their own similar experiences.

C / When making decisions about how to handle a parent who has dementia, there is **no right or wrong response**. This is so situation and person dependent, it should not judge the user.

D / The scenarios and options should not be laid out as flow charts, the answers are not sequential, and the user shouldn’t be guided to a persona in particular area of the room. Once more, this imposes a lot of **presumptions and places the user in a pigeonhole**.

E / One must **first be forced to think** before emphasizing dementia-friendly manners in order to avoid socially acceptable responses.

F / Because situations are greatly influenced by the **stage of dementia** a person is experiencing, it is important to take this into account when creating an experience.

G / **Feelings and emotions** may be highlighted a little more, the theory surrounding dementia is now the main focus.

Idea direction 2

H / This idea literally creates and **gives space for grief** on the table and its emotions and feelings.

I / The **abstract forms of wood fit the image of dementia**, it chafes and does not fit into its own reality.

J / The **simplicity** and not too many steps are strong. The fact that the words already have a form does not bother.

K / Words speak to one’s own **personal imagination and interpretation**, image on the other hand is too personal and already fills in.

L / This concept mainly deals with abstract ideas and emotions, so it still **lacks knowledge about dementia**.

M / It is still **too open** to actually work with it, it needs more guidance.

N / It was not felt nice to have this as a permanent object in a house, it should rather be something you **pick up now and then to start a conversation**.

O / The concept also needs room for **negative aspects and feelings**, they belong there too.

P / Aspects and feelings are mixed up, there is a need to **categorize** these words.

4.3

conceptualization

4.3.1 Co-creations

Both idea directions have valuable aspects. During the next phase, these aspects are tested by dividing them into several prototypes, which were built upon idea direction 1. (figure 43).

These new prototypes and the two prototypes of the co-reflections (chapter 4.2.2) were used in three co-creation sessions with (experience) experts with the aim of enhancing the concept through the use of their experience and knowledge gained from practice and context.

One co-creation was held with D-T62 (Case Manager for Dementia) and took place in a residential care facility for people with dementia (figure 43). A second co-creation took place online with ED-M51 (an activity facilitator for people with dementia and mother diagnosed with Alzheimer's). A third group co-creation (figure 43) took place with four previous participants from the understanding phase, E-G56 (mother Alzheimer's), ED-J45 (father Alzheimer's † & employee nursing home dementia), D-T59 (coordinator and day care worker) and D-B49 (welfare worker meeting center dementia and caregiver small-scale living dementia).

The main insights from all three co-creation sessions are summarized below, these served as the foundation for the concept choice. The test setup and methods, features of the prototypes, and the key insights from each of the three co-creation sessions are listed in appendix 14.

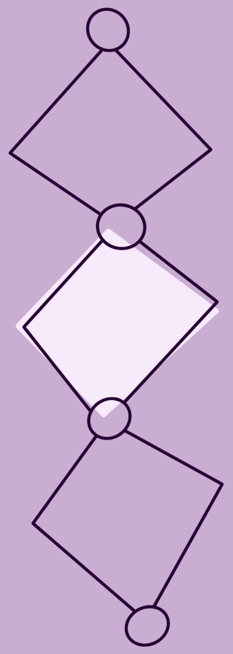
Main insights

Q / Reflection and discovery is quite something **personal** that you like to do in an **intimate** setting, therefore the form in which a conversation can be held using a tool is more in keeping with the purpose as opposed to a publicly accessible experience.
R / It is a **sensitive topic** in which many emotions will be stirred up. From an expert perspective, the importance of guidance - professional or otherwise - in this stirring up was emphasized.
S / An **experience as a trigger** helps the user **recall to personal experiences**.
T / From the professional side, such as the case manager, there is **a need to have more tools to start a conversation with loved ones of their clients**. Especially **to move past the surface** and gain a little more understanding of the more profound layers of their experience and grief.
U / Something **handy** that can be passed around, borrowed or purchased is a low barrier to use.
V / Although an interactive experience sounds like something impressive, the **threshold** is perceived to be **too high to go** there. The people who would visit this place are already interested in learning more about dementia and grief.
W / In the prototypes around an interactive experience, too many layers were incorporated so it was perceived as **too complex**. The purpose was lost sight of.

Figure 43: *Impressions of co-creation sessions*

Concluding: explore

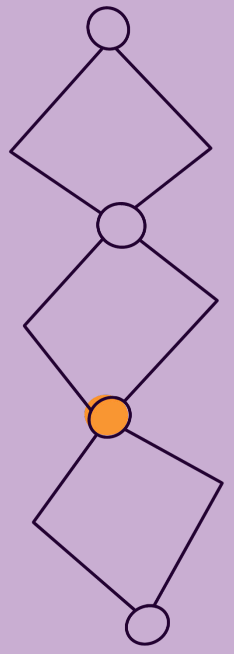
Individual and collaborative brainstorming sessions were conducted to generate ideas within the design goal. Two idea directions emerged, which were tested through two prototypes in six co-reflection sessions. New prototypes were created and tested with co-creations involving experience experts and expert professionals, based on the insights gained. These design activities have led to a package of insights that can be used as a basis for concept selection.



Key take-aways

- The **take-aways A to W** serve as the foundation for the concept selection. These are summarized throughout the explore chapter.

5 decide



This chapter presents the choice of the concept direction. It shows the iterations made in the design based on interaction and tests.

This chapter is structured in the following parts:

5.1 Concept choice
5.2 Concept iterations

concept choice 5.1

Based on design activities and tests in the exploring phase, a concept choice is made. To determine the purpose of the concept, two interaction tests are conducted.

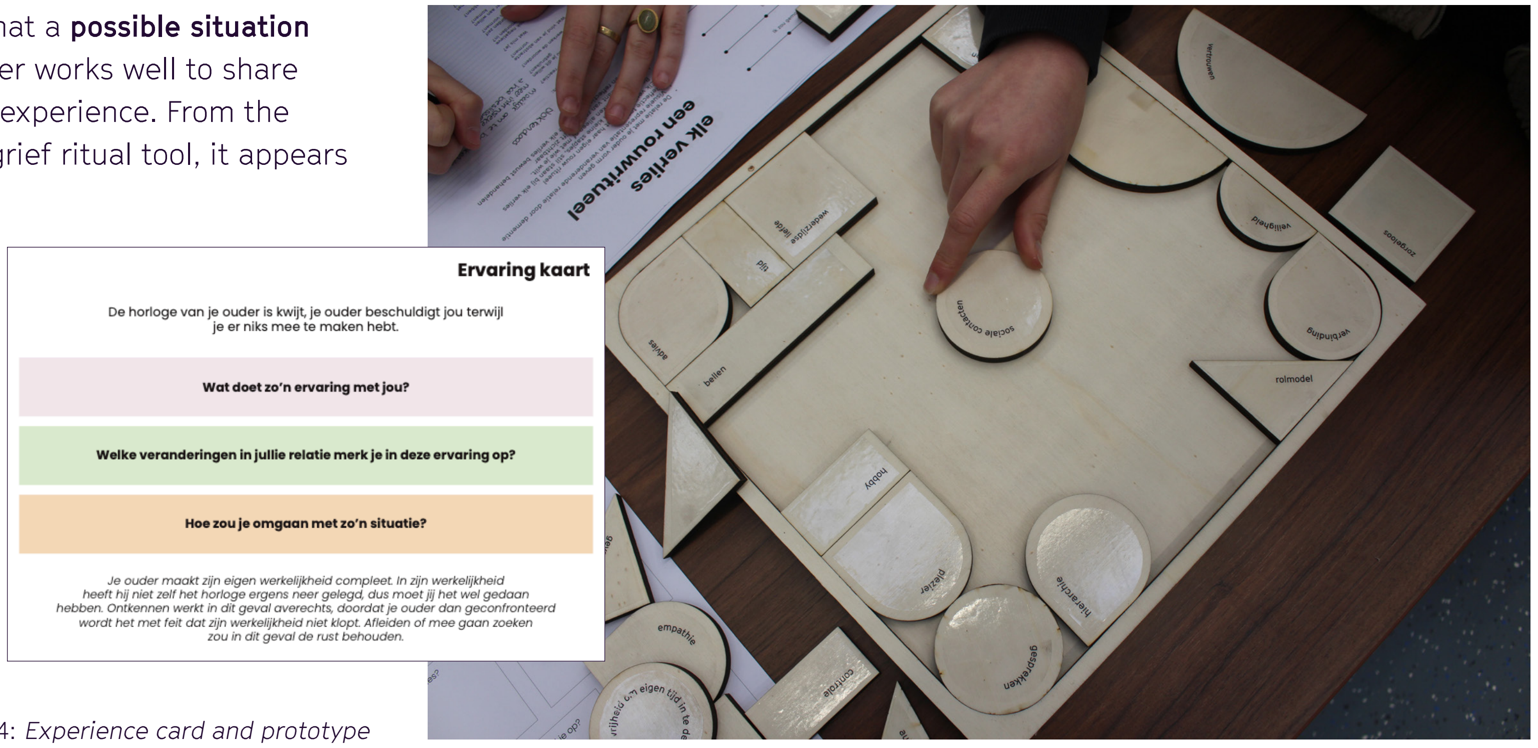
5.1.1 Concept choice

From the two idea directions (chapter 4.2) - an interactive experience and a tangible grief ritual tool - it emerged that adult children of a parent with dementia need a tool on a small scale. Sharing grief is intimate and personal, which is expressed more in personal conversations. Therefore, aspects of both directions have been combined into the concept choice. The interactive experience Future Path showed that a **possible situation** as a trigger works well to share your own experience. From the tangible grief ritual tool, it appears that **holding a tangible object** with emotions and aspects of grief is a valuable addition to being able to tell your story.

In order to test the new concept, the wooden prototype of idea direction 2 'a grief ritual for every loss' (chapter 4.2.1) is modified. New words and additional 'situation' cards are created (figure 44). A situation card consists of a brief description of an experience that a loved one of someone with dementia might have. Based on this experience, the conversation partner can ask three questions listed on the card:

1) How does such a situation affect you? The adult child can respond using the purple words.
2) What changes in your relationship do you notice as a result? The adult child can respond using the green words.
3) How would you deal with the situation? The adult child can respond using the orange words.

After explaining the blocks that correspond to the adult child, the explanation on the card can be addressed. It contains knowledge about dementia and grief that encourages reflection on ways of coping.



Ervaring kaart

De horloge van je ouder is kwijt, je ouder beschuldigt jou terwijl je er niks mee te maken hebt.

Wat doet zo'n ervaring met jou?

Welke veranderingen in jullie relatie merk je in deze ervaring op?

Hoe zou je omgaan met zo'n situatie?

Je ouder maakt zijn eigen werkelijkheid compleet. In zijn werkelijkheid heeft hij niet zelf het horloge ergens neer gelegd, dus moet jij het wel gedaan hebben. Ontkennen werkt in dit geval averechts, doordat je ouder dan geconfronteerd wordt het met feit dat zijn werkelijkheid niet klopt. Afleiden of mee gaan zoeken zou in dit geval de rust behouden.

Figure 44: *Experience card and prototype*

5.1.2 Interaction tests

The concept is tested and iterated through two interaction tests: a semi-structured test with fellow students to gain insight into interactions (figure 35). A second test involved a participant named E-D54 who has a mother who has Alzheimer's (figure 46). The key insights are listed below which, together with those gathered earlier, lead to the final design. The set-up of the test and further insights can be found in the appendix 15.

Figure 45: *Interaction test with fellow students*
Figure 46: *Interaction test with Douwtje*

Main insights

X / This tool can also be used to **get more in tune with other family members** about dealing with the parent with dementia. The tool can be used in multiple ways.
Y / By dividing it into **layers**, a situation becomes understandable.
Z / Grasping the wooden words, gives feeling to it and certain emotions become **tangible**.
AA / Allowing the user to **select** an experience card works well, it gives **control over the subject**.
BB / **Grief does not even need to be emphasized**; that will come later.
CC / Several **accompanying questions** may be asked per layer, to further explore depth.
DD / On the one hand the wooden board gives a grip, on the other hand it **limits** the user. This needs to be tested.
EE / **Iteration and careful word selection** are required regarding the blocks.
FF / The way one **receives it** matters!

Figure 47: *Concept elements*

5.1.3 Goal of concept

To conclude, the choice of concept is a conversation tool which initiates a conversation through an experience that is guided by physical blocks with words on them. See figure 47 for an impression of the concept elements.

The tool consists of blocks with words, a guide, start card, experiences cards and a exploration board. An experience card features three themes to guide conversations between adult children of parents with dementia and a conversation partner, helping them explore their **emotions**, identify **losses and changes**, and develop **coping strategies**.

5.2 concept iterations

Tests are conducted with both dementia experts and fellow students to refine and test the various elements of the concept. This section provides a brief overview of the activities undertaken, with further details available in appendix 16. Chapter 6 presents the outcomes of these tests and how they were incorporated into the final design.

Main insights

GG / The shapes should not be too hard or too diverse, curves give a **softness** to the blocks (figure 51).
HH // The shapes should not initiate that there is only one solution, **prevent users from puzzling**. The shapes should not limit the user.
II // The words should **avoid judgments**, but rather have a generality that allows the adult child to use them for their own interpretation.

5.2.1 Blocks

The blocks of the concept are important to provide the adult child with guidance in finding words to share their story. To design them appropriately, various shapes are tested with three participants (see figure 48) and a careful selection of words per theme is made based on gathered data of several research and design activities (see appendix 16A).

Figure 48: *Detail test on formgiving*

Main insights

JJ// An exploration board should provide both **freedom** for the user to place the blocks according to their **own interpretation**, as well as guidance.
KK// While some users may find guidance helpful, others may feel constrained by a board; providing **multiple options** may be necessary.
LL// It is important to keep this exploration board as **simple** as possible and avoid initiating linear or value judgments.

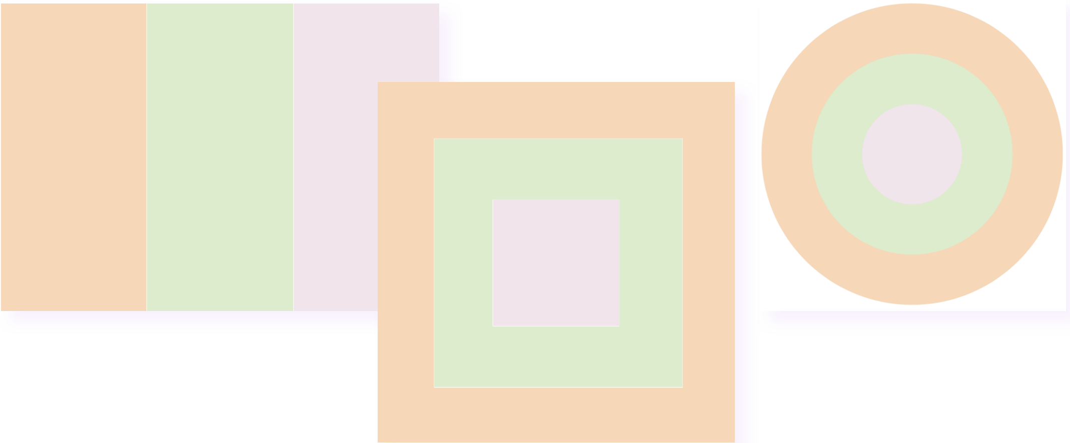
MM// The questions can be the same for each card, so they can be **separated from the card** itself.
NN// The experience should be written **briefly and concisely**, so that there is not too much room for interpretation.
OO// The explanation and knowledge about dementia in the situations can be presented in the **form of possible ways of dealing** with the situation.

PP// Both conversation participants must have the **same expectations and goals** for the conversation.
QQ// The conversation partner of the adult child needs a **backup support** to bring the conversation to deeper levels.

5.2.2 Exploration board

There are different possibilities for the user to place the blocks, from an empty table to a pre-designed exploration board with guidelines. Preferences and interactions are tested (figure 49) with three participants.

Figure 49: *Detail explorations*



5.2.3 Experience cards

The experience cards (figure 50) are essential in providing the adult child with a starting point for a valuable conversation about the impact of dementia. The experiences are selected and based on stories from previous research and design activities. These experiences are carefully reviewed with a dementia expert to ensure their accuracy (appendix 16C).

Figure 50: *Detail explorations*

Ervaring kaart

De horloge van je ouder is kwijt, je ouder beschuldigt jou terwijl je er niks mee te maken hebt.

Wat doet zo'n ervaring met jou?

Welke veranderingen in jullie relatie me

Hoe zou je omgaan met zo

Je ouder maakt zijn eigen werkelijkheid cor heeft hij niet zelf het horloge ergens neer geleg hebben. Ontkennen werkt in dit geval averechts, do wordt het met feit dat zijn werkelijkheid niet klop zou in dit geval de rust be

Je ouder zet koffie in een soepkom

vroege fase

001

Je ouder kan steeds minder goed de voorwerpen linken aan de functie of het woord.

Corrigeer je ouder **niet**. Het is vaak goed bedoeld maar daarmee bevestig je dat je ouder het niet meer zelf kan.

Bied je **hulp aan** in plaats van het overnemen, of doe het samen op een rustig tempo en met **geduld**.

Spiegel het gedrag door rustig voor te doen en je ouder mee te nemen zonder te corrigeren.

Laat de situatie **los** en drink uit een soepkom.

vroege fase

001

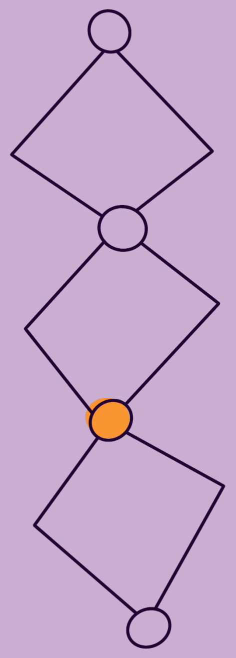
5.2.4 Use of concept

A starting card, a manual and a question card were designed as a result of small iteration on the use of the concept. In addition, a visual style and name are developed in line with the purpose of the concept.

Figure 51: *Prototyping the blocks*

Concluding: decide

Based on the design activities from the explore phase of the project, a concept was chosen. A combination of two earlier idea directions led to a conversation tool that facilitates a conversation between the adult child and a loved one in three different rounds. Starting with an experience card, emotions are explored, changes and losses due to dementia are identified, and coping strategies are developed. Tangible blocks with words supports the adult child in sharing their story through this conversation. This concept was further developed through various interaction and detailing tests that led to important insights for building a final prototype.



Key take-aways

- The **take-aways X to QQ** serve as the foundation for the final design prototype. These are summarized through out the decide chapter.

6 finalize

This chapter presents the project's final design including primary aspects, illustrates the desired user journey, and assesses the design through user testing.

The elements presented in this chapter are linked to the insights found in the previous chapters, 2. understand, 4. explore and 5. decide, and are identified by corresponding roman numerals and letters in brackets. An overview of all these insights can be found in appendix 17.

This chapter is structured in the following parts:

6.1 Introduction to grip: a tangible reflection tool
6.2 Desired journey
6.3 Key aspects of grip
6.4 Interactables: elements of grip explained

6.1 introduction to grip

a tangible reflection tool

grip is a tangible reflection tool designed for adult children of a parent with dementia, aiming to create visual insights into the impact of dementia on their own lives and well-being. By exploring personal experiences in four layers and physically laying them down using tangible words, it facilitates deep conversations between the adult child and a conversation companion. This allow the adult child to express emotions, understand changes and losses caused by dementia through provided knowledge, and explore new perspectives on behavioral norms without judgment.

Grief is often associated with death, and the loss of a loved one to death offers bereavement leave at work, understanding from social circles, and recognition of one's state of being.

However, losing a parent to a progressive brain disease such as dementia is not always socially recognized. Despite the physical presence of the parent, they continue to decline mentally. What impact do these changes and losses have on the life of an adult child, and how can they share this impact with others? Sharing this impact is crucial for creating space for grief and receiving social support (XVIII).

grip is designed for adult children with a parent with dementia to explore together with formal (T) or informal care what experiences and situations caused by dementia impact them, how they feel about it, what aspects of the relationship are lost, and how to act upon it. It also offers loved ones around the adult child a glimpse into a life with a parent with dementia and helps them better understand the adult child's experiences.

This tool provides room to explore how to weave an ailing parent into life and how to confront each loss again.

During the use of grip, the conversation is divided into four rounds (Y): allowing emotions (purple), naming changes and losses (green), exploring ways to cope (orange), and addressing new ways of coping (orange). Based on a child's experience and preferences, these four rounds are followed.

6.2 desired journey

A storyboard is created to illustrate the desired journey of the adult child when using grip. The storyboard shows in detail how an adult child (45 y/o), whose parent is dealing with early stage of Alzheimer, uses the reflection tool. The elements of grip are depicted in Figure X (see page X for detailed descriptions), and the storyboard can be found on the following pages.

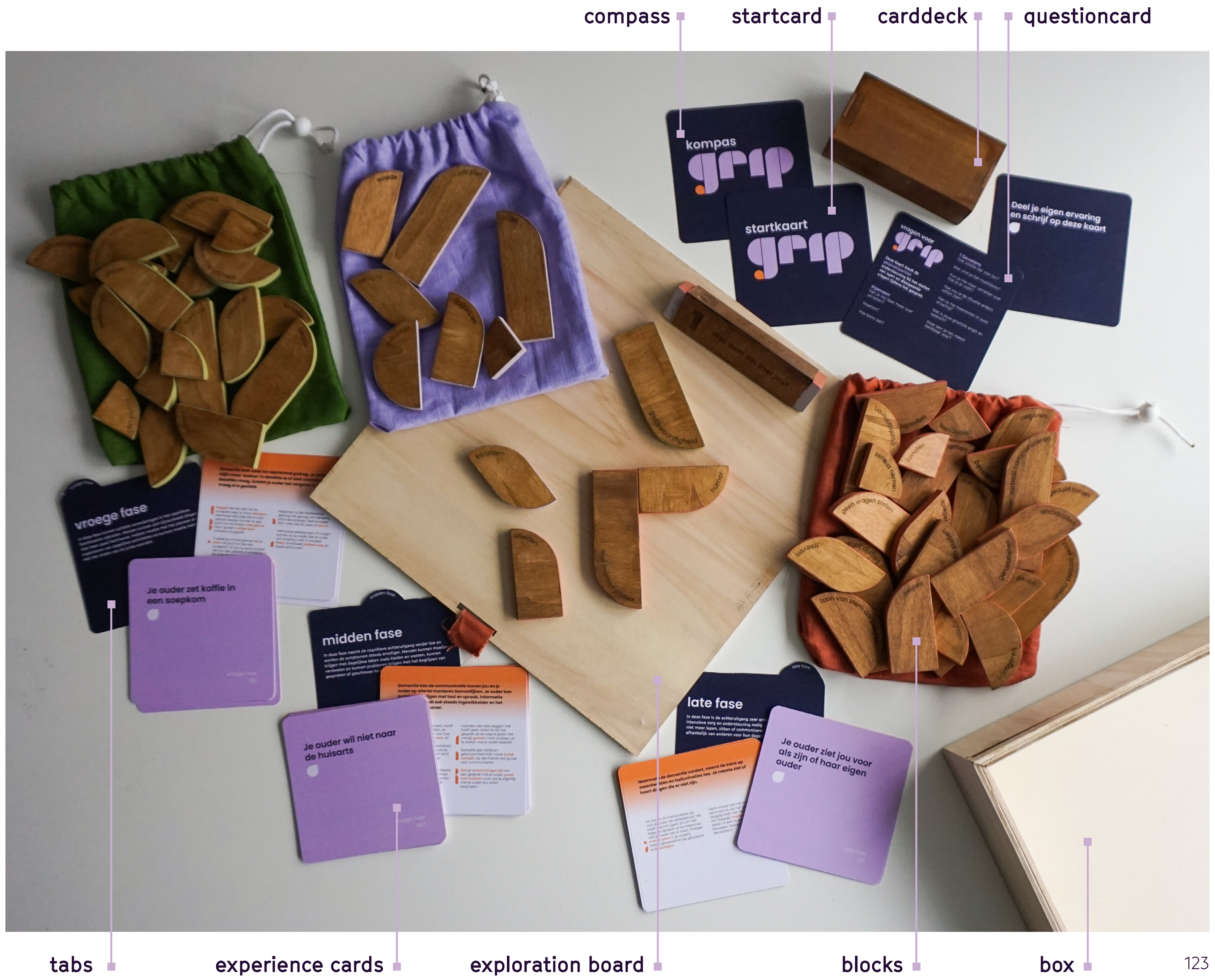
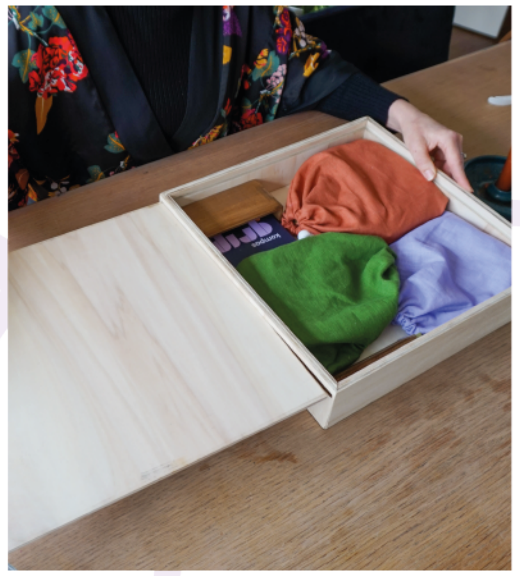


Figure 52: *Elements of grip*

finalize


grip is introduced by a **formal care giver** and an **adult child** is invited.


The grip is **opened**. The lid is placed on the table, which acts as a discovery field for the converstation. The blocks are unpacked and organized by color indicated on the bags. The carddeck is placed next to the lid. The question card is given to the conversation companion. The compass and starting card are laid out. The compass contains the use cues and ways of conversing (chapter 6.4).


The **starting card is discussed** as soon as the setting is ready and both converation companions are prepared. This card fosters a safe and open atmosphere in which sensitive experiences can be discussed without judgement.

Grip biedt een veilige en open ruimte en tastbare tools om de impact van dementie te verkennen en te ontdekken. Elk dementie ziekteverloop is uniek, elke relatie is anders en iedereen rouwt op een eigen manier. Om deze complexe en gevoelige ervaringen te bespreken, is het fijn om met de volgende richtlijnen te starten:

- Geef elkaar **ruimte** om te praten en te luisteren.
- **Respecteer** elkaars mening en gevoelens, oordeel niet.
- Stel **open vragen** om een dieper inzicht te krijgen.
- **Luister actief** naar elkaar en **vat** af en toe **samen** wat de ander zegt.
- Vermijd onderbrekingen en laat elkaar **uitspreken**.
- **Geef aan** wanneer iets moeilijk of gevoelig is om te bespreken.
- Maak afspraken over **vertrouwelijkheid** indien gewenst.
- **Stop** het gesprek indien nodig, er is geen enkele vraag die beantwoord moet worden.

Depending on the stage of the parent's dementia, the child starts by **selecting an experience card**. This card is a trigger to share an personal experience, so it does not need to be the same as described on the card.


Three questions with corresponding blocks serve as a **guide for the conversation** based on the experience card that has been selected. The order in which these questions are dealt with may differ, this is explained in the compass. The following pages illustrate these three steps.

finalize

2

The **question holder rotates** one turn to the second green question after the selected blocks have been discussed. The conversation companion asks if the child can use the green **blocks** to give words to the question "**What will change in your relationship?**". The green blocks contains possible changes. The child and their conversation companion discuss the changes and losses which the experience brings*****.

1

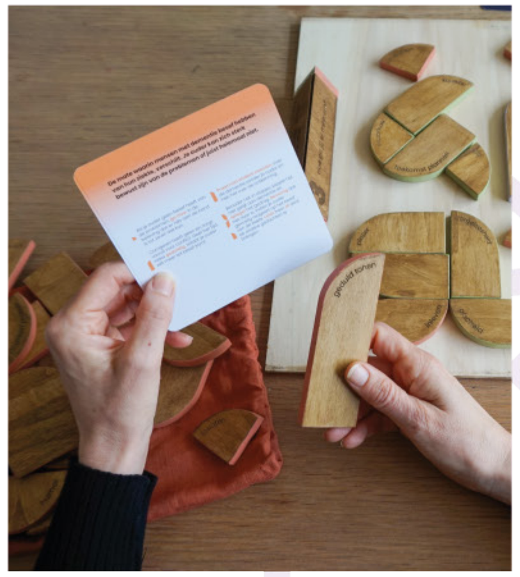
The card is **placed in the question holder** with the purple question first. The conversation companion asks if the child can use the purple **blocks** to give words to the question "**what does that do to you?**". The purple blocks contains possible emotions. The child and their conversation companion talk about the feelings that the experience brings up*****.

3

After discussing this new round of blocks, the **question holder is turned** one last turn to the third **orange** question. The conversation companion asks if the child can use the **orange blocks** to give words to the question "**How do you deal with it?**". The orange blocks contains possible ways of coping. The child and their conversation companion talk about ways of coping with the experience*****.

***** The conversation partner can **refer anytime to the question card** for guidance when posing open-ended questions.

finalize

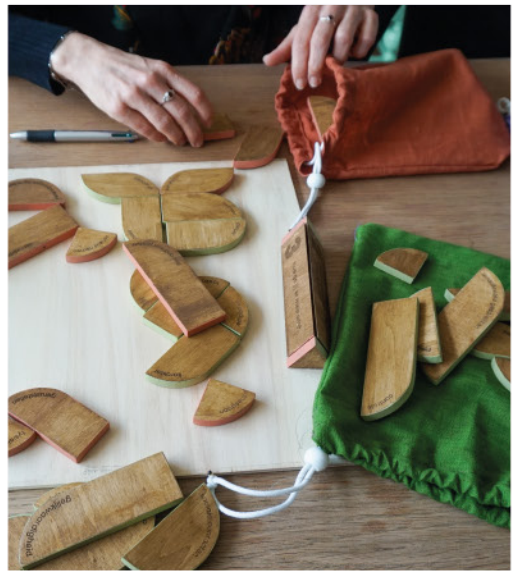


After discussing the three questions, the experience card is turned around. The child and their conversation companion **go over the explanation and evaluate the suggestions** on how to deal such a situation.

4

After the discussion, one can **choose a new card** or **write down their own** experience on a card. A new round will start, or the conversation will end.

After using grip, the elements are cleaned up and **stored** in the box.



The child has been able to express their feelings. and gained new perspectives, insights and ideas from grip. The child feels heard and seen.

6.3 key aspects of grip

Unique process
It is important to acknowledge that while grief is a universal experience, everyone's journey through grief is unique to them. grip is a tool that recognizes and honors this by allowing the individual to explore their own feelings and experiences in their own way (XI, XIII). Additionally, it is worth noting that while grip is not prescriptive, it does provide structure and guidance to help allow the grieving process.

Conversation starter
This aspect is well-stated, but it is important to emphasize that the conversation cards provided with grip are not a script. Instead, they are meant to be used as prompts to help spark meaningful conversations about grief and loss. They provide the loved ones of the adult child with the necessary tools to start a conversation and delve deeper (N,Q).

Grieving is not something one does alone
It is important to emphasize that grip is not just a tool for the adult child, but also for those around them. By facilitating conversations and providing insights about the impact of dementia on the adult child's life, grip helps loved ones better understand their experiences and give support through their grieving process (VII). Furthermore, grip can connect the adult child and his or her siblings by being more on the same page in dealing with their parent with dementia (X).

Anticipatory and reflective
Grip allows for both retrospective and prospective reflection. Grip could be used to reflect on past experiences with a parent with dementia and how those experiences have impact on the adult child's life. Furthermore, grip could be used to anticipate future challenges – brought on by dementia - and explore strategies for coping with them.

Tangible
When laying down the physical components of grip, it clearly shows the space that emotions and grief occupy. With these blocks it provides the option to link, move or exchange words given to these emotions and experiences. Furthermore, the use of tangible blocks can be beneficial for people who struggle to express their emotions verbally (Z).

Own interpretation
Grip is a tool that is meant to be used in a way that is meaningful to the individual (II). By allowing the child to interpret their own emotions and experiences, grip empowers them to take ownership of their grief journey.

Open dialogue without judgement
Grip is a non-judgmental tool (C) that is meant to facilitate open and honest conversations about grief and loss. By providing a safe space for these conversations to take place initiated by the 'start card' component, grip helps adult children to feel seen and heard.

Emotions as a basis
Grip is designed to provide a tangible space for the child to explore and express their emotions in response to the impact of dementia on their lives (G,H). Rather than emphasizing grief (BB), grip focuses on emotions, changes, and manners. By allowing the child to address their emotions first, grip provides a physical place to temporarily park these emotions before exploring the losses that dementia entails and how to cope with them (XVII). This approach supports mourners in better understanding, accepting, and regulating their emotions, as well as adapting to their new circumstances as needed (Greenberg, 2012).

Social support
Grip could be used to help the adult child communicate their needs to loved ones and formal care givers and to explore ways that they can provide support during difficult time (R).

interactables:

6.4 elements of grip explained

grip was designed iteratively by taking it back to the target group several times and incorporating interim insights into the prototypes. This section aims to describe the current interactive elements and the design decisions that are made.

6.4.1 People interacting with grip

Grip facilitates the conversation between the adult child of a parent with dementia and a conversation partner (A).

Adult child (VI) can be anyone whose parent is dealing with Alzheimer's disease (I).

The adult child can choose their **conversation companion** with grip. They are introduced to grip when a formal caregiver initiates a conversation. Alternatively, the adult child can initiate a conversation with a conversation partner of their choice, such as a partner, sibling, or close friend.

Figure 53: *Two people using grip*

6.4.2 grip an its elements

gripbox

Grip is received in a minimalist wooden box. All the elements of grip fit easily inside the box. Grip can be lent, passed on, or purchased, making grip a strong and durable packaging (U). When the box is opened, all the elements of grip can be seen at a glance.

Figure 54: *gripbox*

explorationboard

The lid of the box serves as an exploration board, with one side blank and the other side containing a colorful pattern. This way, the adult child can choose whether they need more support in the form of an underlayer or want to start blank (JJ,KK,LL).

Figure 55: *explorationboard*

cardholder

A triangular wooden card holder serves as a navigator for the conversation (MM). The holder can be rotated one turn after each round to the corresponding question. The colors of the questions correspond to the accompanying blocks of the round. The three rounds on this card holder are (E):

How does it affect you?

What changes in your relationship?

How do you cope with it?

Figure 56: *cardholder*

carddeck

The grip card set comes with a wooden holder. This set contains a compass, a start card, a question card, and 21 experience cards divided into the stages of Alzheimer's dementia (II, F). The three tabs make it easier for the user to choose the right card from the right stage, and there is also a brief explanation of Alzheimer's disease on these tabs.

Figure 57: *carddeck*

compass

The compass serves as a manual for grip (M), providing an overview of the elements of grip, explaining the steps in detail, presenting the order of the rounds, and providing references to further literature, organizations, and events. An outline of the manual can be found in appendix 16F.

Figure 58: *compass*

startcard

The start card is used to align both conversation partners and adjust expectations of each other, creating an open and safe atmosphere for a valuable conversation (PP). The card contains eight short guidelines that promote open communication (Clark & Brennan, 1991).

Figure 59: *startcard*

questioncard

Both conversation partners are equal, but the adult child's conversation companion may need some back-up support to delve into the deeper layers of the conversation (QQ). This support is provided in the form of open questions listed on the question card for each round (CC).

Figure 60: *questioncard*

experience card

An experience card is the important starting point for the adult child to share their own personal experience (B,S). The adult child is in control to choose a card to their preference (AA). The frontside contains a short possible experience that may have arisen from dementia (NN). On this side is also stated from which stage the experience comes and the number of the card. It is a simple and calm layout (J), to keep the attention on the experience and leave room for personal interpretation (IV). On the back are some sentences explaining how the experience arises from dementia. Below are possible suggestions on coping with the experience (OO), as long as the situation allows it. The icons refer to the blocks where these ways of dealing can be found on. These explanations and advice were developed through research activities and validated with a

Figure 61: *experience cards*

Figure 62: *experience cards early stage dementia*

Figure 63: *experience cards middle stage dementia*

Figure 64: *experience cards late stage dementia*

blocks

The box contains three colored linen bags - purple, green, and orange - filled with wooden blocks. The blocks are used to support the adult child in answering the questions and visually represent the impact of dementia. The design of the shape of these blocks allows the adult child to lay them together in multiple ways and hold them easily in the hand (HH). The curves emphasize softness to the words (GG), the material feels natural and friendly (I), and the color gives the child guidance as to which round they belong to. The words are engraved on the curves of the block, subtle but readable. This way, the user is not distracted from the term but can give their own meaning to the block (K). The blocks contains of terms in three themes divided in three colours (P):

Purple blocks

The purple blocks contain emotions (XIV). Six basic emotions from which multiple emotions can be derived and a seventh emotion commonly mentioned in a life with a parent with dementia. See appendix 16A for the words.

Green blocks

The green blocks contain changes and losses caused by dementia (III). Twenty terms that may modify the bond between parents and their adult children, either positively or negatively (O). See appendix 16A for the words.

Orange blocks

The orange blocks contain ways of coping with and responding to situations. Twenty-six coping mechanisms (V) that can have both a positive and negative impact on the parent with dementia, depending on the situation. See appendix 16A for the words.

Figure 65: *overview of blocks*

Figure 66: *purple blocks*

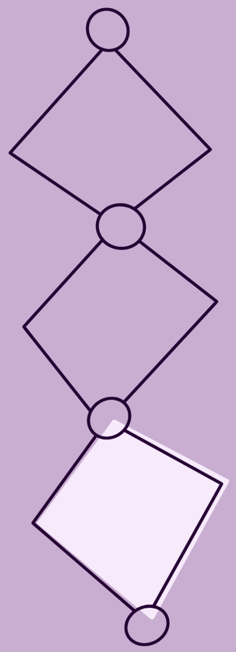
Figure 67: *green blocks*

Figure 68: *orange blocks*

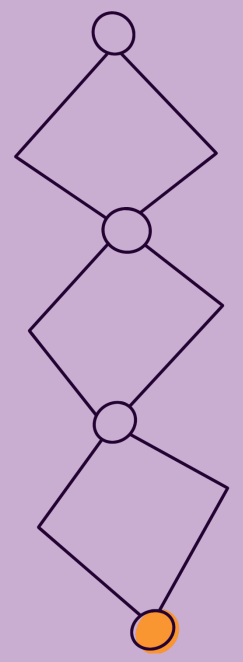
finalize

Concluding: finalize

The tangible reflection tool grip is presented. grip is a tool designed for adult children with a parent with dementia to explore and share their personal experiences and emotions related to the impact of dementia on their lives. The tool facilitates deep conversations between the adult child and a conversation partner by using tangible words to visually represent experiences, emotions and losses. The four rounds of conversation focus on allowing emotions, naming changes and losses, exploring ways to cope, and addressing new ways of coping. The goal of Grip is to help adult children to share their grief, allow their grief and receive social support from loved ones.



7 conclusion



This chapter concludes the project with an evaluation on the current concept, reflection on the design goal and future recommendations for grip.

This chapter is structured in the following parts:

7.1 Evaluation of grip
7.2 Future of grip

evaluation of grip 7.1

7.1.1 Test set-up and participants

In order to evaluate the current design of grip on its aspects and desired effects two final tests are set up and conducted with four participants. By observing the use of grip and evaluating grip with the participants, The goal of these tests is to further improve the design of grip. The set-up of these tests can be found in appendix 18, an introduction to the participants and the main insights are listed below.

The first test is held within the own living room environment of Ilse and her husband (figure 69). Their father (in law) has late phase of Alzheimer's disease for years and is living in Villa L'abri, a home for elderly people with dementia in Zeist.

The second test is held with two IDE students in Delft of which one has lost her grandmother to vascular dementia a few months ago (figure 70). As friends they used grip to guide sharing stories about their loved one with dementia.

Figure 69: *Usertest one*
Figure 70: *Usertest two*

7.1.2 Main insights

Affirmative insights

- Apart from the two coping mechanisms mentioned (chapter 2.4.7) acceptance and avoidance, there are various different ways in which people form social connections with each other. There are families in which discussing feelings and personal experiences is the norm, and there are also families where this is not developed. Grip could contribute to making it **easier to facilitate talking** about feelings, needs and experiences.
- The experience on the card makes it **easier** for the grip participant **to share their own experience**. It provides association possibilities.
- The **tangible** aspect of grip is perceived as **positive support** to share emotional loaded experiences and stories.

Room for opportunities

- Since both participants had (grand)parents in the late phase of dementia, or already had to say goodbye to them, they mentioned recognizing themselves **being in the acceptance phase**. So they could only imagine grip at the first phase of their lives having a parent with dementia.
- Grip's focus should not be limited to one-on-one conversations, but it should also broaden its capabilities to facilitate small **group discussion**s. Among other things, this will help bring siblings closer together and align them in their approach towards the parent with dementia.
- The start card should embrace the fact that there is no wrong or right, that it does not matter where the conversation is going and that it is not a game. It should **reassure** the participants it is about them and their personal experiences.
- The question holder now initiates a follow up for the questions, let the **participants decide which order fits best to their goal** of the conversation.
- Laying out all the blocks on their corresponding bags prior to the conversation is perceived as **overwhelming and unnecessary**.
- Grip knows multiple using layers and elements, which are quite **complex when first using** grip.
- The question card for the conversation partner **initiates a role of quizmaster or discussion leader** instead of an equal conversation partner. Furthermore, it is confusing that the questions are divided over a front and backside and it is hard to choose a matching question to the moment of the conversation.
- It is **unclear** when exactly to **move on to a new round** or conclude the conversation.
- Before answering the question, the participants want to **know which words are written on the blocks**.
- The question holder has only written the question on it, so the participants did **not intuitively connect the question the corresponding themes**. (for example: "What changes in your relationship?" to the "changes and losses blocks")
- The back of the experience card, with the explanation of the causes of the experience, is experienced as **too much information** at once. It can guide the reader a bit more in small steps.

7.1.3 Reflection on design goal

To enable the child in discovering the impact of the dementia on themselves with the help of provided knowledge about dementia and grief, thereby increasing the awareness and creating more room to grieve over time.

Enabling the adult child

Grip provides adult children with a tool that enables them to discover the impact of dementia on themselves. Once Grip is used, the child feels capable of sharing their personal story. The road to the first use of Grip should be guided by a formal caregiver or the instructions should be made simpler and clearer.

In discovering the impact of the dementia on themselves

By discussing an experience in four different rounds with matching words and questions, the adult child can discover what resonates with their own experience. Grip offers the opportunity for discovery, as the impact of dementia translates into changes in the relationship, feelings of grief, and adjustments in dealing with their parent. This makes the impact on different layers in the child's life clearer, but often also more confronting.

With the help of provided knowledge about dementia and grief

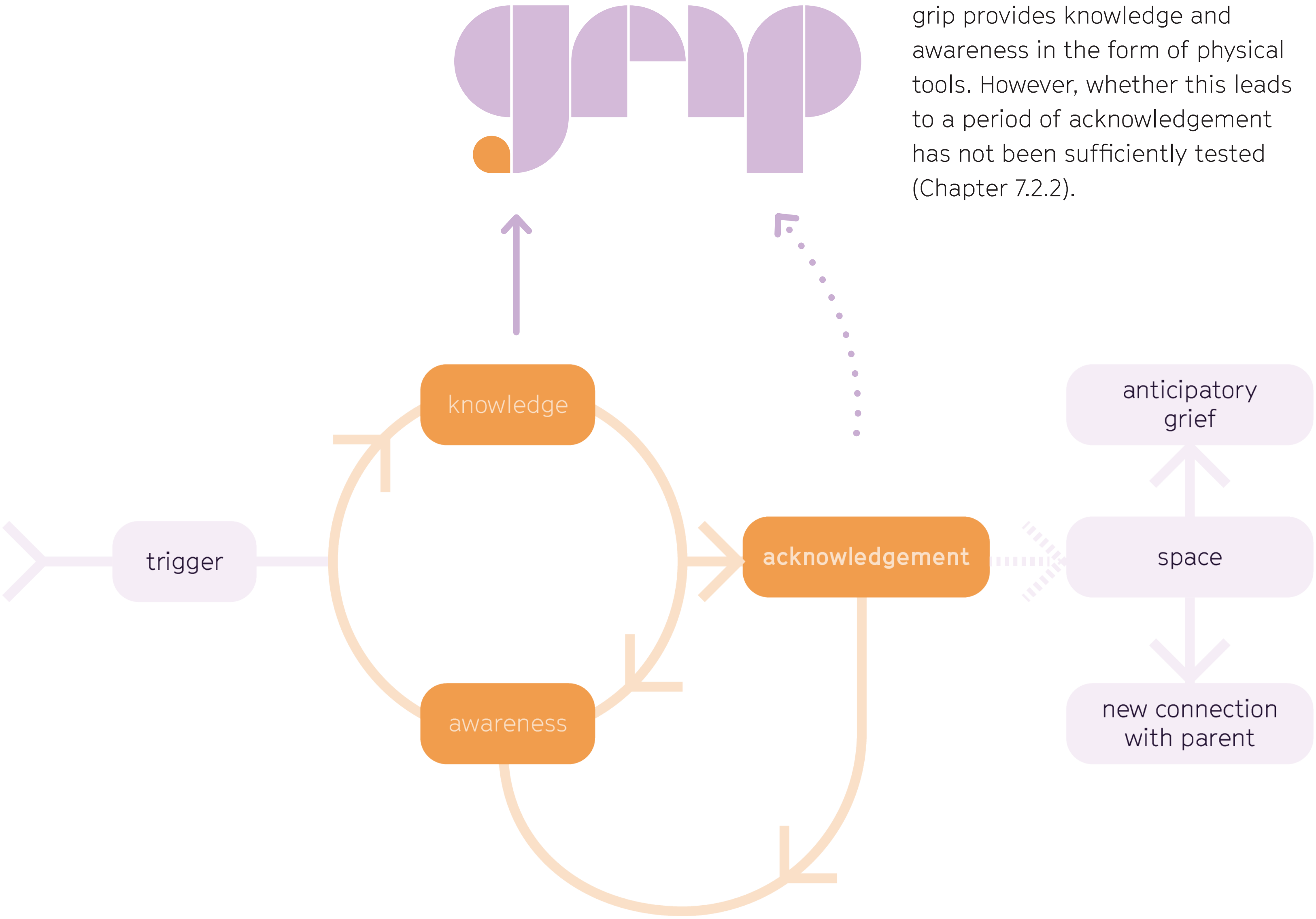
In essence, the information obtained from Grip was perceived as valuable in discovering the impact of dementia. The explanations provided on the experience cards offer the adult child a lot of packaged and concrete information, particularly about dementia and how to deal with it. However, information about grief is lacking and further testing and development is needed to determine the necessity of this information and in what format it should be presented (see chapter 7.2.2). With the guidance of a formal caregiver, this written information can be discussed and personalized in a more meaningful way. Furthermore, the current information provided is static and not visual, and this is an area that can also be further developed.

Increasing the awareness

By visually giving space to feelings, changes, and communication methods on the table, the adult child gains insight into what dementia entails. In addition, physically holding a feeling or a loss is of great importance when discussing it, as it provides a sense of grip and tangibility. The accompanying questions touch on layers of this experience that would have otherwise remained hidden, and because grip requires time from the participants, these layers can be explored.

Creating more room to grieve over time

By giving words to grief feelings and experience, more attention and space is given to grief at that moment. However, due to time constraints of the project, it was not feasible to test the effect of space for grief in the long term.



grip provides knowledge and awareness in the form of physical tools. However, whether this leads to a period of acknowledgement has not been sufficiently tested (Chapter 7.2.2).

7.2 future of grip

This part presents an overview of the project limitations and future recommendations for further developing Grip. These have been established based on the usability tests (Chapter 7.1) and individual iteration cycles.

7.2.1 Project limitations

Participants and target group

Throughout the project, not only adult children of parents with dementia participated in the various design and research activities, but also grandchildren and **other relatives** contributed to the project's activities. Furthermore, this project did not consider other factors of great influence – such as the **presence or absence of a second parent or partner**, or the **intensity of the child's caregiving role** – in recruiting and defining the participant group. In addition, the participants were recruited through the **authors' personal network and direct circles beyond that**, some of whom have a personal connection with the author. Lastly, many participants identified themselves to be within the acceptance stage of the in research found phenomenon (chapter 3.1). However, **less so with the avoidance phase** that grip is designed for. This may all have an influence on the outcomes of the design and research activities.

Duration of the project

The project had a **duration of 6 months**, which had an impact on the recruitment of a diverse participant group, conducting design and research activities, and analyzing the obtained data. For example, Alzheimer cafe's are planned months in advance, so no large scale test could be conducted. The project was structured and supervised by **one author**, which led to all responsibility falling on one individual – despite the frequent involvement of external parties and fellow designer students. The individual approach sometimes resulted in a well-known 'designer's block' (Wood, 2021).

Project focus

The project focuses solely on **adult children** of a parent with dementia, and for example, not on partners of someone with dementia. Children were defined as **anyone 18 years and older**, resulting in a diversity of generations, genders, ethnicities, and childhood backgrounds, among other factors. Additionally, the project focuses mostly on Alzheimer's disease and its symptoms, which has an impact on the project outcomes.

7.2.2 Design recommendations

Before use of grip

- How does one get **invited for a conversation**, especially in informal settings, this has not been sufficiently developed. It needs to be examined whether guidance is needed to initiate a conversation (for example, in the form of an invitation) or whether it can arise naturally.
- The tool may imply that it is a means to go through grief. What needs to be **prevented is recommending the tool after a diagnosis to accelerate or even endure the grieving process** to some extent. That goes beyond the purpose. The grieving person also possesses their own strengths and resources to deal with the loss, and this tool can be one of those resources, but it may not meet the needs of every person experiencing grief.

During use of grip and its elements

Use in general

- Due to the complexity of use, especially for the first time, it is useful to become familiar with the current grip through formal care or to simplify the current design of grip based on research with a user journey. Where are key touchpoints that can be made simpler? Are there elements that can be combined? **Improve the usability of the first use**.
- Another direction that can still be explored is intuitive use. How can **human intuition** be applied to the current design of Grip?
- **Test grip with people** who actual are **in the avoidance phase** of the found phenomenon (chapter 3.1).
- **Conduct long term tests** with adult children, follow them through their personal journey of dealing with a parent living with dementia.
- Grip is currently not designed inclusive, for example people with visual impairments cannot use the tool optimally. Further **design iterations on inclusivity** are needed to involve all possible user groups.

Compass

- No iteration rounds were made and **tested** with participants when **creating the compass**, the manual of grip. These can still be tested with users.
- Perhaps the compass can also be used for **advising** external organizations, informative websites, or events specifically for dementia and grief. This should be tested.
- A possible clarification of the use of grip for the user can be done through an **instructional video**.

Startcard

- The starting card was appreciated for initiating the activity and making agreements together, but it could be **more concise and use clearer language**.

Question card

- There is a thin line in which the supporting **questions can either hinder or support the conversation**. The questions should be visible at a glance and available to all participating conversation partners to ensure equality.
- **The questions need to be reevaluated** with the target audience, experts, and fellow designers.

Carddeck

- Create an **open question on the experience card** that triggers sharing a similar personal experience. This makes it clear that the mentioned experience on the card is intended as a starting point and not as a truth.
- The explanation on the back can be divided into small steps by adding triggering questions between the advices. The explanation is now compiled with a number of dementia experts, but this can be further developed through **co-creation sessions with both dementia experts and experience experts**.
- The card could be supplemented with **a link to more information** online or recommendations for books. It should be checked whether the card is the appropriate place for this information or whether it should be included in the compass, for example.

Cardholder

- **Re-evaluate** whether the card should be placed in such a holder, look at the possibilities of simply putting the card at the front of the card deck and only using the holder to indicate the round.
- Such a 'round navigator' should also **indicate the fourth round**, where the explanation of dementia and possible ways of coping with it are discussed.

Blocks

- The bags of blocks **should be unpacked per question**, and not beforehand. Unpacking them beforehand can be distracting and overwhelming, so focusing attention on the question with the corresponding blocks works better.
- The colours of the blocks should **correspond better** with the colours on the cards.

- The words can be **tested and iterated** multiple times to come up with a set of words that can guide most conversations.
- Put the **terms on both sides of the blocks**, this saves the user from having to search for the term.

After use of grip

- Due to project limitations, **tracking the personal process** has not been explored. It can be examined how a **concluding step** can be given to the long-term use of grip and the personal process that a user goes through with it.
- Within this, a **digital app** can also be considered. An app in which one can easily take a photo of the result of a conversation and thus keep track of the process. This app can also provide an addition in the field of daily grief, for example, reflection diaries or further readings.

7.2.3 Implementation recommendations

Grip has been tested on the interaction between users and the desired effect. However, to further design a future for Grip, it is also important to consider who will become the owner of the tool and how people can obtain the toolkit. Several recommendations are given.

During the iterations and successful testing of the concept with case managers and other dementia experts (insight T, chapter 4), it became clear that there was a need for tools to facilitate conversations with relatives of people with dementia. It should be examined **to what extent grip could add value** in this area. Several tests with case managers will have to be carried out. In addition, a lesson package will need to be developed on how to guide a loved one of someone with dementia using Grip.

If Grip is going to serve more as a **psychoeducation tool**, **collaboration with psychologists and behavioral therapists** will be necessary. This way, all elements can be carefully analyzed and designed.

To further develop Grip, it is important to establish a **multi-headed team**. These can be design colleagues or passionate experts from the dementia world. This way, different perspectives can be taken into account and greater strides can be made in a short amount of time.

During the project, the idea came up to *share Grip* with other people. Preferably, it could be borrowed from the **local library**. Libraries will need to be approached for this.

As grip needs to be introduced well for the first time, a **group workshop** on grip is a possibility to explore. Such a workshop on the use of grip could take place, for example, in an **Alzheimer's Café**, a place where people with dementia, their loved ones and care professionals come together. Alzheimer Netherlands will be approached for this, but this project shows that it works better to start locally at an Alzheimer's Café nearby.

epilogue

As a starting master's student, I had a lot of motivation for the many inspiring and interesting courses, but I would get a slight stomach ache when I thought about the 'big' unknown graduation project. Fortunately, I was able to postpone this mountain in front of me.

Now, at the end of my graduation project, I can happily say that I experienced it differently than I had expected when I look back on the past few months. I have discovered things about myself, but I am especially grateful for the people I have been able to speak with, the knowledge about dementia that I have gained, the growth as a designer that I have experienced during this project, and being able to recognize my own strengths and weaknesses.

I started the project with a sprint, making many appointments with people to give myself a push. It worked, but I also had a lot of fun doing it. I prefer to dive into the context sooner rather than later. When all the acquired data had to come together and a design direction had to be determined, it was different. I sought distraction in other projects, postponed decisions, and temporarily avoided my responsibilities as a designer.

Fortunately, I regained my focus and saw that previous period as a kind of 'designer's block' that I had to overcome. I had to let all the knowledge and personal experiences sink in for a while. It took some time, but then I was able to zoom out again. In that sense, I prefer to work in a team. Because you can help each other zoom out, offer new perspectives, and above all: combine strengths. The end of the project was marked by effectiveness and positive energy - even though the fatigue increased at that time.

Maybe after all these years, I have finally listened to my parents; I really need my sleep. I never wanted to believe it, but secretly I already knew it for a long time. After this half-year, I can add that I benefit greatly from exercising at least twice a week. When I compare productivity with the intensity of sports, I suddenly see many connections. To all future graduates and especially to my own future: take the time and space to exercise, be outdoors, sleep well, and meet social contacts. They work wonders.

Furthermore, reflecting on the personal learning ambitions that were formulated at the start of the project, I have come to some concluding takeaways that I would like to share:

- When dealing with a sensitive subject in a project, the most important thing you can do for the interviewee is to listen. Giving attention and time is often enormously valuable.
- Leading and executing a project individually also means taking time to step back temporarily.
- An individual project, on the other hand, does not mean that you cannot work with other people! Use the knowledge and time of fellow designers or other makers!
- Start recruitment earlier rather than later, finding, contacting, and maintaining possible participants takes time.

Just as grief is a part of life, it also came in various forms during my student days. This graduation project may be a closure of this special time, but it is certainly a beginning of weaving and expand this new knowledge about grief into my further life.

I would like to end with a big kiss to my grandpa, as I wish I had known what I know now through this project when you were still alive. We would have had such a different bond.

Love,
Maureen

M

Two final fun facts of this thesis:
1) The three main colors - purple, green, and orange - are inspired by my favorite flower, the bird of paradise.
2) No black ink was used in this report. Since I believe that death nor grief should not be associated with black, but instead the colors of life should be represented.

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